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Original Article

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

Anthony P. Polednak, PhD

Abstract: Trends in age-specific incidence rates from primary liver (excluding intrahepatic bile duct) cancers were examined, using the US Cancer Statistics database (1999-2009) with data from the National Program of Cancer Registries and the Surveillance, Epidemiology and End Results Program. The largest increase was for ages 55 to 64 years, but the rate for ages 45 to 54 years reached a plateau and showed a recent decline for ages 35 to 44 years, consistent with an impact of the epidemic of hepatitis C virus (HCV) infection which peaked in persons born from 1945 to 1965. Interpretation of trends, however, has been hampered by the lack of data on comorbid HCV infection from central cancer registries. Using a national mortality database with multiple causes of death for all US residents (1999-2010), the increase in the proportion of deaths from liver cancer with comorbid HCV infection also mentioned on the certificate was largest for the group aged 55 to 64 years. Death records are limited to decedents and underestimate comorbid HCV infection, but central cancer registries can use additional sources (such as administrative databases and reports from hospital registries) in interpreting trends in liver cancer incidence rates.

Key words: cancer registries, cancer surveillance, death certificates, hepatitis C virus, hepatocellular carcinoma

Introduction

Increases from 2000 to 2009 in overall age-standardized rates for incidence and mortality rates for primary liver cancer/intrahepatic bile duct cancer (IHBCD) were among the largest of all cancer sites examined, using data from registries funded by the National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) program and/or the Center for Disease Control and Prevention’s (CDC’s) National Program of Cancer Registries (NPCR), covering about 90% of the US population.1 Increases in age-standardized incidence rates for liver cell carcinoma (ie, hepatocellular carcinoma or HCC), the predominant subgroup of liver cancer, have been interpreted as largely due to the epidemic of hepatitis C virus (HCV) infection.2,4 Prevalence of HCV infection has peaked among persons born from 1945 to 1965, who accounted for about 75% of adults with HCV infection in recent national serologic surveys.1,5-8 An estimated 50%-60% of HCC cases in the US may be associated with HCV versus 5%-10% with hepatitis B (HBV) infection.7

A CDC report examined trends (2001-2006) in age-specific incidence rates from the combined NPCR-SEER databases for 45 states, for HCC (ie, site code C22.0 and morphology codes M8170-8175 in the International Classification of Diseases for Oncology Version 3 [ICD-O-3]).9 Linear regression analysis showed that the average annual percentage change (APC) in HCC incidence rates was 3.5% (statistically significant, P < .05) for all ages combined but was largest for ages 50 to 59 years and declined only for ages 40 to 49 years.9 Interpretation of trends in relation to the epidemic HCV infection, however, has been hampered by the lack of systematic data on risk factors in cancer registries.3,9

The present study examined recent trends (1999-2009) in age-specific incidence rates for liver cancer (excluding IHBCD) using all US cancer registries with “high-quality data.”10 These trends are discussed in relation to known features of the HCV epidemic. In addition, death certificates were explored as one source of information on comorbid HCV infection; although ascertainment of HCV is incomplete,13 trends may still be evident. The survival rate for liver cancer is low (about 50% for 1-year and 18% for 5-year cause-specific survival after diagnosis of HCC in SEER);2,3 thus, death records will be available for many patients soon after diagnosis. Because SEER-wide databases include only the underlying cause of death, a national mortality database with multiple causes of death for each US resident death was used to examine temporal trends in the proportion of deaths from liver cancer that also mentioned HCV infection. Implications of findings were considered for enhancing the role of central cancer registries in interpreting trends in liver cancer incidence rates, in relation to HCV infection and other risk factors.

Methods

The US Cancer Statistics (USCS) online incidence database in CDC WONDER (available at the time that analyses were conducted) included data from 50 states and the District of Columbia diagnosed in 1999-2009; 8 of these areas were excluded for 1 or a few calendar years.10 NPCR registries had to meet specific data quality criteria for all cancer sites combined, including: estimated completeness of ascertainment of unduplicated cases using methods

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aRetired. Formerly with the Connecticut Tumor Registry, Connecticut Department of Public Health, Hartford, Connecticut.

Address correspondence to Anthony P. Polednak, PhD. Email: appoled7@yahoo.com.
developed by the North American Association of Central Cancer Registries (NAACCR); missing information on specific sociodemographic variables (eg, age at diagnosis); successfully passing a set of computerized edits designed by the SEER Program but expanded into NAACCR edits software; and proportion ascertained by death certificate only (DCO) (ie, 5.0% or less).11 Similar quality-control issues for SEER registries are addressed by SEER contract requirements (eg, DCO rate 1.5% or less as a standard) and by the SEER Quality Control Profile system.12

Liver cancer (excluding IHBDC) is defined in USCS by the SEER Incidence Site Recode group for “liver” or ICD-O-3 site code C22.0 (ie, excluding IHBDC or site C22.1). Also excluded are lymphomas of the liver (which are classified in the lymphoma site group), along with certain histological types that are extremely rare for the liver; these tumors are defined by ICD-O-3 Morphology codes M9590-9989. Data were available in 5-year age groups through ages 75–84 years, along with 85+ years; due to small numbers at younger ages, the present report used 10-year age groups. Rates per 100,000 population within each age group were standardized to the age distribution of the 2000 US standard population, although these rates differed little from non-standardized (crude) rates within each age group; for 85+ years, data were available only as a crude rate.10 Cases diagnosed at < 15 years were excluded due to small numbers. Age-specific rates were tabulated for 1999, 2004 (ie, the mid-year) and 2009.

Table 1. Age-adjusted Incidence Ratesa per 100,000 for Primary Liver Cancer in Registries Included in the US Cancer Statistics Database10 for Selected Age Groups and Calendar Years, and Annual Percent Change (APC) in the Rate from 1999 to 2009

<table>
<thead>
<tr>
<th>Age</th>
<th>1999 Rate (CL)</th>
<th>2004 Rate (CL)</th>
<th>2009 Rate (CL)</th>
<th>1999-2009 APC % (CL)b</th>
<th>Total Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-34</td>
<td>0.2 (0.2, 0.3)c</td>
<td>0.3 (0.3, 0.3)c</td>
<td>0.3 (0.2, 0.3)c</td>
<td>2.0 (–0.2, 4.2)</td>
<td>2,049</td>
</tr>
<tr>
<td>35-44</td>
<td>1.3 (1.2, 1.4)d</td>
<td>1.2 (1.1, 1.4)d</td>
<td>1.1 (1.0, 1.2)d</td>
<td>–0.9 (–1.5, –0.3)</td>
<td>5,714</td>
</tr>
<tr>
<td>45-54</td>
<td>5.3 (5.1, 5.6)d</td>
<td>8.0 (7.7, 8.2)d</td>
<td>8.9 (8.7, 9.2)d</td>
<td>5.0 (3.6, 6.4)</td>
<td>34,461</td>
</tr>
<tr>
<td>55-64</td>
<td>9.2 (8.7, 9.6)d</td>
<td>13.1 (12.7, 13.5)d</td>
<td>21.0 (20.6, 21.5)d</td>
<td>8.3 (7.3, 9.3)</td>
<td>45,145</td>
</tr>
<tr>
<td>65-74</td>
<td>17.3 (16.7, 17.9)d</td>
<td>20.0 (19.3, 20.6)d</td>
<td>23.1 (22.4, 23.7)d</td>
<td>2.8 (2.4, 3.2)</td>
<td>40,643</td>
</tr>
<tr>
<td>75-84</td>
<td>20.9 (20.1, 21.8)d</td>
<td>24.0 (23.1, 24.8)d</td>
<td>27.1 (26.2, 28.0)d</td>
<td>3.0 (2.6, 3.4)</td>
<td>33,668</td>
</tr>
<tr>
<td>85+</td>
<td>18.4 (17.0, 19.8)d</td>
<td>20.2 (18.9, 21.5)d</td>
<td>20.8 (19.6, 22.0)d</td>
<td>1.2 (0.8, 1.6)</td>
<td>10,103</td>
</tr>
<tr>
<td>15+</td>
<td>5.3 (5.2, 5.4)</td>
<td>6.6 (6.5, 6.7)</td>
<td>8.1 (8.0, 8.2)</td>
<td>4.3 (4.1, 4.5)</td>
<td>171,783</td>
</tr>
</tbody>
</table>

CL, confidence limits (95%), lower and upper, which define the confidence interval.

aRates within each age group were standardized to the age distribution of the 2000 US standard population; the rate for 85+ years is crude, not age-standardized.10 Liver cancer was defined by using ICD-O-3 codes10 (see text).

bAPC (annual percent change) (see text) used rates calculated to 3 decimal places.

cIncludes at least some persons born after 1965.

dIncludes at least some persons born in 1945-1965.

eIncludes persons born before 1945.

fCLs do not include zero.

Table 2. US Deaths Coded to Primary Liver Cancera as the Underlying Cause: the Proportion That Also Had Hepatitis C Virus (HCV) Infection Mentioned Elsewhere on the Death Record, by Age Group for Selected Calendar Years, 2000-2010

<table>
<thead>
<tr>
<th>Age</th>
<th>2000 HCV/Total</th>
<th>% HCV/Total</th>
<th>2005 HCV/Total</th>
<th>% HCV/Total</th>
<th>2010 HCV/Total</th>
<th>% HCV/Total</th>
<th>2000-2010 HCV/Total</th>
<th>% HCV/Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-34</td>
<td>1/94 1.1</td>
<td>2/92 2.2</td>
<td>1/86 1.1</td>
<td>14/1,032 1.4 (0.7, 2.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35-44</td>
<td>45/357 12.6</td>
<td>26/285 9.1</td>
<td>26/219 11.9</td>
<td>374/3,109 12.0 (10.9, 13.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-54</td>
<td>301/1,431 21.0</td>
<td>502/2,156 23.3</td>
<td>579/2,082 27.8</td>
<td>5,396/21,431 25.2 (24.6, 25.8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>214/1,819 11.8</td>
<td>417/2,792 14.9</td>
<td>1,329/4,772 27.8</td>
<td>6,422/32,778 19.6 (19.2, 20.0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>194/2,713 7.2</td>
<td>212/2,886 7.3</td>
<td>352/3,504 10.0</td>
<td>2,603/32,426 8.0 (7.7, 8.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>75-84</td>
<td>113/2,721 4.2</td>
<td>129/3,071 4.2</td>
<td>180/3,332 5.4</td>
<td>1,581/33,433 4.7 (4.5, 4.9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>85+</td>
<td>17/989 1.7</td>
<td>24/1,188 2.0</td>
<td>36/1,470 2.4</td>
<td>283/13,374 2.1 (1.9, 2.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15+</td>
<td>885/10,124 8.7</td>
<td>1,312/12,470 10.5</td>
<td>2,503/15,465 16.2</td>
<td>16,673/137,583 12.1 (11.9, 12.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CL, confidence limits (95%), upper and lower.

aNumber of death records with mention of HCV infection (ICD-10 codes B17.1, B18.2) divided by the total deaths coded to liver cancer (ICD-10 code C22.0 or C22.9) as underlying cause (see text).
Confidence limits (CL) (95%) on all incidence rates were obtained; the confidence interval (CI) is the range covered by the lower and upper CL. Statistical significance (P < .05) of the difference between 2 rates is indicated by CIs that do not overlap. CDC’s EpiInfo software (Version 3.5.3, Jan. 26, 2011) was used to obtain the annual percent change (APC) in rate and also the standard error (SE) of each APC. The APC was estimated as the slope of the line obtained by fitting a linear regression model to the natural logarithm of each annual rate which was calculated to 3 decimal places. This method assumes that rates change exponentially (ie, by a constant percentage each year), so that the slope of the regression line can be associated with a fixed APC. CLs on each APC were estimated as the rate ± [2x SE]. CIs that do not include zero are statistically significant.

Trends in age-specific incidence rates were also analyzed for the 18 SEER registries combined (covering about 28% of the US population), for comparison with data from the USCS database. Data were available for each SEER registry for every year from 2000 to 2009. The SEER database also includes ICD-O-3 Morphology codes, so that incidence rates for HCC (M8170-8175) can be obtained. APCs for trends in age-adjusted liver cancer incidence rates within 10-year age groups (plus age 85+ years) were obtained by creating and exporting data files, with rates and their SEs, from SEER*Stat into the SEER Joinpoint Regression Program (version 4.0.1, January 2013). Joinpoint regression with a weighted least squares method is widely used to identify statistically significant changes in trends over time. With 10 calendar years of data (2000-2009), the maximum number of joinpoints is 1 (ie, with 2 segments), due in part to the requirement that the minimum time period between consecutive joinpoints is 3 years. Statistically significant APCs are indicated by CIs that do not include zero; P values (two-tailed) were also obtained.

The National Center for Health Statistics (NCHS) database with multiple causes of death for all US residents (1999-2010) was also used. As many as 20 causes of death are coded for each person using International Classification of Diseases Version 10 (ICD-10). Liver cancer was defined by ICD-10 codes C22.0 (liver cell carcinoma or HCC), C22.2-C22.4 (hepatoblastoma, angiosarcoma, and other sarcoma), C22.7 (other specified liver carcinoma) and C22.9 (unspecified liver cancer); separate morphology codes are not used in ICD-10. Trends were examined in the proportion of US resident deaths (age 15+ years) coded to liver cancer (underlying cause) that mentioned HCV infection (ICD-10 B17.1, B18.2). Deaths with mention of HBV infection (ICD-10 B16, B17.0, B18.0, B18.1) were also examined.

In graphs, the vertical scale used was logarithmic (to base 10), for depicting temporal trends in rates or proportions that differed by age group (Tables 1 and 2).

**Results**

**Trends in US Age-Specific Incidence Rates for Primary Liver Cancer**

The numbers of US liver cancer cases (in the USCS database) diagnosed in the group aged 15 to 24 years were small (ie, 26–85 per year, not shown). The age-adjusted rate for age 15 to 34 years (127–231 cases per year) was used, which was low and showed little change over time (Table 1); the rate (to 3 decimal places) was 0.242 (CL = 0.207, 0.281) in 1999 and 0.259 (CL = 0.225, 0.297) in 2009. The rate for ages 35 to 44 years declined slightly after about 2006 (Figure 1) and the negative APC reached statistical significance (Table 1). Rates for older age groups increased over time, with the largest increase at ages 55 to 64 (approaching the rate for the 65-74 year age groups (Table 1, Figure 1).

Liver cancer incidence rates were higher for the SEER population (2000-2009) than for the entire United States, but trends were similar. The rate for ages 35 to 44 years in SEER (Figure 2), for example, declined from 1.4 per 100,000 in 2000 to 1.2 in 2009 (APC = -0.7%, CL = -2.6, +1.3%, P = .462, using joinpoint regression). For ages 45 to 54 years, the SEER rate increased from 2000 to 2005 (APC=7.5%, CL=2.1, 13.2%, P = .015) followed by a slight decline (APC= -2.0%, CL = -8.0, +4.3%, P = .441). The rate for ages 55 to 64 years in SEER showed a large increase (Figure 2), and the APC (8.4%, CL = 7.3, 9.6%, P < .001) was similar to that for the entire
Trends in Proportion of US Deaths from Liver Cancer that also had Hepatitis C Virus (HCV) Infection Mentioned on the Death Certificate, 1999-2010

United States. The rate for age 15+ years in SEER increased from 6.3 per 100,000 in 2000 to 9.1 in 2009; the increase from 2000 to 2005 (APC = 5.1%, CL = 3.9, 6.3%, P < .001) was larger than that from 2005 to 2009 (APC = 3.1%, CL = 1.7, 4.5%, P = .002) (data not shown).

HCC in the SEER database comprised 2,893 (79.9%) of all 3,622 liver cancers diagnosed (at age 15+ years) in 2000 and 5,467 (85.2%) of all 6,414 diagnosed in 2009. For ages 35 to 44 years, the HCC rate declined from 1.2 in 2000 to 1.0 in 2009 (APC = -1.3%, CL = -3.4, +0.9), while the HCC rate for ages 55 to 64 years showed the largest increase (APC = 9.2%, CL = 8.0-10.4, P < .001), which was similar to the trend for all liver cancers.

Trends in Proportion of US Deaths from Liver Cancer that had HCV Infection Mentioned

For all US resident deaths from liver cancer as the underlying cause at age 15+ years, available in the NCHS database for 1999-2010, HCV infection was mentioned for 13,157 (16.8%) of 78,438 deaths coded to HCC (ICD-10 C22.0) as the underlying cause. 4,022 (5.8%) of 68,919 deaths coded to unspecified liver cancer (ICD-10 C22.9) but only 4 (1.3%) of 300 deaths coded to other liver cancer (C22.2-C22.4, C22.7); the latter 300 deaths were excluded from analyses.

Among deaths coded to C22.0 or C22.9, the proportion with mention of HCV increased sharply from 1999 to 2000 (Figure 3) with the advent of ICD-10. From 2000 to 2010, the increase was largest for ages 45 to 54 years and (especially) for ages 55 to 64 years, reaching 28% in 2010 for both age groups (Figure 3, Table 2). Although the overall proportion (2000-2010) with HCV mentioned was highest for ages 45 to 54 years, the temporal increase was larger for ages 55 to 64 years (from 11.8% in 2000 to 27.8% in 2010) (Table 2). For deaths coded to C22.0 as underlying cause, the proportion with HCV mentioned was higher and large temporal increases were evident—eg, from 16.1% in 2000 to 37.0% in 2010 for ages 45 to 54 years, and from 9.6% in 1999 to 34.7% in 2010 for ages 55 to 64 years (data not shown).

The proportion of deaths from liver cancer (C22.0, C22.9) as underlying cause that mentioned HBV infection was only 2.4% (3,506/147,357) (of these 3,506, HCV was also mentioned for 699) and increased sharply from 1999 to 2000 but not from 2000 (248/10,124 or 2.4%) to 2010 (393/15,465 or 2.5%); in view of these low proportions, detailed analyses by age group are not shown.

Discussion

Trends in Liver Cancer Incidence Rates, in Relation to the Epidemic of HCV Infection

Incidence rates in the 18 SEER registries were higher than rates obtained from the USCS database (Figure 2). SEER includes areas with large ethnic minority populations with relatively high liver cancer rates that increased from 2000 to 2009. Trends in SEER, however, were similar to those using the USCS database (Figure 2). In previous studies, SEER data have been compared to data available for the entire United States with regard to cancer mortality rates, and trends were similar for some but not all cancer sites. The representativeness of SEER data is important in view of their use in surveillance of long-term trends in cancer incidence rates, and the availability of follow-up data (including causes of death) as well as SEER-Medicare linkages that include comorbidity data (as discussed below).

Time trends in US incidence rates for all primary liver cancers (Table 1, Figures 1 and 2) and for HCC1,4,7,9 have been interpreted as being related mainly to the epidemic of HCV infection. HCC trends in developed countries have paralleled the HCV epidemic. In the United States, mortality rates (using multiple causes) from HCV (but not HBV) infection have continued to increase, along with overall incidence rates for liver cancer or HCC. The US epidemic of HCV infection has involved predominantly persons born from 1945 to 1965 (peaking around birth-year 1960). By 1999, liver cancer cases diagnosed at ages 15 to 34 years represented only persons born in 1965 or later; the low incidence rate showed little temporal change (Table 1). The age group 35 to 44 years in 1999 represented persons born from 1955 to 1964 (or the peak cohort) but by 2004, almost all persons were born after 1960, and the incidence rate declined; after 2005, some persons aged 45 to 54 years were born after 1960 and the rate stopped increasing (Figures 1 and 2).

Study limitations include some complex trends in liver cancer incidence rates (Figures 1 and 2) that are difficult to describe with an overall estimate for APC (Table 1), and are better characterized by using joinpoint regression (as done for SEER data). Also, liver cancer incidence rates (Table 1, Figures 1 and 2) were not adjusted for delayed reporting of cancers to central registries, but this is unlikely to be a major factor because recent declines were largely limited to ages 35 to 44 years and 45 to 54 years (Figure 1).

Liver cancer rates for ages 55 to 64 years have been rising rapidly (Figures 1 and 2), and further increases are expected because many persons born from 1945 to 1965 were not yet included (through 2009) (Table 1). Age groups 65+ years include only persons born before 1945 and showed much smaller temporal increases (Table 1, Figure 1). Slight increases in HCC incidence rates have been reported...
for persons born after 1910,7 and HCV infection rates also increased slightly across birth cohorts after 1920 (prior to the peak in 1945-1965 cohorts).5

Increases in liver cancer rates also may involve other or unidentified risk factors and increasing diagnosis of liver cancer through non-invasive techniques without microscopic confirmation.2,3,9 Other risk factors for liver cancer rates that have been rising in prevalence in the population include diabetes mellitus, obesity, and human immunodeficiency virus infection (but not cigarette smoking or heavy alcohol use).7,21

**Trends in US Deaths from Liver Cancer with Mention of HCV Infection**

Among all US residents who died from liver cancer (underlying cause) at age 15+ years, the proportion with comorbid HCV infection mentioned on the death record was highest at ages 45 to 54 years in 1999 or 2000 (Figure 3) but reached 28% in 2010 for both ages 45 to 54 and 55 to 64 years (Table 2). US prevalence and mortality rates for HCV infection have been highest at ages 40 to 49 years, but average age at diagnosis or death from HCV has been increasing over time (due to the aging of the highest-risk birth cohorts).5,11

The sharp increase from 1999 to 2000 in the proportion of deaths from liver cancer that had HCV infection on the death record (Figure 3) may be an artifact related to the adoption of ICD-10. After 2000, the largest increase was for ages 55 to 64 years, and the trends (Table 2, Figure 3) provide some support for the hypothesis that trends in HCV infection prevalence rates are involved in explaining trends for age-specific liver cancer rates. In contrast, the present study found little temporal increase in the proportion of deaths from liver cancer that had HBV infection mentioned on the death record. Overall mortality rates from HCV infection, but not HBV infection, have increased in the US population after 1999.20

Consistent with the generally poor survival rate for liver cancer patients,2,3 the total number of incident cases at age 15+ years in the USCS database (though coverage was not entirely complete for all states) for 1999-2009 was 171,783 (Table 1) and the number of deaths coded to liver cancer in US residents aged 15+ years in 2000-2010 was 137,583 (Table 2). A limitation of the present report (Table 2, Figure 3), however, is the inability to consider inaccuracies in coding of liver cancer as the cancer site (underlying cause) on death certificates versus the diagnosis in a central cancer registry. Registries would need to address this issue through linkages with death records, by comparing cancer site codes for individual patients.22

**Implications for Future Surveillance and Interpretation of Liver Cancer Rates**

Multiple causes of death (including HCV infection) for each patient have been included in the SEER database management system (DMS)23 but not in SEER-wide databases;14 therefore, individual SEER registries need to collaborate or SEER-wide analytic databases should be modified to include multiple causes of death.

Central cancer registries, however, routinely link their databases with death record files (including multiple causes of death) for selected calendar years, as part of the “death clearance” process in case ascertainment.24-25 NAACCR plans to add underlying cause of death to an analytic file with de-identified data from all US registries that meet NAACCR requirements for completeness and quality of data.26 The addition of multiple causes of death as data items in databases for registries (other than those using SEER DMS)14 also could be considered.

Because of the small numbers of incident liver cancers by age group in many states, collaboration would be needed to examine age-specific trends in deaths from liver cancer with mention of HCV infection. Cancer registries linked with mortality databases including multiple causes of death, for example, have been analyzed in 3 states (California, Colorado and Idaho) to address certain surveillance issues.27

Death certificate data (Table 2) are limited to deceased patients, however, and considerable underreporting of HCV infection on the death record (vs a hospital discharge database) has been shown.15 Recognition of HCV infection, and its role in liver cancer, may have increased over time among certifiers, although this is an unlikely explanation for the large differences in trends by age group (Table 2, Figure 3). Both death records and hospital discharge databases should be used for surveillance of HCV infection.13 SEER databases linked with Medicare files (limited to elderly persons) include hospitalization data, and the proportion with HCV was low but the increase (1993-1999) was much greater than for HBV-related HCC among patients diagnosed with HCC.29 Birth cohorts (1945-1965) at highest risk for HCV infection have just begun to reach age 65+ years, and expected future increases in liver cancer rates can be examined with SEER-Medicare linked databases.

Linkages with hospital discharge databases can provide data on comorbid conditions regardless of patient age or insurance coverage.20,29 In 2010, NAACCR organized a Discharge and Claims Data Work Group project, for developing best-practice guidelines.31

Although HCV infection is often undiagnosed,1-8 central registries also could potentially be linked with state surveillance systems for diagnoses of reportable infectious diseases that recently have included chronic HCV infection; however, HCV infection reporting may be biased (eg, by age and calendar year) and improvements are needed in HCV infection surveillance by states.32

Ten data items for comorbid conditions/complications (ie, ICD-9-CM codes) are included on the standard record used by hospitals to report incident tumors to central cancer registries;33 reporting of comorbid HCV infection should be studied, but obtaining data on certain other risk factors for liver cancer including comorbid diabetes and weight to height ratio may be feasible.34-36 Hospital records and administrative databases may be complementary sources for ascertaining certain comorbid conditions such as diabetes in cancer patients.37

Versions of comorbidity evaluations suitable for administrative or claims databases have been developed (with 2 to 3 levels of severity for most conditions), and
concordance with medical record-based comorbidity was high for diabetes among patients with certain cancers. Ideally, epidemiologic case-control studies (eg, hospital-based) could estimate the proportion of liver cancers attributable to risk factors such as obesity, diabetes and (especially if blood samples can be obtained) HCV and HBV9 for patients diagnosed in different calendar years. Also, analysis of paraffin-embedded liver tissue specimens may detect HCV and HBV infections that were unrecognized clinically in serum of HCC patients, and some population-based cancer registries have maintained tissue repositories for research purposes.

Conclusions

US trends in primary liver cancer incidence rates vary by age group and are generally consistent with the hypothesis of an impact of the epidemic of HCV infection, as also suggested by trend in the proportion of US liver cancer deaths with mention of HCV infection on the death certificate. Central cancer registries, however, could use various resources for estimating the proportion of incident liver cancer cases related to HCV infection and other risk factors, by year of cancer diagnosis, in efforts to improve interpretation of trends in age-specific liver cancer rates. Continued surveillance of these trends is needed, in view of projected increases (due to the aging of the 1945-1965 birth cohorts) but also potential benefits through increased use of antiviral treatment of diagnosed HCV infection found through routine screening of certain high-risk groups before advanced liver disease develops.

References


Abstract: Objective: To learn the frequency of conflicting race/ethnicity reports, to examine patterns of conflicting reports, and to identify possible avenues for data quality improvement. Methods: As part of the Data Improvement Project on Patient Ethnicity and Race (DIPPER), an analysis of conflicting race/ethnicity reports for cancer cases was conducted. Using matched hospital discharge data and central cancer registry data from 2009, the race/ethnicity of patients in the 2 datasets were compared. Those with conflicting reports (“mismatched”) were examined more closely. From a sample of 2,356 patients, 187 had conflicting reports for their race (7.9%) and 357 had conflicting reports for their ethnicity (15% was thus developed). Results: In the 2009 hospital discharge data, an unknown response occurred nearly twice as often for Hispanic ethnicity as for race. Almost 85% of the mismatched race cases were classified as non-white in the hospital discharge data and white in the central cancer registry data. The most common ethnicity mismatch was coded unknown by the hospital but non-Hispanic by the registry. Conclusions: Hospital cancer registrars occasionally lack easy access to race and, more often, ethnicity data. More attention should be given to discrepancies (including allowing staff to flag and verify existing data), and staff training should improve both perceived and real data accuracy. In the future, hospitals and registries would be better served by pairing race and ethnicity together in the electronic medical record. This would ensure quick, easy access for cancer registrars. Perhaps standard setters should add ethnicity to the gold standard criteria for registries.

Keywords: accuracy, data quality, ethnicity, granular ethnicity, race.

Introduction

Cancer is a leading cause of death in developed countries. In the United States, cancer is the second leading cause of death. Age-adjusted cancer rates vary by race and ethnicity. Overall, cancer incidence is highest for black men, while cancer mortality is highest for African Americans of both sexes. For example, black men have a 33% higher death rate from cancer than white men. When one looks at data by cancer site/type, different racial/ethnic groups have the greatest risk depending on the cancer we examine. Asians have the highest mortality from liver cancer and cancer of the nasopharynx. Both are associated with infectious agents. Asians also have high rates of stomach cancer when compared with other racial groups. Blacks have the highest death rates from cancers of the digestive system, breast, cervix, uterus, and prostate. Whites have the highest mortality for non-Hodgkin’s lymphoma, melanoma, urinary bladder cancer, cancer of the brain or central nervous system, and leukemia. In order to eliminate cancer mortality disparities, we need to understand them in more detail. For example, if blacks have the highest death rates, is that for all patients of African descent, just recent immigrants from African countries, or only African Americans that have been in the United States for 4 generations?

Cancer statistics help inform policies and public health studies regarding cancer etiology and distribution. The utility of these statistics depends on the quality of data collection and reporting. Accurate measurement is often the first step towards reducing health disparities. In the United States, hospital cancer registries rely on multiple sources of information to report required elements of a cancer diagnosis to a central cancer registry, and the central registry consolidates reports from multiple hospitals as needed.

In 2010, the Hospital Association of Rhode Island (HARI) secured funding for a new project, the Data Improvement Project on Patient Ethnicity and Race (DIPPER). The project, initiated in 2011, evaluated current data collection practices and implemented a new pilot approach for race and ethnicity data collection at 5 acute care hospitals (Women and Infants Hospital, Kent Hospital, South County Hospital, Roger Williams Medical Center, and St. Joseph Health Services). The Institute of Medicine Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement recommends that institutions “collect data on granular ethnicity.” The new pilot approach added some locally relevant ethnicities as choices in the race and ethnicity response sets. Despite the need for accurate and complete data, there remains substantial room for improvement in this area today.

This paper reports on a study to assess the accuracy and completeness of race/ethnicity information in hospital discharge and cancer registry records. This analysis compares...
2009 hospital discharge data, which can involve multiple reports for a single patient if he or she was admitted and discharged more than once, to 2009 central cancer registry data. The study focuses on cases where reported race and ethnicity differ. The analyses were conducted in order to identify possible avenues for data quality improvement.

**Methods**

There are 11 acute care hospitals in the state of Rhode Island and each reports data on cancer cases to the Rhode Island Cancer Registry (RICR). RICR aggregates these data and reports them to the National Program on Cancer Registries Cancer Surveillance System. Since health care facilities are required to report cancer cases to the central registry as part of state-wide surveillance efforts, and quality assurance is part of those activities, institutional review board approval was not necessary. Confidentiality and patient privacy were assured. RICR data meet the highest standards for data quality set by the North American Association of Central Cancer Registries (NAACCR) for complete, accurate, and timely data. They have received the Gold Standard certification continuously since at least 1999.

Rhode Island participates in the reporting of data to the Healthcare Cost and Utilization Project (HCUP). This analysis matched 2009 hospital discharge data with central RICR records. Cases with discrepant race or ethnicity reports in the 2 databases were identified. In some cases there were duplicates because the same patient could have more than 1 hospital discharge in calendar year 2009. Once duplicates were eliminated (“deduplicated”), there were 2,356 matches between the hospital discharge data and the central RICR data. Cases with discrepant race or ethnicity reports in the 2 databases were identified. From the matched sample, 187 had conflicting reports for their race (7.9%) and 357 had conflicting reports for their ethnicity (15%).

Where possible, an audit was conducted at the hospital where the database material originated. This audit process proceeded differently for hospitals participating in the pilot that introduced the new approach to race and ethnicity data collection designed for Rhode Island. For race, 4 hospitals were audited, totaling 71 of the 187 conflicting reports identified, or 38.0% of conflicting race reports. For ethnicity, 3 hospitals were audited. Two of those audited constituted 80 of the 357 cases, or 22% of the mismatches. The third, which had an issue of non-reporting to the participating database, constituted another 36% of the mismatches, totaling 58.5% of the ethnicity mismatches in all.

Categories were modified to allow comparison between the 2 data sources. RICR records race data at a more detailed level (sometimes called “granular” level) than the hospital discharge data, so cancer registry race categories were consolidated to be more inclusive. Data from both sources were categorized into 7 groups: white, black/African American (referred to as blacks), American Indian and Alaskan Native (referred to as American Indians), Asian, native Hawaiian or Pacific Islander, other, and unknown.

### Table 1. Race in Rhode Island Hospitals (2009)

<table>
<thead>
<tr>
<th>Category</th>
<th>Total</th>
<th>2010 US Bureau of the Census—statewide data for Rhode Island</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian or Alaskan Native</td>
<td>226 (0.2%)</td>
<td>–</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>2,436 (1.8%)</td>
<td>–</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>9,018 (6.6%)</td>
<td>–</td>
</tr>
<tr>
<td>White</td>
<td>113,717 (83.4%)</td>
<td>–</td>
</tr>
<tr>
<td>Other</td>
<td>4,498 (3.3%)</td>
<td>–</td>
</tr>
<tr>
<td>Unknown</td>
<td>6,432 (4.7%)</td>
<td>–</td>
</tr>
<tr>
<td>Total</td>
<td>136,327</td>
<td>–</td>
</tr>
</tbody>
</table>

### Table 2. Ethnicity in Rhode Island Hospitals (2009)

<table>
<thead>
<tr>
<th>Category</th>
<th>Total</th>
<th>2010 US Bureau of the Census—statewide data for Rhode Island</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic/Latino</td>
<td>10,538 (7.7%)</td>
<td>–</td>
</tr>
<tr>
<td>Not Hispanic/Latino</td>
<td>113,225 (83.1%)</td>
<td>–</td>
</tr>
<tr>
<td>Unknown</td>
<td>12,564 (9.2%)</td>
<td>–</td>
</tr>
<tr>
<td>Total</td>
<td>136,327</td>
<td>–</td>
</tr>
</tbody>
</table>

2010 US Bureau of the Census—statewide data for Rhode Island

2010 US Bureau of the Census—statewide data for Rhode Island
Results

Summary of Demographics, Census Versus Hospital

Tables 1 and 2 show the race and ethnicity distributions from the hospital discharge data. Compared to the 2010 US Census Bureau data, the percentage of hospital discharges for minorities were generally lower than expected, except for blacks. The proportion of hospital discharges identified as black was slightly higher than expected in comparison to census data (6.6% vs 5.7%). In Rhode Island, whites and blacks appear most likely to be admitted to a hospital.

For ethnicity, 7.7% of hospital discharges were reported as Hispanic, while the census found that 12.4% of the state’s population is Hispanic. Only 3.3% of the cases reported “other” for race in 2009.

Observed rates of unknown race and ethnicity leave room for improvement. Ethnicity was not reported for almost 10% of the cases while race was not reported for about 5%.

Data Congruency

Overall, agreement between the databases was high. For the 3,476 unduplicated matches (duplicates not yet eliminated), 92% of the cases were reported with the same ethnicity and 92.7% with the same race. Nevertheless, examining those cases where reports were inconsistent, and hence inaccurate, is informative. Table 3 shows the mismatched cases for race. In 2009, there were 187 cases mismatched for race, which represents 7.9% of the de-duplicated matched cases.

There were several commonly occurring patterns of mismatched data. The most frequently occurring mismatches were cases where the registry coded the patient as white and the hospital coded the patient as other (54 cases). The second most common pattern was a code of white in the central cancer registry data while hospital records had unknown recorded (43 cases). Another frequent pattern was the central registry coding the patient as white when the hospital coded the patient as black (40 cases). This pattern was more than 6 times as common as the reverse (black in the registry and white in the hospital discharge data). Cases where the central registry has the race on record as white and the hospital has any valid non-white response (black, American Indian, Asian, Native Hawaiian, or other) accounted for 61% of the mismatched cases. If one also includes those mismatches where the hospital has unknown as the race on record and the central registry has white, these records constituted 84% of the 2009 cases with mismatched race information.

Table 4 displays the patterns of mismatched cases for ethnicity. The number of mismatched cases was considerably higher for ethnicity (357 cases) compared to race (187 cases). Since race and ethnicity are not mutually exclusive, there was some overlap in the mismatched cases (some of the patients with mismatched race also had mismatched ethnicity).

Over one-third of the cases for mismatched ethnicity were caused by non-reporting at a single facility. The most frequently occurring mismatch was cases coded as unknown by the hospital and coded as non-Hispanic by the registry. The 194 cases (129 from non-reporting facility) with this pattern constituted just over half (54%) of the mismatched ethnicity cases. The second most frequently occurring mismatch (19.9%) was cases where the hospital recorded that the patient was Hispanic and the registry reported that they were non-Hispanic. Two other patterns were notable. About 13% are cases where the registry reported the patient as Hispanic and the hospital reported the patient as non-Hispanic. Another 11% are cases that the registry reported as unknown and the hospital reported as non-Hispanic.

Table 3. Mismatched Race Data (2009) for Rhode Island

<table>
<thead>
<tr>
<th>Hospital codes</th>
<th>Central cancer registry codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>Black</td>
</tr>
<tr>
<td>White</td>
<td>–</td>
</tr>
<tr>
<td>Black</td>
<td>40</td>
</tr>
<tr>
<td>AIAN</td>
<td>3</td>
</tr>
<tr>
<td>Asian</td>
<td>15</td>
</tr>
<tr>
<td>NH0PI</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>54</td>
</tr>
<tr>
<td>Unknown</td>
<td>43</td>
</tr>
<tr>
<td>Total</td>
<td>158</td>
</tr>
</tbody>
</table>

AIAN, American Indian or Alaskan native; NH0PI, native Hawaiian or other Pacific Islander.

Table 4. Mismatched Ethnicity Data (2009) for Rhode Island

<table>
<thead>
<tr>
<th>Hospital DD codes</th>
<th>Central cancer registry codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic</td>
<td>Non-Hispanic</td>
</tr>
<tr>
<td>Hispanic</td>
<td>–</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>48</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
</tr>
</tbody>
</table>
Discussion

This study compared race and ethnicity data on patients matched from 2 datasets, and closely examined those with conflicting reports for lessons on data quality improvement. The analysis was limited to those with a cancer diagnosis, recorded in the RICR, and discharged from a hospital in Rhode Island during 2009.

Two patterns emerged most frequently among mismatches: Cancer registrars were more likely to code a patient as white than other hospital personnel (61% of mismatches); and cancer registrars were more likely to use the non-Hispanic code for ethnicity (74% of mismatches). The most common mismatched race pattern was for a patient to be coded white by a cancer registrar and non-white (most often other, black or Asian) in the hospital data (including unknowns, almost 85% of cases). For the ethnicity data, we found a non-reporting problem, and almost double the number of mismatched ethnicity cases relative to the number of mismatched race cases. Mismatched ethnicity cases predominantly arose from hospital cancer registrars reporting non-Hispanic when hospital records say the patient is of unknown ethnicity or Hispanic. The problem of reporting to the database was a unique situation, and having this resolved should reduce ethnicity mismatches in the state by about half.

In Rhode Island, the DIPPER initially piloted a new approach to standardize data collection at 5 acute care hospitals, as has been described elsewhere.8 Locally relevant categories were added and staff received training and coaching in best practices. Pilot data received thus far have shown promising results, suggesting a training program of modest size can yield substantial changes in a hospital’s demographic racial and ethnic composition.

When possible, we conducted audits of mismatched cases and created logs to better understand how conflicting reports arose. One pilot hospital audit with excellent medical records suggested two-thirds of the mismatched race records on file at RICR were incorrect. Of those records, nearly two-thirds were Hispanic patients that the registry had coded as white, but that hospital record documentation showed that the patient self-identified as other or black. Only 2 cases confirmed that the RICR information was correct, and preferable to the reported unknown race from the hospital discharge database. One limitation of this study was that when conducting audits at the non-pilot hospitals, we had no means of determining which of the 2 mismatched codes was true. Taken as a whole, what might contribute to these patterns?

Based on our qualitative observations made during audits of mismatched data and staff interviews, there may be several factors that might contribute to these patterns: 1) access issues, 2) perceived data accuracy, and 3) pressure to meet the NAACCR “Gold Standard” criteria. First, cancer registrars may not trust the validity of patient registration data. Prior to the pilot, some of the registrars interviewed knew that hospital staff sometimes code race or ethnicity based on observation rather than asking the patient to self-identify. More training to increase staff comfort asking for race and ethnicity data would increase patient self-identification and validity. In addition, cancer registrars examine multiple sources of information to report cancer incidence, and conflicting information among a single patient’s records may arise. Moreover, interviews with cancer registrars statewide revealed that no clear guidelines exist for deciding which source is most likely to be accurate.9 When faced with conflicting information, and lacking guidelines for which entry is most accurate, cancer registrars may be basing their decision on the state’s demographics.

The last factor arises from trying to meet certain standards for data quality. NAACCR sets quality standards to identify complete, accurate, and timely data. To meet gold certification, one of their criteria for central cancer registries is to have less than 3% of cases missing meaningful information on race. (Other criteria include case ascertainment of 95% or higher for completeness; no more than 3% reported cases are death certificate-only cases; fewer than 0.1% duplicate case reports in file; all data variables used to create incidence statistics by cancer type, sex, race, age, and county are 100% error free; less than 2% missing age, sex and county information; and file submitted within 23 months of the close of the diagnosis year under review.)

Cancer registrars may therefore feel pressured to minimize the proportion of cases reported as unknown. If ethnicity is also collected and adds useful information to our understanding of cultural patterns of cancer occurrence, perhaps ethnicity should be included with race in gold-standard criteria.

On the basis of the mismatches identified and evaluated, there is another problem that can arise: the central cancer registry can also receive conflicting race/ethnicity codes. Registry personnel will need to devote time to consolidate those conflicting codes. While this problem occurs more frequently in hospitals, it can require staff time to resolve in either setting.

The patterns described here have implications for cancer data reporting at the state and federal government and are a cause for concern. This study shows that there is over-reporting of people who consider themselves white or non-Hispanic and by extension, under-reporting of minority groups. It also reveals how cancer registrars are not always reporting accurate data on ethnicity, due to lack of access (or easy access) to these data in the medical record. These data elements are used to inform health policies and interventions and to study trends over time. Continued efforts must be made to improve the accuracy and completeness of race/ethnicity data.

Lessons for improvement in data quality have been identified from this study. There are at least 4 ways health
care organizations or standard setters can improve data quality.

1) Resolve access issues. Standard setters should ensure easy access to required race/ethnicity information for hospital cancer registrars and others in need of this information to provide culturally competent care. Possible solutions include requiring vendors to pair race and ethnicity, moving those variables to more prominent locations in the medical record, and pairing them with preferred language. Race and ethnicity could also be part of the Commission on Cancer program standards for patient-centered care.

2) Identify and address discrepancies. Reports conflict within and between hospital departments (and records), and can conflict between hospitals. During our audit, conflicting race and ethnicity reports were found even between multiple visits to the same department. Hospitals could address these issues in a few ways. First, health care organizations should provide registration staff with training that explains how to ask about race and ethnicity and why we ask. Ideally, granular ethnicities can be recorded. Last, hospitals and IT/IS staff should create ways to identify discrepancies and flag records in need of verification to assure accuracy. Records that are flagged could allow staff to work better as a team to resolve discrepancies in a timely manner.

3) Train staff and improve trust in the data. Train patient registration staff about best practices in standardized race/ethnicity data collection, and improve the perceived data accuracy for cancer registrars and others utilizing the data.

4) Include ethnicity in NAACCR Gold Standard criteria. Current requirements include race but not ethnicity. Expanding them to include ethnicity would improve the quality of these data. Ideally, our ability to record patient ethnicity should go beyond Spanish origin to include other possibilities as well.

In our increasingly diverse population, where there is tremendous interest in eliminating health disparities among racial and ethnic minority groups, the quality of race and ethnicity data must be high. Moreover, granular ethnicity is sometimes being used as a consideration in cancer testing and/or treatment decisions, and is a criteria in some clinical research trials. Collecting more detailed, granular race and ethnicity information (as the DIPPER pilot hospitals are collecting) allows one to examine the data in new ways and to search for hidden disparities not previously identified.

Following this Institute of Medicine recommendation would also improve a cancer registrar’s ability to resolve conflicting race and ethnicity reports. In addition, the NAACCR Hispanic/Latino Identification Algorithm (NHIA) works poorly in Rhode Island, often mistakenly assigning Portuguese residents Hispanic ethnicity. If patient records include whether a patient is Portuguese, these mistakes could be corrected. It would also improve a state’s ability to prevent and to control cancer by better targeting interventions based on cancer disparities. Since the comprehensive cancer control program aims to assess and reduce the burden of cancer, better race/ethnicity data would also benefit that program and potentially increase its effectiveness.

Improved accessibility and accuracy not only helps to uncover hidden disparities, but also increases the overall efficiency of cancer registry operations. Hospital-based registrars can work more efficiently if race and ethnicity information were paired and more readily accessible. Most mismatched cases examined here would not be readily identified by the central cancer registry. Only 29% of the 2009 cancer cases in Rhode Island had more than 1 hospital reporting on his/her case (this figure is for Rhode Island only). When conflicting race or ethnicity reports arrive for consolidation by central registry staff, these utilize staff time to resolve. Fewer conflicting race/ethnicity reports can improve efficiency for both hospital cancer registries and central cancer registry operations.

References

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

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

Abstract: A method was developed to categorize prostate cancer treatments for epidemiologic and outcomes studies. A total of 60,497 prostate cancer cases from the Florida Cancer Data System diagnosed between 2001 and 2007 were used. The classification has the following properties. First, the treatments classified in the same group are clinically comparable and capture all prostate cancer treatments or combinations of treatments (exhaustive classification). Second, the grouping was set up in a way that each patient is captured in only 1 treatment category without leaving out any patient due to treatment type (mutually exclusive categories). The prostate cancer cases were initially categorized into 14 combinations of treatment, which were then collapsed into 8 broader groups in order to maintain a large sample size for all groups, with treatments remaining clinically comparable within a group.

Key words: data management, Florida Cancer Data System, prostate cancer, treatment

Prostate cancer (PCa) is recognized as one of the principal medical problems in the male population. It is estimated that there will be 238,590 new cases and 29,720 deaths from PCa in the United States in 2013.1 The introduction of the prostate-specific antigen (PSA) has contributed to detection and diagnosis at an earlier stage (prostate confined, localized) when treatments can be potentially curative. The majority of men diagnosed with localized PCa are likely to choose among 3 primary definitive therapies: radical prostatectomy, external beam radiotherapy, or brachytherapy.2-4 Combinations of these treatments with or without hormonal therapy are also offered to some men. Some men with early, low risk prostate cancer may choose active surveillance.5,6 Under active surveillance, patients are closely monitored with continuous PSA assessment, biopsies, and several other tests to identify early signs of progression.7 Other patients may defer treatment for other reasons not related to active surveillance. According to the Surveillance, Epidemiology and End Results (SEER) program, from 2005 to 2009, median age at diagnosis of PCa was 67 years.8 Because of advanced age, older patients may already be coping with other concomitant major physical illnesses, also known as comorbidity.9,10 Clinical stage at diagnosis is an important determinant of treatment outcomes, as it is strongly associated with treatment-related complications and the risk of mortality.9,11 Specifically, patients diagnosed with localized disease have fewer complications and substantially better survival than those diagnosed at later stages.12-15 Although this general association between diagnosis stage, treatment, and health outcomes has been well documented, there is no single agreed upon standard for treatment of PCa. State cancer registry data are a good resource for research to better understand patterns of PCa treatment and management, and to assess racial and/or economic disparities in types of treatments.16,17 However, the many combinations of treatments are often cumbersome, nebulous, and not conducive to quality epidemiologic research studies using cancer registry data. A method that systematically and schematically groups different treatments into a limited set of categories would greatly facilitate epidemiologic and health disparities research.

The objective of this article is to present a new method for categorizing PCa treatments for epidemiologic and outcomes studies using cancer registry data. Treatment classes need to be mutually exclusive and exhaustive so as to capture all PCa treatments.

PCa cases diagnosed between 2001 and 2007 were obtained from the Florida Cancer Data System (FCDS). The FCDS was established as the state central cancer registry in 1981, and has been part of the Centers for Disease Control and Prevention National Program of Cancer Registries since 1996. The FCDS has met or exceeded the highest standard of completeness, quality, and timeliness set by the North American Association of Central Cancer Registries (NAACCR) since 2002.

The FCDS dataset provides several information including the first course of treatment, which encompasses all methods of treatment specified in the original treatment plan and administered to the patient before any disease progression or tumor recurrence. Data on the first course of treatment were reported by hospitals, freestanding radiation therapy centers, and surgical treatment facilities. FCDS began to enforce cancer reporting from private physician offices in recent years. However, few private urologist or oncologist offices reported cancer treatments during the study period, and the data might have missed information...
on treatments provided by physician offices. Types of treatment included in the FCDS are surgery, radiation therapy, chemotherapy, hormonal therapy, immunotherapy, and other therapy. FCDS data descriptions are provided in the Data Acquisition Manual, implemented based on the NAACCR standards.\textsuperscript{18}

Fourteen combinations of treatments were found among the 60,497 cases included in this study (Table 1). These combinations were based on major treatment categories. The number of cases varied significantly, from 24,517 for surgery alone to 8 for surgery with biological response modifiers (BRM) or other treatment.

The 14 treatment categories were collapsed into broader groups in order to achieve large sample sizes for all groups while ensuring that all treatments were clinically comparable within a group (Table 1 and Figure 1). These meaningful, broader groups resulted in 8 mutually exclusive treatment categories.

---

**Table 1. Treatment Group Scheme, Treatment Categories, and Frequencies**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Frequency</th>
<th>%</th>
<th>New Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery: Inclusive of all surgical procedures</td>
<td>24,517</td>
<td>40.62</td>
<td>Surgery only (Sx)</td>
</tr>
<tr>
<td>Surgery with chemotherapy only</td>
<td>43</td>
<td>0.07</td>
<td>Exclude from further analysis due to possible misclassification</td>
</tr>
<tr>
<td>Surgery plus chemotherapy (SxChemo)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery with BRM or other treatment (no RT, HT, chemo allowed)</td>
<td>8</td>
<td>0.01</td>
<td>Exclude from further analysis due to possible misclassification</td>
</tr>
<tr>
<td>Surgery plus Other treatments (SxOther)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery with radiation but no hormone (regardless of other therapy)</td>
<td>584</td>
<td>0.97</td>
<td>Surgery plus radiation (SxRT)</td>
</tr>
<tr>
<td>Surgery with hormone and radiation (regardless of other therapy)</td>
<td>391</td>
<td>0.65</td>
<td>Surgery plus radiation plus hormone therapy (SxRTHT)</td>
</tr>
<tr>
<td>Surgery with hormone but no radiation (regardless of other therapy)</td>
<td>1,682</td>
<td>2.79</td>
<td>Surgery plus hormone therapy (SxHT)</td>
</tr>
<tr>
<td>NO SURGERY—hormone but no radiation (no other treatments)</td>
<td>2,622</td>
<td>4.34</td>
<td>Hormone</td>
</tr>
<tr>
<td><em>Hormone therapy alone (HT)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NO SURGERY—hormone but no radiation (with other treatments)</td>
<td>52</td>
<td>0.09</td>
<td>Radiation</td>
</tr>
<tr>
<td><em>Hormone therapy plus other treatments (HTOther)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NO SURGERY—radiation but no hormone and no other treatments</td>
<td>13,986</td>
<td>23.17</td>
<td>Radiation plus hormone</td>
</tr>
<tr>
<td>Radiation alone (RT)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NO SURGERY—radiation but no hormone, but with other treatments</td>
<td>59</td>
<td>0.1</td>
<td>No definitive treatment*</td>
</tr>
<tr>
<td>Radiation plus other treatments (RTOther)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NO SURGERY—hormone and radiation but no other treatments</td>
<td>8,237</td>
<td>13.65</td>
<td>Radiation plus hormone</td>
</tr>
<tr>
<td>Hormone and radiation (HTRT)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NO SURGERY—hormone and radiation, but with other treatments</td>
<td>36</td>
<td>0.06</td>
<td>No definitive treatment*</td>
</tr>
<tr>
<td>Hormone and radiation plus other treatments (HTRTOther)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NO SURGERY—no hormone and no radiation, other treatments included</td>
<td>91</td>
<td>0.15</td>
<td>No definitive treatment*</td>
</tr>
<tr>
<td>Other treatment (Includes chemotherapy or BRM or other treatments without hormone and no RT) (OtherTx)</td>
<td></td>
<td></td>
<td>Exclude from further analysis due to possible misclassification</td>
</tr>
<tr>
<td>NO SURGERY—no hormone, no radiation, and no other treatments</td>
<td>8,053</td>
<td>13.34</td>
<td></td>
</tr>
</tbody>
</table>

*Includes active surveillance (AS) and deferred treatment for any reason.
BRM, biological response modifiers.

Procedures and NAACCR data item numbers: Surgery, 1200; radiation, 1210; chemotherapy, 1220; hormone, 1230; BRM, 1240; other treatment, 1250.

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**Figure 1. Flowchart of Regrouping Treatment**

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\textsuperscript{18}For more information on treatments provided by physician offices, types of treatment included in the FCDS are surgery, radiation therapy, chemotherapy, hormonal therapy, immunotherapy, and other therapy. FCDS data descriptions are provided in the Data Acquisition Manual, implemented based on the NAACCR standards.\textsuperscript{18}
The classification was based on 3 major types of treatment: surgery, radiation, and hormone therapies. Patients were first divided into 2 categories: receiving surgery and receiving no surgery. Patients who received surgery were classified into 4 groups: surgery plus radiation, surgery plus radiation plus hormone therapy, surgery plus hormone therapy, and surgery only.

Patients who did not receive surgery were grouped based on whether they received radiation plus hormone therapy, radiation treatment, hormone treatment, or no definitive treatment (received neither radiation nor hormone treatment).

The following categories were excluded from further analysis due to possible misclassification and small number of cases: surgery plus chemotherapy only; surgery with BRM or other treatments; and no surgery (no hormone, no radiation, and no other treatments). Descriptive statistics such as sample proportion were used to summarize group frequencies. A chi-square test was used to assess bivariate association between categorical variables.

Surgery (40.6%) and radiation (23.2%) were the most frequently received single treatment modality. Among those receiving combination therapies, 13.7% received radiation plus hormone therapy and 2.8% had surgery plus hormone therapy. A great number of men (13.3%) were classified into the no definitive treatment category, which includes active surveillance or treatment deferral for any reason. Lower treatment frequencies were observed in many combination treatments, especially in surgery with BRM or other treatments, hormone and radiation but no other treatments, and surgery plus chemotherapy only.

A statistically significant difference ($P < .0001$) was observed in the receipt of treatment by race, stage, and age (Table 2). Surgery, radiation therapy, and radiation plus hormone therapy were the most sought treatments for nearly identical proportions of patients. Approximately 41.0% of both black and white patients received surgery. Radiation therapy was received by 20.7% of black and 23.8% of white patients. Approximately 12.8% of black and 14.0% of white patients received radiation plus hormone therapy.

The vast majority of patients with local-stage cancer (41.5%) and regional-stage cancer (72.3%) received surgery. Patients with late-stage disease mostly received hormone therapy (33.7%) and no definitive treatment (31.0%). Table 2 shows that treatment selection varied markedly by patient age. Patients within the age categories 40–65 and 65–70 were frequently treated by surgery (57.4% and 42.5% respectively). The greater number (27.3%) of patients with age ≥ 70 years underwent radiation therapy.

No single optimal treatment exists for early stage PCa. However, definitive treatment of PCa has been linked to positive patient health outcomes. The objective was to develop a practical and clinically meaningful method for grouping treatments of PCa to facilitate health outcomes research in PCa. The classifications based on state cancer registry data meet the following constraints: 1) the treatments classified in the same group are clinically comparable, 2) the groups capture all PCa treatments or combinations of treatments, so no patient regardless of type of treatment is left out, and 3) each patient is allocated to only 1 treatment category. Nevertheless, it is noteworthy that these same constraints could be satisfied by other classifications. Categorization of treatment in this paper is by no means entirely indicative of disease stage which is another important factor to be considered in PCa outcome studies.

References


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

Pamela S. Warren, PhD, CTR

Abstract: Most cancer registrars work with cancer committees and are challenged by the many struggles associated with maintaining compliance with the Commission on Cancer standards regarding attendance and participation. Facility-mandated participation may improve the attendance of those participants who are employed by the facility, but even then, fully engaged involvement often remains elusive. Ironically, it is often the cancer registrar who is held responsible for finding ways to keep the cancer committee engaged. Viewing and respecting cancer committee members as volunteers offers the cancer registrar a unique opportunity to utilize the tools of volunteer management to meet these challenges. Several techniques were taken from experts in the field of volunteer management and adapted for use with cancer committees.

Key words: American College of Surgeons Commission on Cancer, cancer committee, cancer registrar, cancer registry, engagement, volunteers

Introduction

Most cancer registrars are faced with challenges associated with maintaining cancer committee attendance and participation in compliance with Commission on Cancer (CoC) standards. When participation is facility-mandated, attendance may be increased, but that is no guarantee of a fully engaged committee. Often, the responsibility of keeping the cancer committee engaged falls to the cancer registrar.

The committee’s level of engagement often depends on its members’ attitudes toward accreditation and its value to their work. Some see the standards and accreditation as a marketing tool, a valuable asset in an economic downturn. Many resent the imposition on their private practice, which can cost them both time and money, while others view it as a way to increase patient caseload.

Regardless of how a committee member perceives the accreditation process and its applied requirements, it is still necessary to maintain the required level of engagement for compliance. Not everyone on a cancer committee is going to believe his or her participation in the accreditation process will make a meaningful difference in patient care, certainly creating a challenge for every cancer registrar. While no single intervention is going to miraculously resolve this issue, looking at the cancer committee from a different perspective might provide us with a few more tools.

Several times throughout my professional life, I have worked with volunteers and as a volunteer coordinator, including while working as a cancer registrar. An article in the spring 2006 issue of the Journal of Registry Management describes a particularly wonderful volunteer working in the cancer registry field. Although she was not a cancer committee member, the article recognizes the value of volunteerism in the field of cancer registry.1

So once again it is time to look for new ways to engage members of cancer committees, and if we look closely, we will see that cancer committee members are, indeed, volunteers. This revelation necessitated a literature review to gain understanding of engaging and caring for volunteers. As a volunteer coordinator, like most cancer registrars, you are part of a critical element in nearly every culture across the globe. Volunteerism is as American as apple pie, as British as fish and chips and… well, you get my meaning.2,3 How do we engage cancer committee members and care for them in order to improve the quality of their involvement?

Discussion

Experts in the field of volunteerism offer several suggestions that can be easily adapted and applied to cancer registrars’ work with their cancer committees. Here are some steps suggested by several different sources. Simple as they may appear, applying them to cancer committee volunteers may be a new approach to consider. After all, the cancer program is a physician-led initiative. It’s easy to assume that everyone is or should be self-motivated, but cancer registrars know better. Here are some suggestions.

1. Volunteers should be recruited based on their qualifications.2 The CoC standards support this notion, as they describe those who are qualified to serve as cancer committee coordinators.3 Those of us who have been cancer registrars for a while remember the days when the responsibilities for all these positions fell to the registrar. Use the CoC’s support in this area to make sure your committee is built with individuals who are qualified to do what they have been asked to do. This will make your job easier.

2. Just because a surgeon knows surgery does not mean he or she knows specifically what is expected of a cancer committee member. Therefore, it is necessary to orient and educate all members of the cancer committee whether they are new or returning. Change is nothing new to the cancer registrar, but the committee members are not always privy to...
all the changes and simply mentioning them in cancer committee is not always the optimal way to achieve our goal of educating members. At least annually, revisit individual responsibilities with each committee member. This would be a good time to reinforce the purpose, policies, expectations, and programs involved in the cancer program, and to provide any resources that might be useful to committee members.

3. While not the easiest task, it might be beneficial to discover what motivated each of your committee members to participate and what motivates them in general. This knowledge is useful to you when you have conversations with your members and will help you know how to approach them. A student once had difficulty getting a professor to stop long enough to engage in meaningful conversation about a project. The student decided to purchase the professor’s favorite cup of coffee. Catching him in the hallway, the student and was able to get the information needed—simply by recognizing what motivated the professor. It is not suggested that you get extravagant, but it is worth considering as a way to get the attention of your committee members.

4. Volunteers appreciate feedback about their performance. Luckily for the cancer registrar, the CoC standards have a built-in process for this activity. It may seem like overlook to report member attendance on a quarterly basis for both the cancer committee and the cancer conference (tumor board), but this 10 second activity at each meeting does 2 things: It recognizes everyone for their effort and attendance and highlights any non-compliance. Reiterating the required percentage rate for attendance reinforces goals and highlights any shortcomings without a lot of fuss. It’s also the perfect time to thank everyone for their efforts toward improving patient care.

5. Find ways to make the cancer committee members feel needed and appreciated. Kirwan states, “No matter how idealistic your volunteers are and how dedicated to the cause, everyone needs a healthy dose of external appreciation to keep them going.” You may ask yourself if you are the person to do this and I think that’s a good question. If you think the show of appreciation needs to come from someone else to be more effective, set it up that way. Nearly every cancer registrar knows we are the feet and hands behind almost every operation, but we also know how to make the praise look like it comes from someone else when necessary.

6. Remember that just because they are cancer committee members does not mean they know the details of what is expected. Remember, working with the cancer committee is part of our job, but cancer committee members all have other jobs and this is a volunteer activity for them, not necessarily part of their employment activities. So be very specific with them about what is expected, and what needs to be presented. Surgeons often rush to a committee meeting having just scrubbed up after a difficult surgery, and have to rush back for another surgery after the meeting. Have things prepared for them and make sure it’s clearly laid out so they know exactly what to say. This may seem like spoon-feeding them, but my experience has been that they appreciate the extra hand because it shows recognition for the huge effort they are putting forward to participate.

7. Inspire your volunteers with the cause, not the organization. If your volunteer cancer committee members hear that meeting standards is the only goal, they are not going to feel the need for their participation. Cancer registrars must stay focused on the CoC standards; they are our responsibility. But consider presenting them to the cancer committee as a question of quality or patient care improvement rather than just a standard. For instance, instead of saying, “The standard requires that we set a percentage of breast cancer cases to be presented in the breast cancer tumor board; what should that be?” present it this way: “What percentage of breast cancer cases do you feel should be presented at tumor board annually to really understand our breast cancer patient population and the care they need?” Reframing all the standards in terms of patient care and quality of service will engage their patient concerns.

8. Communicate usefully with your cancer committee. Cancer committee members, whether they be physicians or non-physicians, don’t want to be bombarded with communications from the cancer registrar. However, keeping in touch with them in a meaningful way will increase the quality of your communications. When you run a report that is particularly useful in some way, you might send it to either the entire committee, or just to those it impacts directly; if they decide it should be presented to the other members, they will have a first look and may have some ideas as to the best way to present it.

9. Show them they have made a difference. When improvements are made and the quantity and quality of patient care is affected, take extra care with presenting the findings so that those who were directly responsible are publicly acknowledged for making a difference, and everyone else is shown how their own contributions played an important role.

Conclusion
Respecting cancer committee members as volunteers may require a different mindset but may also provide some tools to help meet the challenges faced by the cancer registrar. I encourage you to adapt each of these suggestions to your own situation and share your successes with other cancer registrars.

References
Edits: An Electronic Tool for Cancer Registry Data Quality

Elaine Collins, MA, RHIA, CTR

Abstract: Edits are a standardized tool for cancer registry data quality. The development of edits is overseen by the North American Association of Central Cancer Registries Edits Workgroup. Edit software tools are supported by the National Program of Cancer Registries. Collaborative Stage (CS) edits are available to support registrar coding of the CS data items. Edits enforce consistent coding across multiple related data items. Understanding where to look for information on edit logic and how to read the edit documents will enable registrars to correctly resolve data discrepancies identified by edit reports.

Introduction

Edits are the most standardized tool that registrars use to ensure that collected cancer data make sense. An edit is a logic statement that checks the value of a coded data item against specified criteria, implemented through a set of specially designed software programs. Registrars rely on their knowledge and experience from collecting cancer data—the presentation of disease, the diagnostic workup, staging elements, and treatment patterns—to guide their search for data components within the patient’s medical record and from information sources outside the record. They rely on the coding manuals and guidelines published by cancer data standard setters for instructions on translating the medical documentation into discrete data elements that convey the story of each patient’s cancer diagnosis and treatment, and that can be aggregated into information useful for clinical monitoring and assessment and public health surveillance purposes. And they rely on edits to ensure that valid codes are selected and that codes entered for related data items are consistent in meaning from one data item to another.

Types of Edits

Traditionally, 3 types of edits have been written for registry use:

1. Single-field edits: what are the allowable values for this data item? For example, codes for sex include 1-male, 2-female, 3-transsexual, 4-hermaphrodite, 9-unknown.

2. Multi-field edits: what constraints do allowable values in 1 field put on allowable values in another field? For example, if primary site is prostate, C619, sex must not be coded as female, 2.

3. Inter-record edits: what constraints do coded values in 1 record put on coded values for the same person for another primary cancer? For example, if the patient’s sex is coded as female in 1 record, the same patient’s sex must also be coded as female in a second record for another cancer.

A fourth type of edit, a more recent addition to the edit catalogue, is labeled as a clinical data check. These edits have grown out of standard setter interest in monitoring the quality of cancer care on a timely basis. They focus on expected types of cancer treatment based on site and stage of disease at diagnosis. For example, if a patient is diagnosed with early stage breast cancer and is treated with lumpectomy and axillary dissection, clinical treatment guidelines indicate that the patient should be offered radiation therapy within a certain time period after date of diagnosis. The edit would check for diagnosis date and stage, and treatment codes, and dates.

The first 3 types of edits are very useful for finding typographical errors in data entry, for identifying codes that may have become obsolete from one publication of data standards to the next, and for drawing attention to relationships among data items that the registrar may not have considered. The fourth type of edit reminds the registrar to look for information on treatment that may well have been given but not yet coded in the cancer abstract, or to document reasons why treatment was not given. This type of edit is an integral component of quality of care studies such as the Comparative Effectiveness Research Project sponsored by the National Program of Cancer Registries (NPCR) and the Rapid Quality Reporting System of the Commission on Cancer (CoC).

Edit Management and Software

Cancer registry edits are managed by the Edits Subcommittee within the North American Association of Central Cancer Registries (NAACCR) committee structure. The Surveillance Epidemiology and End Results Program of the National Cancer Institute (SEER-NCI), and the CoC of the American College of Surgeons initially developed and published edits independently for their data reporters. This activity was brought under the auspices of NAACCR in the mid-1990s, with the support of the NPCR of the Centers for Disease Control and Prevention (CDC). SEER, CoC, NPCR, and the Canadian Council of Cancer Registries (CCCR) continue to request and sponsor edits within the entire catalogue of edits; NAACCR may also sponsor edits. There may be versions of the same edit with variations requested by different standard setters, depending on data requirements for their reporters. Edits are published via a NAACCR metafile released periodically, though SEER also continues to publish its required edits through the SEER
Database Management System.


The NPCR has made 4 software programs available to the registry community to develop, maintain, and apply edits to cancer data:

1. EditWriter: Software for writing and updating edits, creating edit sets or collections of edits to be applied to cancer records, and creating runtime metafiles or the package of edit sets and edits that are applied to the data. This program is used primarily by the NAACCR Edits Workgroup and central registry staff who compose edits and create edit sets and metafiles for reporting entities.

2. Edit Engine: Software that provides the program interface or library of functions for applying the edits to cancer data. The program may be incorporated into registry software by vendors or central registries for processing cancer abstracts.

3. GenEdits Plus: Standalone program, using the edit engine, that allows edits to be applied to a standardized cancer data set. GenEdits Plus may be used by hospital or central registries to edit files in a batch mode outside of, or as an adjunct to, the registry database management system.

4. RegistryPlus Online Help: A library of coding information, including edit information reported from EditWriter which provides lookup access to edit information outside of the EditWriter program itself. The online help program is current through NAACCR version 13 and includes:
   • NAACCR Data Standards and Data Dictionary, version 12.2
   • NAACCR V12.2C Edits Metafile Online Help
   • FORDS (Facility Oncology Registry Data Standards) 2012
   • Collaborative Stage Data Collection System: User Documentation and Coding Instructions, Version 02.04
   • SEER Program Coding and Staging Manual 2012
   • ICD-O-3, Introductory Material and Morphology Numerical Lists
   • Multiple Primary and Histology Coding Rules (updated through September 27, 2011)

   **Edit Content**

The edits documentation in Registry Plus Online Help is a very useful tool that provides significant information to assist registrars in resolving edits, and should be added to the list of downloadable programs if possible for every hospital registry. Edit failure information provided in most registry implementations is limited to the edit error messages, data items, and codes which have failed; the more extensive information in the online help includes descriptions of the underlying logic for each edit.

Each edit document is composed of a standard set of information. All sections for each edit, except for the edit logic, are included in Registry Plus Online Help:
- Title, composed of major fields involved and the sponsoring organization
- Sponsoring organization and date of last revision
- Edit Sets containing the edit
- Data Fields referenced by the edit
- Default Error Message when data fail to pass the edit
- Description of the edit in natural language
- Edit logic in programming language
- Administrative Notes, including the first metafile in which the edit appears and a description of modifications made to the edit

**Collaborative Stage Edits**

The Collaborative Staging System (Csv1) was first developed and implemented for use with cancer diagnoses as of January 1, 2004. The system was expanded for cancer diagnoses as of January 1, 2010 and renamed the Collaborative Stage Data Collection System (Csv2). The system is built of data items and codes for collecting stage components and other prognostic information, and an application program interface or software functions for deriving stage elements as output based on the coded input data. A CS Edits Workgroup was established under the auspices of the NAACCR Edits Workgroup in 2008 to develop edits focused on the CS data items, in preparation for the expanded set of CSv2 data items.

<table>
<thead>
<tr>
<th>NAACCR Metafile</th>
<th>Date of Implementation</th>
<th>Number of Edits</th>
</tr>
</thead>
<tbody>
<tr>
<td>NAACCR 10B</td>
<td>1/1/04</td>
<td>55</td>
</tr>
<tr>
<td>NAACCR 10C</td>
<td>1/1/05</td>
<td>58</td>
</tr>
<tr>
<td>NAACCR 10D</td>
<td>1/1/06</td>
<td>60</td>
</tr>
<tr>
<td>NAACCR 10E</td>
<td>1/1/07</td>
<td>81</td>
</tr>
<tr>
<td>NAACCR 11</td>
<td>1/1/08</td>
<td>88</td>
</tr>
<tr>
<td>NAACCR 11.1</td>
<td>1/1/09</td>
<td>96</td>
</tr>
<tr>
<td>NAACCR 11.2</td>
<td>1/1/10</td>
<td>102</td>
</tr>
<tr>
<td>NAACCR 11.3</td>
<td>1/1/11</td>
<td>106</td>
</tr>
<tr>
<td>NAACCR 12</td>
<td>1/1/12</td>
<td>222</td>
</tr>
<tr>
<td>NAACCR 12.1</td>
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</tr>
<tr>
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</tr>
<tr>
<td>NAACCR 13</td>
<td>1/1/13</td>
<td>407</td>
</tr>
<tr>
<td>NAACCR 13A</td>
<td></td>
<td>426</td>
</tr>
</tbody>
</table>

CS edits are shown in Table 1. The first were released in the NAACCR 10B metafile for use with 2004 data. The numbers of total CS edits in each metafile show the growth in activity, both in writing edits and using them for CS data elements. The initial 36 edits for 2004 data through the release of NAACCR 11.1 reflect the work of the Edits Subcommittee. Eleven CS edits were added for the 2009 release based on the work of the CS Edits Workgroup,
which continues through the edits released for subsequent metafiles. Much of the increase in CS edits between CSv1, in use 2004 through 2009, and CSv2, implemented in 2010, reflects a large number of edits written to specify different standard requirements for the 19 site-specific factor fields that were added in CSv2.

Based on the NAACCR 13A release, the CS edits can be grouped into categories as shown in Table 2.

<table>
<thead>
<tr>
<th>Table 2. Collaborative Stage Edits by Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid Codes</td>
</tr>
<tr>
<td>Obsolete Codes</td>
</tr>
<tr>
<td>Required data items</td>
</tr>
<tr>
<td>Comparison w/non-CS items</td>
</tr>
<tr>
<td>Other CS fields</td>
</tr>
<tr>
<td>CS Admin Fields</td>
</tr>
</tbody>
</table>

Sources of CS Edits

CS edits are prompted by 4 main sources:

1. **Coding system requirements:** The CS system itself has certain intrinsic data requirements. The edits on valid codes, obsolete, and derived codes are dictated by the codes in the CS schema tables. The edits themselves are written to directly access the CS dynamic link library (DLL) to identify valid and obsolete codes. The edits on CS administrative fields, the CS version edits, check that a valid version of the system, such as CSv0204 for 2012 and 2013 diagnoses, is in use. These edits make up approximately one-third of the total number of CS edits.

2. **Standard setter requirements:** The standard setters, SEER, CoC, NPCR, and CCCR, each determine the data that must be collected by their reporting agencies. The requirements address both the basic components of the CS system that are defined across schemas, as well as the site-specific factors for each schema that must be collected. Edits check that each data field required by a standard setter is not left blank, and is coded with a value other than not applicable. These edits make up approximately one-third of the total number of CS edits.

3. **CS Edits Workgroup (CSWG):** The volunteers in the group review the CS data items and instructions, identify data relationships, and suggest possible edits to enforce consistent coding among related data items. Each proposed edit statement is first discussed by the group. If the logic is approved, the chair of the Edits Subcommittee prepares the edit document for further review and discussion by the CSWG, and also tests the edit on a testfile of data from a central registry. The CSWG reviews the edit document and the test results, and either makes recommendations for modification of the edit logic and further testing, or approves the edit. All approved edits are forwarded to the larger Edits.

4. **Coding system requirements:** The coding system requires certain intrinsic data requirements. The edits on valid codes, obsolete, and derived codes are dictated by the codes in the CS schema tables. The edits themselves are written to directly access the CS dynamic link library (DLL) to identify valid and obsolete codes. The edits on CS administrative fields, the CS version edits, check that a valid version of the CS system, such as CSv0204 for 2012 and 2013 diagnoses, is in use. These edits make up approximately one-third of the total number of CS edits.

**Figure 1. Example of a Collaborative Stage Edit**

**CS SSF 3, Extension, KidneyParenchyma Schema (CS)**
Agency: CS  Last changed: 05/27/2013

Edit Sets
- Hosp: vs13 COC Required—ALL
- Hosp: vs13 COC Required Non-Confidential

SEERT vs 13 Transmit Edits
- Fields
- Primary Site [Std# 400]
- Histologic Type ICD-O-3 [Std# 522]
- Behavior Code ICD-O-3 [Std# 523]
- CS Site-Specific Factor 3 [Std# 2900]
- CS Extension [Std# 2810]
- CS Site-Specific Factor25 [Std# 2879]

Default Error Message

[3510] KidneyParenchyma schema: If %F4 = %V4, %F5 must not = %V5
KidneyParenchyma schema: If CS Site-Specific Factor 3 = “value of CS Site-Specific Factor 3”, CS Extension must not = “value of CS Extension”

Additional Messages

[3517] KidneyParenchyma schema: If CS Extension = “value of CS Extension”, CS Site-Specific Factor 3 must not = “value of CS Site-Specific Factor 3”

**Description**

For cases coded using the KidneyParenchyma schema, if CS SSF 3 (ipsilateral adrenal gland involvement) indicates involvement of ipsilateral adrenal gland, then CS Extension must indicate involvement of ipsilateral adrenal gland or more extensive involvement.

This edit is skipped if any of the following conditions are true:

1. CS Site-Specific Factor 3 is blank or 988
2. CS Extension is blank
3. Behavior Code ICD-O-3 = 0 (benign) or 1 (borderline)
4. CS schema is invalid

If schema is KidneyParenchyma:

1. If CS Site-Specific Factor 3 = 010 or 030 (codes indicating ipsilateral adrenal gland involvement)

   THEN
   
   CS Extension must be greater than or equal to 630
   involvement of ipsilateral adrenal gland

2. If CS Extension = 630, 640, or 645 (involvement of ipsilateral adrenal gland or more extensive involvement)

   THEN
   
   CS Site-Specific Factor 3 must not = 000 (ipsilateral adrenal gland not involved) or 020 (noncontiguous involvement of ipsilateral adrenal gland)

This edit first determines the correct CS schema by doing a function call to the CS Dynamic Link Library (dll). The function call passes Primary Site, Histologic Type ICD-O-3, and CS Site-Specific Factor25 (schema discriminator) to the dll and the CS schema name is returned.

**Administrative Notes**

New edit—added to NAACCR v13A metafile.

In the SEER*Edits software, the title of this edit is: IF450
4. **Registry community:** Both the Edits Subcommittee and the CSWG also receive recommendations for CS edits from the registry community. Recommendations come primarily from central registries and also standard setters, and are often based on findings from data quality studies. Recommendations also come from the teams which respond to questions posed by registrars and others in the CAnswerForum, the website managed by the CoC to address coding issues. The process for handling these edit requests is similar to the steps taken by the CSWG as described above. Existing edits are first reviewed when a request is received to determine if a modification could be made to address the data quality concern, or if a new edit should be written. The edits developed through schema review and data review make up approximately the remaining one-third of the total number of CS edits.

**Example of a CS Edit**

The CS edit released in the NAACCR 13A metafile is shown in Figure 1. This is an edit developed by the CS Edits Workgroup. The Kidney/Parenchyma schema contains a number of site-specific factors which “repeat” elements of tumor extension coded in the CS Extension field. The purpose of this edit is to ensure that codes used for CS Site-Specific Factor 3, Ipsilateral Adrenal Gland Involvement, are consistent with codes used for CS Extension that may indicate ipsilateral adrenal gland involvement or further extension. In a case such as this, where the same data concept is addressed in 2 different data fields, an edit is useful to ensure that the same information is being conveyed in both places, and that the thought processes of the coder carry over from one field to the next. A failure of the edit would not specify which data field was coded incorrectly. The edit message would present the codes used in both data items with the message that they are inconsistent, calling for review of the codes in both fields to resolve the inconsistency.

**Resolving Edits**

Anecdotally, registrars face problems in resolving edits for a number of reasons. With a complex edit that requires looking at multiple fields, registrars may not know how to resolve the edit or what tools or resources to use to look up what they do not know. They might just start changing codes until the edit “goes away.” Lack of interest, a presumed waste of time, or ignorance may hinder the registrar from exploring the real “why” behind the edit.

Word of mouth, whether current thinking or not, may be how many registrars clear edits, without regard to whether something has changed and a rethinking of what they are editing and looking at. Additionally, software vendors may provide inline help and often retooled descriptions of the edits in lieu of the original edit documents. The closer the edit message approaches to the original intent of the edited codes, the better; the closer the registrar’s understanding of the original intent of the edited codes, the better.

Edits trace their origin back through edit logic to coding instructions and codes, and the cancer, diagnostic, prognostic, and treatment information they are meant to represent. Resolution of any edit failure involves:

- Identification of the relationships among the data items and codes in the edit message. For example, is a CS Lymph Node code specified as a pathologic N category, while the CS Lymph Node Eval code indicates clinical evaluation?
- Review of coding instructions and examples for each data item in the edit message. For example, do the coding instructions in Part I of the CS Manual and/or the code definition in the CS Tumor Size table specify that a specific CS Tumor Size code should be used with a particular histology?
- Identification of any changes in coding instructions which may not have been internalized. For example, has a new coding instruction been added to the notes above a CS Site-Specific Factor table specifying which code must be used for an in situ carcinoma?
- Identification of database changes over time and possible edit impacts. For example, did the database undergo a coding conversion from one version of CS to another, and now there are cases which failed to convert and no longer derive Collaborative Stage values?

Understanding codes, coding instructions, changes in codes and coding instructions, database manipulations, and personal coding habits support editing for data quality as opposed to coding to edits. Resolving edits with understanding is an effective learning tool for the registrar. It also tends to improve edits, as edit problems are uncovered through this process and can be reported to the edit writers for correction.

**Problems in Edit Development and Application**

The first two-thirds of edits, valid codes and required data fields, are generally ready and available before the release of a new CS version. The edits may be fairly intricate and require a lot of structural analysis and careful programming, but their purpose and application are fairly straightforward. The last third of edits, for schema-specific coding relationships, are much slower in development; they are prepared by a volunteer committee workforce, and dependent on the depth of experience held by the committee members in both cancer data collection and edit writing. The development of edits lags behind the development of the CS Data Collection System, with one of the persistent problems being the fallout from the application of new edits to older data coded and collected before the edits were available. This can pose a particular problem for central registries, with voluminous databases and few resources to review and possibly recode thousands of reported cases.

An Edits Impact Group has been established to develop recommendations for central registries about dealing with large-scale edit fallout. A number of suggestions have been aired, though the group is still in the process of defining its mission and establishing its own procedures. Suggestions include publishing an assessment of the potential impact of new edits with the publication of new metafiles and
developing recommendations for global updates, or systematic changes to large numbers of records based on logical selection criteria rather than individual record review. Edits are currently being developed in response to revised coding instructions and code definitions for CS v0205, to be implemented for 2014 cases; these edits will include a check for CS v0205, as the instructions were not in place for earlier versions of CSv2. As with all changes in codes and coding instructions, the burden for reconciling codes for data across versions is placed upon the data analyst, though edits could be used if desired to identify cases for recoding for special studies.

The CS edits are at the forefront of edit concerns and recommendations at the present time, which may reflect larger concerns with the CS system and the value and collectability of the multiple new site-specific factors with CSv2. However, perhaps outweighing the concerns regarding implementation and impact issues is the recognition that on an individual case and individual abstractor level, edits are a most useful tool. Most abstractors probably encounter any single edit only 2 or 3 times in their abstracting career, unless they are tired when working, in which case they may see the same edits in a string of cases but know immediately what the problems are. One of the problems with the success of edits, and probably contributing to the central registry burden with new edits, is that abstractors may tend to rely on edits as indicators of good abstracting practices, and slight other methods of data review that could suggest improved coding in unedited data fields.

A valuable suggestion coming out of the impact discussions, considering the requirements of data abstractors, has been the ongoing publication of articles in cancer registry publications such as The Connection about the concepts behind new edits that are being released in upcoming metafiles. Focus is on the development of an educational program that will prepare abstractors to understand and hopefully even anticipate the edits they will be dealing with. Such an educational program should reach further back to considering the changes in codes and coding instructions and the rationale for such changes that the edits are attempting to enforce. Understanding begins with the recognition of data patterns and data relationships that prompt the edits. As registrars move more into data review and data analysis roles, the well-honed ability to recognize and express internally consistent patterns of structured cancer data is a valuable skill. Edits are guides to quality data, they are not the determinants of quality data.
On September 2, 2013, I watched 64-year old Diana Nyad swim up to the shore of Key West, Florida and make those last few painful and exhausted steps to dry land. Amid the cheering crowd and with her face swollen from exposure and jellyfish stings, she said, “I have 3 messages. One is you should never ever give up. Two, you never are too old to chase your dreams. Three is, it looks like a solitary sport but it’s a team.”

In subsequent interviews, she shared more details about her experience and the mental struggles she experienced while completing the 53-hour, 103-mile swim from Cuba to Key West without a shark cage. She set this goal for herself 35 years ago and, even though she failed miserably on her first 4 attempts, on this day she achieved what others felt was impossible. Within hours after her arrival in Key West, she told CNN reporter Dr. Sanjay Gupta that “...even with all the experience I have ... I never knew I would suffer the way I did.” She went on to describe the wind, the claustrophobia she experienced wearing the prosthetic mask, and other challenges she faced, before saying: “My whole mantra this year was, find a way. You don’t like it or you’re not doing well, find a way.”

What can cancer registrars learn from Diana Nyad’s historic achievement?

For starters, you need to have an extreme dream. What is yours? Do you have something you would like to do or accomplish in your life that will take every ounce of strength, motivation, and determination you can muster and then still demand more from you? Write it down, draw it out in a picture, and make it real. Put it in a big, bold and conspicuous place so it is in front of you every day.

While personal goals and dreams are important, in this article we are specifically talking about your biggest dreams as a cancer registrar. What is it that you want to accomplish? Is it a quality or performance-related goal? Is it collaboration with physicians and administrators you want to achieve? Or do you want to expand your knowledge and skill set so that you are the best of the best in cancer registry? Perhaps you see how you can collect and deliver health care data to your cancer program team so that it has an even greater positive impact on patient care? Or maybe you want to make a difference in the life of a cancer registry student and help them achieve their dream of becoming a registrar?

Just how important is this dream to you? Are you willing to do whatever it takes, for however long necessary, to get to your goal? Any dream or goal you have that does not require hard work or sacrifice is either not big enough or not important enough to spend precious time and energy on it. What are you doing to continually find a way to make it happen in your life?

How long have you been chasing this dream? Did you fail at some point along the way and give up, or are you still pressing forward and using every ounce of creativity and energy you have to find a way to the goal? And, if you have failed in previous attempts, did you get back up and continue looking for a way to make it happen?

Then there is the whole nonsense with age and our thinking that we might be too old to do something. While the human body does let us know from time to time that we are growing older, why do we let it limit our accomplishments and achievements in our lifetime? If you really want something, go for it, no matter what! We hear people joke around, claiming that age is all about mind over matter or that we are only as old as we feel. Whether this is true or not, why even spend time worrying about it? Like Diana Nyad, find a way to make it work for you.

The third and most important mantra Ms. Nyad has given us is to never forget that it’s all about the team. The moment we think it is about ourselves, we fail. Daily living, even at its best, is not a solitary sport, yet many cancer registrars go to work every day thinking that they are alone in their work or that the cancer registry could not possibly survive with them.

Our ability to develop our gratitude and appreciation for others and their contribution to our lives is paramount to success. If you are supervising others or working with a collaborative team, you are in that position by the grace of the team, not by your own efforts. Regardless of your social status, skill sets, or experience, we are cancer registrars by the grace of others. Never forget the team and the support you have. By developing a lifestyle rooted in gratitude and service to others, you will set the stage for success. It has been proven over and over that the more you focus your energy on serving others and helping them to become successful, the less stressed you will be and the greater success and happiness you will experience.

Now, as Diana Nyad knows, it takes a loyal and talented team to accomplish something worthwhile. But there’s something even more important, and that is our dedication and service back to the team. Diana Nyad had some of the best coaches and support available in the world.
But, what if she had jumped off that dock in Cuba and announced that, now that she was in the water, her work was done and that the team would be responsible for doing the rest? You may laugh and think this is ridiculous, but is it really?

Most of us have moments in our journey when we get discouraged or tired. And it is not those random moments here and there that determine our path in life. What keeps us from incredible success are the thought patterns, behaviors, and habits that we respond to automatically, minute by minute and day by day. What you do after you realize you are whining or complaining will differentiate you from 97% of all other individuals. Will you adjust your self-talk, actions, and behaviors to refocus on your goal and continue to search for ways to make it happen? Or will you take a sudden turn into the parking lot of self defeat? It’s a choice we all must make.

Being accountable for ourselves and our actions has less to do with our failures than it does with our successes and how we manage our thoughts and words. Your peers and collaborative partners in the workplace need to hear words of encouragement and support. Are you doing everything you can, plus a bit more, to make sure that everyone reaches the goal and celebrates with you? Don’t ever forget that when you are in the final lap, reaching the shore is not going to be meaningful if you step out of the water and are alone. Who you surround yourself with, who you mentor and support as a person on your team, will determine just how long you can stay in the water and whether you will reach your goal or not. Be the best, the strongest, and the most awe-inspiring, appreciative, and supportive cancer registrar you can be, and then you will accomplish your extreme dream.

References

Michele is a cancer registry speaker, educator, coach, and independent contractor living in Rancho Cucamonga, California. She is the founder of www.CancerRegistrar.com, http://CancerRegistryAcademy.com, and www.RegistryMindset.com offering cancer registry leadership, mentoring and continuing education opportunities. Your comments are welcomed by email to michele@michelewebb.com.
ICD-O-3 Terminology Approved for Use with Cases Diagnosed January 1, 2014 and After

April Fritz, CTR

The Change Management Board of the North American Association of Central Cancer Registries (NAACCR) has approved 36 new terms to be added to existing codes in the International Classification of Diseases for Oncology, Third Edition (ICD-O-3) for use in the United States beginning with cases diagnosed on or after January 1, 2014. Of these terms, 22 are malignant (/3) terms, with the exception of 1 new borderline tumor of the central nervous system, and all of these are reportable. The remaining 14 are benign (/0) or uncertain malignancy (/1) and are not reportable conditions. Table 1 displays the terms approved for use with 2014 diagnoses and forward.

Background

The list of new approved terms is the result of more than 15 months of work by the NAACCR ICD-O-3 Updates Implementation Work Group. In September 2011, the World Health Organization published the first update to the ICD-O-3 since its publication in 2000. The update is based on terms and codes approved by the International Agency for Research on Cancer (IARC)/World Health Organization (WHO) Committee for the International Classification of Diseases for Oncology and incorporated into recently published editions of the WHO Classification of Tumors series, sometimes referred to as the “Blue Books.” These volumes include:

- WHO Classification of Tumors of the Central Nervous System (2007)
- WHO Classification of Tumors of the Hematopoietic and Lymphoid Tissues (2008)
- WHO Classification of Tumors of the Digestive System (2010)

It should be noted that the terms and codes pertaining to the WHO Classification of Tumors of the Hematopoietic and Lymphoid Tissues (fourth edition, 2008) had already been reviewed and accepted by NAACCR and were implemented for use in North America effective with cases diagnosed January 1, 2010. These hematopoietic and lymphoid terms comprised almost half of the terms on the 2011 WHO ICD-O-3 Update List.

In mid-2012, NAACCR formed the ICD-O-3 Updates Implementation Work Group, which is charged with reviewing the WHO Update list and determining the possible impact of implementing the new terms and codes. The Work Group has met about once per month since July 2012 by conference call. On several calls, guest experts were invited to present information about some of the codes and to answer questions from the group. Members reviewed the Updates List and drafted the recommendations. Work Group members also identified more than 20 files, programs, lists, and other documents that will be affected by the implementation of new codes and terms on the Update List, including code ranges in both the Collaborative Stage Data Collection System and the American Joint Commission on Cancer (AJCC) Cancer Staging Manual. The Work Group presented a report to the NAACCR Change Management Board on April 24, 2013, recommending that a list of new ICD-O-3 terms and codes published by the WHO be accepted for inclusion in cancer registry code references for use on and after January 1, 2014. It should be noted that Canada has already implemented the Update List for their national, provincial, and territorial cancer registries. Work Group members from Canada have provided invaluable advice about implementation of the Update List.

The Need for New Terminology

Changes and improvements in diagnostic technology, such as cytogenetics, immunophenotyping, immunohistochemistry, new tumor biomarkers, and advances in equipment have increased the understanding of many malignant diseases. As a result, the terminology used to describe these cancers has been evolving for more than a decade. The newer terminology describes specific subsets of cancers when they are clinically unique, sometimes appending to and sometimes replacing existing terminology. When the WHO’s Blue Books are updated and published, the newer terminology becomes mainstream for pathologists and ends up on pathology reports reviewed by cancer registries.

For example, the islet cell tumors of the pancreas (glucagonoma, insulinoma, and others) are now preferably called pancreatic endocrine tumors and further subcategorized as functioning and non-functioning. Neuroendocrine tumors of the gastrointestinal tract were called carcinoids from 1980 to 2000, then split into well-differentiated endocrine tumors, well-differentiated endocrine carcinoma, and poorly-differentiated endocrine (small cell) carcinoma. Since the 2010 publication of the WHO Digestive System Blue Book, they are now preferably called neuroendocrine tumor grade 1 (carcinoid) (8240/3), neuroendocrine tumor grade 2 (atypical carcinoid) (8249/3), and neuroendocrine carcinoma (large cell 8246/3; small cell 8041/3). The terminology for diffuse adenocarcinoma of the stomach (8145/3) is evolving to poorly cohesive carcinoma, a new synonym for signet ring cell carcinoma (8490/3).

As pathology terminology evolves, it is necessary to add new terms to our standard references, but this must be done with a carefully considered approach.
Table 1. ICD-O-3 Changes Effective January 1, 2014

Use the following new terms, synonyms, and related terms for existing ICD-O-3 codes. Italics indicate a new reportable term.

<table>
<thead>
<tr>
<th>New preferred term</th>
<th>8150/0 Pancreatic endocrine tumor, benign (C25._)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Move former preferred term to synonym</td>
<td>8150/0 Islet cell adenoma (C25._)</td>
</tr>
<tr>
<td>New related term</td>
<td>8150/0 Pancreatic microadenoma (C25._)</td>
</tr>
<tr>
<td>New preferred term</td>
<td>8150/1 Pancreatic endocrine tumor, NOS (C25._)</td>
</tr>
<tr>
<td>Move former preferred term to synonym</td>
<td>8150/1 Islet cell tumor, NOS (C25._)</td>
</tr>
<tr>
<td>New preferred term</td>
<td>8150/3 Pancreatic endocrine tumor, malignant (C25._)</td>
</tr>
<tr>
<td>Move former preferred term to synonym</td>
<td>8150/3 Islet cell carcinoma (C25._)</td>
</tr>
<tr>
<td>New related term</td>
<td>8150/3 Pancreatic endocrine tumor, nonfunctioning (C25._)</td>
</tr>
<tr>
<td>New related term</td>
<td>8152/1 L-cell tumor</td>
</tr>
<tr>
<td>New related term</td>
<td>8152/1 Glucagon-like peptide-producing tumor (C25._)</td>
</tr>
<tr>
<td>New related term</td>
<td>8152/1 Pancreatic peptide and pancreatic peptide-like peptide within terminal tyrosine amide producing tumor</td>
</tr>
<tr>
<td>New synonym for related term</td>
<td>8152/1 PP/PYY producing tumor</td>
</tr>
<tr>
<td>New preferred term</td>
<td>8154/3 Mixed pancreatic endocrine and exocrine tumor, malignant (C25._)</td>
</tr>
<tr>
<td>New related term</td>
<td>8154/3 Mixed endocrine and exocrine adenocarcinoma (C25._)</td>
</tr>
<tr>
<td>New synonym for related term</td>
<td>8154/3 Mixed islet cell and exocrine adenocarcinoma (C25._)</td>
</tr>
<tr>
<td>New related term</td>
<td>8154/3 Mixed acinar-endocrine-ductal carcinoma</td>
</tr>
<tr>
<td>New related term</td>
<td>8201/3 Cribriform comedo-type carcinoma (C18._,C19.9, C20.9)</td>
</tr>
<tr>
<td>New synonym</td>
<td>8201/3 Adenocarcinoma, cribriform comedo-type (C18._,C19.9, C20.9)</td>
</tr>
<tr>
<td>New synonym to primary term</td>
<td>8213/0 Traditional serrated adenoma</td>
</tr>
<tr>
<td>New related term</td>
<td>8213/0 Sessile serrated adenoma</td>
</tr>
<tr>
<td>New related term</td>
<td>8213/0 Sessile serrated polyp</td>
</tr>
<tr>
<td>New related term</td>
<td>8213/0 Traditional sessile serrated adenoma</td>
</tr>
<tr>
<td>New related term</td>
<td>8240/3 Neuroendocrine tumor, grade 1</td>
</tr>
<tr>
<td>New related term</td>
<td>8240/3 Neuroendocrine carcinoma, low grade</td>
</tr>
<tr>
<td>New related term</td>
<td>8240/3 Neuroendocrine carcinoma, well-differentiated</td>
</tr>
<tr>
<td>New preferred term</td>
<td>8244/3 Mixed adenoneuroendocrine carcinoma</td>
</tr>
<tr>
<td>Move former preferred term to synonym</td>
<td>8244/3 Composite carcinoid</td>
</tr>
<tr>
<td>New synonym</td>
<td>8244/3 Combined/mixed carcinoid and adenocarcinoma</td>
</tr>
<tr>
<td>New synonym</td>
<td>8244/3 MANEC</td>
</tr>
<tr>
<td>New synonym</td>
<td>8249/3 Neuroendocrine tumor, grade 2</td>
</tr>
<tr>
<td>New related term</td>
<td>8249/3 Neuroendocrine carcinoma, moderately differentiated</td>
</tr>
<tr>
<td>New synonym</td>
<td>8263/0 Tubulo-papillary adenoma</td>
</tr>
<tr>
<td>New related term</td>
<td>8290/0 Spindle cell oncocytoma (C75.1)</td>
</tr>
<tr>
<td>New related term</td>
<td>8490/3 Poorly cohesive carcinoma</td>
</tr>
<tr>
<td>New related term</td>
<td>8811/0 Plexiform fibromyxoma</td>
</tr>
<tr>
<td>New related term</td>
<td>8970/3 Hepatoblastoma, epithelioid (C22.0)</td>
</tr>
<tr>
<td>New related term</td>
<td>8970/3 Hepatoblastoma, mixed epithelial-mesenchymal (C22.0)</td>
</tr>
<tr>
<td>New related term</td>
<td>9471/3 Medulloblastoma with extensive nodularity</td>
</tr>
<tr>
<td>New related term</td>
<td>9474/3 Anaplastic medulloblastoma</td>
</tr>
<tr>
<td>New related term</td>
<td>9506/1 Extraventricular neurocytoma</td>
</tr>
</tbody>
</table>

**NOTE:** It is important to understand that cancer registry reportability rules based on behavior code still apply. The addition of a /0 or /1 coded term to ICD-O-3 does not imply that it is now reportable, with the exception of benign and borderline tumors of the central nervous system.
islet cell carcinoma" is now a synonym (unbolded and endocrine tumor, malignant) and the former preferred term forward, the new preferred (bolded) term is "pancreatic endocrine tumor, nonfunctioning" and new terms and codes. For example, the code 8150/3 Pancreatic endocrine tumor, malignant (C25._)

[former preferred term]

Islet cell carcinoma (C25._)

former preferred term, now a synonym]

Pancreatic endocrine tumor, nonfunctioning (C25._)

[new related term]

In 2015, 16 new codes and terms will be added to ICD-O-3 (Table 2). Of these, 7 are reportable malignant (/3) tumors and 5 more are reportable borderline (/1) tumors of the central nervous system. Because these are new codes, the terms cannot be used until the codes have been added to registry look-ups and code ranges in software, edits, and/or documentation have been reviewed and updated. Most of these new codes and terms are rare or very site-specific. They are not known to be programmed in any vendor registry software, so trying to use them may result in edit/error messages.

It is important to understand that cancer registry reportability rules based on behavior code still apply. The addition of a /0 or /1 coded term to ICD-O-3 does not imply that it is now reportable, with the exception of benign and borderline tumors of the central nervous system.

Also proposed for 2015 is a behavior and reportability change for carcinoid of the appendix. This change was made in the WHO Classification of digestive system tumors published in 2010. The Work Group agrees with this reportability change, since current terminology for “carcinoid”—well-differentiated neuroendocrine tumor—is coded to 8240/3 and most “former carcinoids” of appendix are already being accessioned under the new terminology. Based on an analysis of data from a large university hospital pathology department and cancer registry, the Work Group believes there will be only a minimal effect on casefinding and abstracting if all carcinoids of the appendix are made reportable.

Remaining Issues

The publication of this list of approved new terms and its dissemination through the US standard setters does not mean that the job of the ICD-O-3 Updates Implementation Work Group is complete. The group continues to meet to draft an implementation guide and education materials for registrars.

In addition, the review of other terms that were included in the WHO Updates List has not been completed. While the WHO Blue Books reflect current thinking and current terminology among pathologists and specialists, reportability to population-based cancer registries is not clear in many instances. NAAACCR is taking a close look at some of the terms and the potential challenges in implementing them as reportable neoplasms in the United States. Most of the problematic terms include the words “high grade neoplasia” or “high grade dysplasia” or “severe dysplasia” in digestive system sites and breast. These dysplasia terms are not included in most states’ reporting legislation. The implications of accepting these terms as reportable

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Table 2. ICD-O-3 Changes Effective January 1, 2015

<table>
<thead>
<tr>
<th>Code</th>
<th>New Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>8150/3</td>
<td>Pancreatic endocrine tumor, malignant (C25._)</td>
</tr>
<tr>
<td>8157/3</td>
<td>Enteroglucagonoma, malignant.</td>
</tr>
<tr>
<td>8240/3</td>
<td>Carcinoid tumor, NOS, of appendix</td>
</tr>
<tr>
<td>8265/3</td>
<td>Micropapillary carcinoma, NOS (C18., C19.9, C20.9)</td>
</tr>
<tr>
<td>8480/1</td>
<td>Low grade appendiceal mucinous neoplasm (C18.1)</td>
</tr>
<tr>
<td>8522/3</td>
<td>Mixed acinar-ductal carcinoma</td>
</tr>
<tr>
<td>8975/1</td>
<td>Calcifying nested epithelial stromal tumor (C22.0)</td>
</tr>
<tr>
<td>9395/3</td>
<td>Papillary tumor of the pineal region</td>
</tr>
<tr>
<td>9425/3</td>
<td>Pilomyxoid astrocytoma</td>
</tr>
<tr>
<td>9431/1</td>
<td>Angiocentric glioma</td>
</tr>
<tr>
<td>9432/1</td>
<td>Pituitocytoma</td>
</tr>
<tr>
<td>9509/1</td>
<td>Papillary glioneuronal tumor</td>
</tr>
<tr>
<td>9509/1</td>
<td>Rosette-forming glioneuronal tumor</td>
</tr>
<tr>
<td>9741/1</td>
<td>Indolent systemic mastocytosis</td>
</tr>
</tbody>
</table>

NOTE: It is important to understand that cancer registry reportability rules based on behavior code still apply. The addition of a /0 or /1 coded term to ICD-O-3 does not imply that it is now reportable, with the exception of benign and borderline tumors of the central nervous system.

Make the following reportability change.

Behavior code change

- Delete code and term, 8240/1, Carcinoid tumor, NOS, of appendix (C18.1).
- Code carcinoid tumor, NOS, of appendix to 8240/3.

Recode the following conditions as shown.

Recode all cases of enteroglucagonoma, NOS, as 8152/1. Then delete code 8157/1 Enteroglucagonoma, NOS. Enteroglucagonoma is now a related term for glucagonoma. Recode all cases of enteroglucagonoma, malignant, as 8152/3. Then delete code 8157/3 Enteroglucagonoma, malignant.

Stepwise Implementation

The Change Management Board approved implementation of a number of terms in the WHO Update List, but in a stepwise manner. For 2014, only terms added to existing codes have been approved (Table 1). This will minimize the impact on vendors, software developers, and registries to update their programs with new codes and terms. The list includes 5 new ‘preferred’ terms added to existing reportable codes (replacing the prior bolded term with a new term). In addition, there are many new ‘related’ terms (aligned even with the bolded preferred term in the ICD-O numeric list) and many new ‘synonyms’ (indented under the preferred term or a related term) for both existing codes and new terms and codes. For example, the code 8150/3 exists in ICD-O-3 as Islet cell carcinoma. Effective 2014 and forward, the new preferred (bolded) term is “pancreatic endocrine tumor, malignant” and the former preferred term “islet cell carcinoma” is now a synonym (unbolded and indented). In addition, the new related term “pancreatic endocrine tumor, nonfunctioning” is aligned with the preferred term as shown below:

8150/3 Pancreatic endocrine tumor, malignant (C25._)

[new preferred term]

Islet cell carcinoma (C25._)

[former preferred term, now a synonym]

Pancreatic endocrine tumor, nonfunctioning (C25._)

[new related term]
are being carefully studied as they may affect not only reporting legislation, but also workload in case ascertainment (casefinding), abstracting, follow-up (as applicable) and incidence reporting. The ICD-O-3 Work Group is cooperating with the Cancer Registry Steering Committee and the College of American Pathologists (among others) to make recommendations on the adoption of various dysplasia terminologies for future implementation.

In addition, other issues regarding morphology coding have been identified. These are not within the original scope of the Work Group but should be addressed sooner rather than later by this or another group established by NAACCR.

• The WHO Classifications of Soft Tissue and Bone, Breast, and Female Genital Organs have been published since 2011. These pathology references include more new terms and codes but they have not been organized into update lists for future adoption. More updated volumes of WHO Classification are planned. If the current Work Group is to continue its charge of reviewing new ICD-O terms for potential implementation in the United States, it will need proactive guidance from the standards setters on handling the new codes, designating codes as obsolete, other changes published in these volumes, and timing of implementation.

• Although the new edition of the Lung WHO Classification is not expected until 2015, updated terms for bronchioalveolar carcinoma—including changes in behavior codes—are already in use by pathologists around the United States and Canada. The new terminology should be reviewed and recommendations for interim codes should be disseminated for consistent use in registries long before the WHO Lung Classification is published.

• Reportability guidelines for gastrointestinal stromal (GIST) tumors have been partially addressed in a sentence added to Facility Oncology Registry Data Standards (FORDS) 2013 and the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) 2013 Coding Manual, which indicate that GIST tumors and thymomas are reportable when there is evidence of multiple foci, lymph node involvement, or metastasis. However, better guidelines for GIST tumors are needed, such as formal interpretation of the “risk assessment” categories as benign, borderline, or malignant.

Publication of ICD-O-3 2012 Revision

The World Health Organization has announced a 2012 revision of ICD-O-3. This updated printing of ICD-O-3 is in press at the time this article was written and is due to be published in the fall of 2013. Be advised that this new printing includes all the terms added to ICD-O-3 in the 2011 WHO Update. Consequently, purchasers of the 2012 revision may be confused by terms added internationally but not yet implemented in the United States. If your ICD-O-3 book is still in reasonably good shape, do not order a replacement yet, as only the terms in Table 1 and Table 2 have been approved in the United States for 2014 and 2015.

Acknowledgements

I gratefully acknowledge the contributions of Shannon Vann, CTR and the other members of the NAACCR ICD-O-3 Updates Implementation Work Group in the preparation of this article. Any questions regarding the new terms or the implementation process can be directed to April Fritz (april@afritz.org) as Chair of the Work Group.
SURVEILLANCE AND INTERPRETATION OF TRENDS IN US AGE-SPECIFIC INCIDENCE RATES FOR PRIMARY LIVER CANCER, IN RELATION TO THE EPIDEMIC OF HEPATITIS C INFECTION

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 trends in age-specific incidence rates for primary liver cancer
- Explain the relationship between hepatitis C virus (HCV) infection and primary liver cancer incidence rates
- Identify sources that can aid in interpreting trends in liver cancer incidence

1. Between 2000 and 2009, overall age-standardized rates for incidence and mortality for primary liver cancer-intrahepatic bile duct cancer were:
   a) among the smallest of all cancer sites examined
   b) among the largest of all cancer sites examined
   c) smallest for individuals aged 50-59 years
   d) smallest for individuals aged 55-64 years

2. According to a Centers for Disease Control and Prevention (CDC) report, age-specific incidence rates showed a decline only for ages:
   a) 20-29
   b) 30-39
   c) 40-49
   d) 50-59

3. The present study examined recent trends (1999-2009) in age-specific incidence rates for liver cancer, excluding:
   a) intrahepatic bile duct cancers
   b) extrahepatic bile duct cancers
   c) liver cell carcinoma
   d) hepatocellular carcinoma (HCC)

4. 5-year cause-specific survival after diagnosis of HCC in Surveillance, Epidemiology and End Results (SEER) is:
   a) 68% for 1-year cause-specific survival
   b) 68% for 5-year cause-specific survival
   c) 18% for 1-year cause-specific survival
   d) 18% for 5-year cause-specific survival

5. Liver cancer is defined in the US Cancer Statistics (USCS) by the SEER Incidence Site Recode group as including:
   a) ICD-O-3 site code C22.0
   b) ICD-O-3 site code C22.1
   c) lymphomas of the liver
   d) hematopoietic diseases of the liver

6. Due to small numbers of cases, the present report:
   a) included cases diagnosed at less than 15 years of age
   b) excluded cases diagnosed at greater than 85 years of age
   c) used 5-year age groups
   d) used 10-year age groups

7. In the USCS database, the numbers of US liver cancer cases diagnosed in the age group 55-64:
   a) decreased slightly
   b) increased slightly
   c) showed the largest increase
   d) showed the smallest increase

8. Among deaths coded to C22.0 or C22.9, the proportion with mention of HCV:
   a) decreased sharply from 1999 to 2000
   b) increased sharply from 1999 to 2000
   c) was smallest for ages 45 to 54
   d) was smallest for ages 55 to 64

9. Time trends in US incidence rates for all primary liver cancers, including HCC, have been interpreted as being related mainly to the epidemic of:
   a) HCV
   b) HIV
   c) diabetes mellitus
   d) obesity

10. According to the article, epidemiologic case-control studies (eg, hospital-based) could estimate the proportion of liver cancers attributable to risk factors such as:
    a) HCV
    b) HIV
    c) tobacco abuse
    d) alcohol abuse
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 □ E □ F □ G □ H
2 □ A □ B □ C □ D □ E □ F □ G □ H
3 □ A □ B □ C □ D □ E □ F □ G □ H
4 □ A □ B □ C □ D □ E □ F □ G □ H
5 □ A □ B □ C □ D □ E □ F □ G □ H
6 □ A □ B □ C □ D □ E □ F □ G □ H
7 □ A □ B □ C □ D □ E □ F □ G □ H
8 □ A □ B □ C □ D □ E □ F □ G □ H
9 □ A □ B □ C □ D □ E □ F □ G □ H
10 □ A □ B □ C □ D □ E □ F □ G □ H

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