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Descriptive Epidemiology of Malignant Primary Osteosarcoma Using Population-based Registries, United States, 1999-2008

Linh M. Duong, MPH; Lisa C. Richardson, MD, MPH

Abstract: Background: Osteosarcoma is a rare bone tumor that is the most frequently diagnosed among children and adolescents, although this cancer affects people of all ages. This study aims to augment the current literature by examining the incidence of osteosarcoma by its subsites on a national level. Methods: Data from central cancer registries in the National Program of Cancer Registries (NPCR) and Surveillance, Epidemiology, and End Results (SEER) programs for diagnosis years 1999-2008 and covering 90.1% of the US population were analyzed. Analyses included cases of malignant primary osteosarcomas, which were further segmented by topography, appendicular (C40) and axial (C41), to assess differences between these sites. Descriptive statistics, including estimated age-adjusted incidence rates standardized to the 2000 US standard population, were calculated using SEER*Stat 7.0.5 software. Results: Approximately 7,104 cases of malignant primary osteosarcomas were identified during 1999-2008, of which 5,379 were appendicular and 1,725 were axial. The incidence of malignant primary osteosarcomas differed by age, gender, race, ethnicity, region, grade, and stage. These differences in incidence persisted when malignant primary osteosarcomas were categorized by topography codes. Conclusions: These analyses provide a better understanding of the incidence of malignant osteosarcoma which cover 90.1% of the US population from 1999-2008. This study provides a more detailed understanding of age, gender, race, and ethnicity by primary site for malignant osteosarcoma incidence on a national level in the United States. More importantly, differences between appendicular and axial sites were observed overall by selected demographic characteristics, in particular regional variations.

Key words: osteosarcoma, epidemiology, malignant, incidence, primary site

Introduction

Osteosarcoma is a rare bone tumor that is most frequently diagnosed among children and adolescents, although this cancer affects people of all ages. While the incidence of primary osteosarcoma peaks during adolescence, a second incidence peak occurs among individuals over age 60, most commonly in the seventh or eighth decades of life. Among 15-29 year olds, most osteosarcomas occurred in the metaphyses of long bones and particularly the distal femur, proximal humerus, and the proximal tibia. Among older adults, osteosarcomas are more likely to occur in the axial skeleton locations and in areas that have been previously irradiated or have underlying bone abnormalities. Males are affected more frequently than females except during the first decade of life.

Currently, there is a paucity of information on osteosarcoma in the US population. In order to understand the burden of osteosarcoma, this study will analyze the incidence of osteosarcoma by topography (primary site) and demographic characteristics, including age groups, race, ethnicity, and gender.

Materials and Methods

Microscopically confirmed incident cases of invasive primary osteosarcoma were identified from population-based cancer registries that participated in the Centers for Disease Control and Prevention’s (CDC) National Program of Cancer Registries (NPCR) or the National Cancer Institutes’ (NCI) Surveillance, Epidemiology, and End Results (SEER) Program. NPCR supports central cancer registries (CCRs) in 45 states, the District of Columbia, Puerto Rico, and US Pacific Island jurisdictions, which cover approximately 96% of the US population. Together, NPCR and SEER collect cancer incidence data for the entire US population. Cancer incidence data for this study included those from the NPCR-Cancer Surveillance System (NPCR-CSS) November 2010 submission and the November 2010 SEER submission. The analyses focused on microscopically confirmed incident malignant primary osteosarcoma cases diagnosed between 1999-2008 from CCRs in 44 states that met case ascertainment and quality criteria for all 10 years. These data cover approximately 90.1% of the US population during these 10 years. Data from 6 states and the District of Columbia (7 CCRs) were excluded because case ascertainment and...
quality criteria standards were not met for the entire time period.

Tumors were included in the study if they were the only primary tumor or the first of 2 or more independent primary tumors for the patient. All malignant primary osteosarcomas were classified according to the International Classification of Diseases for Oncology (ICD-O-3). Since the International Classification of Childhood Cancers (ICCC) is similar to ICD-O-3 for osteosarcomas, it was decided to use the classification schemes from ICD-O-3 only. We included all malignant primary osteosarcomas (primary site code C40.0-40.9 and histology codes 9180/3-9187/3, 9192/3-9195/3, 9200/3) in these analyses. Table 1 shows the topography codes (primary site) used to define appendicular and axial sites for malignant primary osteosarcomas. Osteosarcoma histologic groupings were coded according to the version of the International Classification of Diseases for Oncology (ICD-O) used at the time of diagnosis. The osteosarcoma cases diagnosed from 1999 to 2000 used the ICD-O second edition (ICD-O-2), and those from 2001 to 2008 used the ICD-O third edition (ICD-O-3); data from the 1999-2000 diagnosis years were converted to the ICD-O-3 codes. Table 2 shows the histologic codes used to define malignant primary osteosarcomas in these analyses.

Cancer stage was assigned SEER summary stage 1977 (SS77) for cases diagnosed before 2001, SEER summary stage 2000 (SS2000) for cases diagnosed during 2001-2003, and derived summary stage using the collaborative stage algorithm for cases diagnosed in 2004 or later. These data were then aggregated to obtain an overall frequency count for stage. Stage was categorized as in situ, localized, regional, distant, or unstaged. Grade was categorized as I (well differentiated), II (moderately differentiated), III (poorly differentiated), IV (undifferentiated/anaplastic), or unknown.

Race was categorized as white, black, American Indian/Alaska Native (AI/AN), Asian/Pacific Islander (API), or other/unknown race. To increase the accuracy of the AI/AN designation, linkages between the CCRs and the Indian Health Service (IHS) database were completed before data submission to NPCR and SEER. Ethnicity was categorized as Hispanic or non-Hispanic based on the North American Association of Central Cancer Registries (NAACCR) Hispanic/Latino Identification Algorithm (NHIA) which employs a combination of variables to assign Hispanic/Latino classification to cancer cases. Cases that are not classified as Hispanic by NHIA are classified as non-Hispanic which leaves no cases with an unknown Hispanic status. Race and ethnicity are not mutually exclusive.

Frequencies by demographic and tumor characteristics for all malignant primary osteosarcomas were calculated. Age-adjusted incidence rates with 95% confidence intervals

| Table 1. Topography Codes* Used to Define Malignant Primary Osteosarcomas† by Appendicular and Axial Sites, United States, 1999-2008 |
|-----------------|-----------------|
| **Topography Definitions for Malignant Primary Osteosarcomas** | **Topography Codes** |
| Appendicular | C40 |
| Long bones of upper limb, scapula, and associated joints | C40.0 |
| Short bones of upper limb and associated joints | C40.1 |
| Long bones of lower limb and associated joints | C40.2 |
| Short bones of lower limb and associated joints | C40.3 |
| Overlapping lesion of bones, joints, and articular cartilage of limbs | C40.8 |
| Bone of limb, NOS‡ | C40.9 |
| Axial | C41 |
| Bones of skull and face and associated joints | C41.0 |
| Mandible | C41.1 |
| Vertebral column | C41.2 |
| Rib, sternum, clavicle, and associated joints | C41.3 |
| Pelvic bones, sacrum, coccyx, and associated joints | C41.4 |
| Overlapping lesion of bones, joints, and articular cartilage | C41.8 |
| Bone, NOS | C41.9 |

†The analyses were limited to microscopically confirmed osteosarcomas.
‡NOS, not otherwise specified.

| Table 2. Histology Categories and ICD-O-3,* Codes Used to Define Malignant Primary Osteosarcomas,† United States, 1999-2008 |
|-----------------|-----------------|
| **Histology Definitions for Primary Malignant Osteosarcomas** | **ICD-O-3 Codes** |
| Osteosarcoma, NOS‡ | 9180/3 |
| Chondroblastic osteosarcoma | 9181/3 |
| Fibroblastic osteosarcoma | 9182/3 |
| Telangiectatic osteosarcoma | 9183/3 |
| Osteosarcoma in Paget disease | 9184/3 |
| Small cell osteosarcoma | 9185/3 |
| Central osteosarcoma | 9186/3 |
| Intraosseous well differentiated osteosarcoma | 9187/3 |
| Paraosteal osteosarcoma | 9192/3 |
| Periosteal osteosarcoma | 9193/3 |
| High grade surface osteosarcoma | 9194/3 |
| Intracortical osteosarcoma | 9195/3 |
| Malignant osteosarcoma | 9200/3 |

*ICD-O-3 indicates International Classification of Diseases for Oncology-3rd Edition.
†The analyses were limited to microscopically confirmed osteosarcomas.
‡NOS, not otherwise specified.
(95% CI) for all malignant primary osteosarcomas were calculated overall, and by gender, race, ethnicity, US Census regions (Northeast, Midwest, South, and West), grade, and stage. Rates were expressed per 1,000,000 persons and age-adjusted using the US 2000 population standard (19 age groups—Census P25-1130). Counts and rates based on fewer than 16 cases were not presented to ensure rate stability and confidentiality. All data analyses for this study were performed using SEER*Stat version 7.0.5.\(^6\)

**Results**

Table 3 shows demographic and tumor characteristics for malignant osteosarcomas by topography (primary site) for cases diagnosed during the 1999-2008 period. Of the reported 7,104 malignant osteosarcoma incident cases diagnosed from 1999 to 2008, 5,379 (76%) were appendicular and 1,725 (24%) were axial. The age-adjusted incidence rate for appendicular malignant osteosarcomas (2.06 per 1,000,000) was higher than axial (0.65 per 1,000,000).

Rates for appendicular malignant osteosarcoma peaked for 2 age groups: 10-19 years and 80+ years. However, for axial malignant osteosarcomas, incidence rates were much lower and the peaks varied more with peaks at 10-19 years of age, at 40-49 years of age, and 80+ years. The age-specific incidence rate for appendicular malignant osteosarcomas was lowest among adults aged 50-59 years (0.78 per 1,000,000) and was highest among adolescents aged 10-19 years (7.08 per 1,000,000). However, the age-specific incidence rate for axial malignant osteosarcoma was lowest among children aged less than 10 years (0.11 per 1,000,000) and highest among adults aged 80+ years (1.17 per 1,000,000).

Moreover, differences in malignant osteosarcomas by gender were also observed. Among axial malignant osteosarcoma, the frequency was distributed almost equally by gender, whereas among appendicular malignant osteosarcoma cases, the distribution was slightly higher among males (57%) compared with females (43%). In addition, the appendicular malignant osteosarcoma age-adjusted rates among males (2.32 per 1,000,000) were higher than those observed among females (1.79 per 1,000,000) but no difference was seen in axial malignant osteosarcomas age-adjusted incidence rates by gender.

Among appendicular and axial cases, the predominant race group was whites (approximately 80%) followed by blacks (16%). Age-adjusted rates for appendicular and axial malignant osteosarcomas were higher among blacks than whites, American Indian/Alaska Natives, or Asian/Pacific Islanders. With respect to ethnicity, non-Hispanics accounted for approximately 81% of the reported cases among appendicular malignant osteosarcomas but almost 90% among axial malignant osteosarcomas. Moreover, Hispanics age-adjusted incidence for appendicular malignant osteosarcomas was higher than non-Hispanics.

Among appendicular and axial cases the geographic region with the largest proportion of cases (approximately 30%) occurred in the South with about 20%-26% of the remaining cases distributed in each of the remaining 3 regions (Northeast, Midwest, and West). Appendicular and axial rates among the 4 geographic regions were not different.

More than one third of appendicular cases were grade IV (37%), followed by unknown grade (29%) and grade III (25%). For the axial site, unknown grade contributed 33% of cases followed by grade III (27%), and grade IV (25%). The age-adjusted incidence rates were higher among appendicular cases for grade IV (0.77 per 1,000,000) when compared with other grades, whereas unknown cases accounted for the highest incidence rate (0.22 per 1,000,000) for axial cases.

For appendicular osteosarcomas, the highest proportion of cases were localized (41%). Most axial cases were diagnosed with regional stage (37%). The age-adjusted rates were higher among appendicular cases for localized stage (0.84 per 1,000,000), whereas regional stage (0.24 per 1,000,000) was higher for axial cases. Total malignant osteosarcomas had the highest age-adjusted incidence rates in localized stage (1.01 per 1,000,000) compared with other stages at diagnosis. Appendicular osteosarcomas had the highest age-adjusted incidence rates in the localized stage (0.84 per 1,000,000) compared with regional stage (0.24 per 1,000,000) among axial osteosarcomas.

Figure 1 presents the incidence of malignant osteosarcomas by primary site and age (5-year intervals). Incidence rates peaked among 2 age groups: 15-19 year-olds (adolescence) and 80-84 year-olds (elderly).

**Discussion**

These analyses provide detailed information on the descriptive epidemiology of malignant osteosarcomas complementing 2 recent studies published by Mirabello et al which reported the incidence and survival rates of osteosarcoma from 1973 to 2004 using SEER data in the United States, as well as the international osteosarcoma incidence patterns among children and adolescents, and middle-aged and elderly persons.\(^3,17\) The current study covers more than 90% of the US population. Together, these studies provide a detailed assessment of the burden of primary osteosarcomas.

Our results confirms previous findings of a bimodal frequency distribution for osteosarcoma incidence by age with the first peak occurring during adolescence and the second peak among adults over 60 years of age in the United States.\(^3,6,17,317\) Anfinsen et al reported a bimodal distribution with the highest incidence rate occurring in the second decade of life, with a decline between 30 and 50 years of age, followed by a second peak among those aged 75-79.\(^5\) Mirabello et al study reported an observed bimodal osteosarcoma incidence pattern.\(^3\)

Differences in incidence rates by gender were found overall and by primary site. Among axial osteosarcoma, the frequency was distributed almost equally by gender, whereas among total and appendicular malignant osteosarcoma cases, the distribution was higher among males compared with females. An international study by Mirabello et al on osteosarcomas also reported that osteosarcoma was more common in males than females in most countries.\(^17\) Bleyer et al reported a higher incidence of malignant osteosarcomas among males than females among the adolescent and
young adult population in the United States. Anfinsen et al reported that male predominance was generally apparent at the older ages and at ages less than 30 years, in contrast to modest and inconsistent sex differences among the middle age groups in the United States. A possible explanation for these observed sex differences in osteosarcoma incidence rates may be attributed to hormonal differences between genders. The effects of these sex steroids have been well-documented both in vivo and in vitro. However, there is limited research on the possible effects of sex steroids in human osteosarcomas. Study findings by Dohi et al, however, suggest that inhibitors of sex steroid actions could be a potential treatment for osteosarcoma in the future. A study in England by Arora et al reported that a key factor in osteosarcoma development may be related to pubertal bone growth due to observed variations in incidence patterns by age and site. However, Arora et al stated that although pubertal growth may be a biological plausibility, further research may be required to establish this link.

Differences were observed in our study by race and ethnicity separately. Among appendicular and axial cases, approximately 80% were found among whites followed by blacks (16%). In contrast, age-adjusted incidence rates for appendicular and axial malignant osteosarcomas were higher among blacks compared with other racial groups. Mirabello et al have reported similar results using SEER data. With respect to ethnicity, non-Hispanics accounted for approximately 81% of the reported cases among total and appendicular malignant osteosarcomas but almost 90% among axial malignant osteosarcomas. Moreover, Hispanics had a higher age-adjusted incidence rate than non-Hispanics for appendicular but a similar rate for axial cases. Bleyer et al reported that Hispanics had the highest incidence of osteosarcoma among those aged 15-29 in the United States. There were no differences observed in the regional data within subsites we analyzed. The Northeast, Midwest, South, and West all had similar incidence rates within their

<table>
<thead>
<tr>
<th>Table 3. Description of Primary Osteosarcoma Incidence by Selected Characteristics, United States, 1999-2008</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appendicular (C40)</strong></td>
</tr>
<tr>
<td>Count (%)</td>
</tr>
<tr>
<td>Total</td>
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<tr>
<td>Age at diagnosis, years</td>
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<td>00-09</td>
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<td>20-29</td>
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<td>South</td>
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<td>West</td>
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</table>
Table 3, cont. Description of Primary Osteosarcoma Incidence by Selected Characteristics, United States, 1999-2008

<table>
<thead>
<tr>
<th>Grade</th>
<th>Appendicular (C40)</th>
<th>Axial (C41)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count (%)</td>
<td>Rate† (95% CI)</td>
<td>Count (%)</td>
</tr>
<tr>
<td>Grade I</td>
<td>220 (4.1%)</td>
<td>0.08 (0.07, 0.09)</td>
<td>95 (5.5%)</td>
</tr>
<tr>
<td>Grade II</td>
<td>261 (4.9%)</td>
<td>0.10 (0.09, 0.11)</td>
<td>153 (8.9%)</td>
</tr>
<tr>
<td>Grade III</td>
<td>1,350 (25.1%)</td>
<td>0.52 (0.49, 0.54)</td>
<td>462 (26.8%)</td>
</tr>
<tr>
<td>Grade IV</td>
<td>2,012 (37.4%)</td>
<td>0.77 (0.74, 0.81)</td>
<td>439 (25.4%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1,536 (28.6%)</td>
<td>0.59 (0.56, 0.62)</td>
<td>576 (33.4%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage at diagnosis§</th>
<th>Appendicular (C40)</th>
<th>Axial (C41)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>In situ</td>
<td>0 (0.0%)</td>
<td>0.00 (0.00, 0.00)</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td>Localized</td>
<td>2,181 (40.5%)</td>
<td>0.84 (0.80, 0.87)</td>
<td>472 (27.4%)</td>
</tr>
<tr>
<td>Regional</td>
<td>1,837 (34.2%)</td>
<td>0.70 (0.67, 0.74)</td>
<td>630 (36.5%)</td>
</tr>
<tr>
<td>Distant</td>
<td>938 (17.4%)</td>
<td>0.36 (0.34, 0.38)</td>
<td>393 (22.8%)</td>
</tr>
<tr>
<td>Unstaged</td>
<td>423 (7.9%)</td>
<td>0.16 (0.15, 0.18)</td>
<td>230 (13.3%)</td>
</tr>
</tbody>
</table>

*Counts pertain to 90.1% of U.S. population covered by eligible cancer registries. Data from 7 central cancer registries are not included.
†Rates are per 1,000,000 persons and age-adjusted to the 2000 US standard population (19 age groups—Census P25-1130) except age-specific rates which were not age-adjusted.
‡95% CI indicates 95% confidence interval and were calculated using the Tiwari modification.
§Other unspecified/unknown race accounted for 106 (1.5%) cases of primary osteosarcomas.
||Race and ethnicity are not mutually exclusive.
¶SEER summary stage 1977 was used for 1999–2000 cases, SEER summary stage 2000 was used for 2001–2003 cases, and derived summary stage 2000 (also known as collaborative stage) was used for 2004–2008 cases.
#Not presented due to count or rate instability or complementarily suppressed for confidentiality.
AI/AN, American Indian/Alaska Native; API, Asian/Pacific Islander; SEER, National Cancer Institute’s Surveillance, Epidemiology, and End Results Program.
Percentages may not add to 100% because of rounding. The analyses were limited to microscopically confirmed osteosarcomas.

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Figure 1. Incidence of Primary Malignant Osteosarcomas, United States, 1999-2008

Rates are per million persons and age-adjusted to the 2000 US standard population (19 age groups—Census P25-1130). Rates pertain to 90.1% of the US population covered by eligible cancer registries. Data from 7 central cancer registries are not included.
respective subsites. However, differences were observed between subsites. The incidence of osteosarcoma in the appendicular sites tended to be higher (ranged between 2.03-2.10 per 1,000,000) in these regions than axial (ranged between 0.57-0.70 per 1,000,000). An international study by Mirabello et al reported minimum variability in osteosarcoma incidence rates between countries in individuals ≤24 years. The country data were from the Cancer Incidence in Five Continents from the International Agency for Cancer Research (IARC) database. Overall, they reported that worldwide osteosarcoma incidence rates varied mostly among the elderly with little geographic variation among the younger age group.24

Our findings should be considered in light of several limitations. In registry data, there is a possibility of misclassification or miscoding especially with rare tumors. In addition, data were not available for 7 CCR in the 1999-2008 analytic dataset because they did not meet case ascertainment and quality criteria.9 The exclusion of these CCRs may have influenced the observed osteosarcoma incidence rates. Although we used data that had been linked to the IHS database to increase the accuracy of the AI/AN designation, race misclassification of these cases and other cases may still remain. However, a study by Clegg et al indicated that this may not be a strong limitation for cancer incidence any longer.24 Finally, even though the NHIA algorithm was used to assign ethnicity for Hispanics, ethnicity misclassification may also occur.24 Despite these limitations, our study is one of the first to report on malignant osteosarcoma incidence by primary site which covers over 90% of the US population. In addition, we were among the first studies to categorize osteosarcoma by appendicular and axial sites. Differences observed in these analyses between these sites provide further insight into the incidence of these tumors in these sites.

These analyses provide a better understanding of the incidence of malignant osteosarcoma using population-based data covering approximately 90.1% of the US population during 1999-2008. In addition, these analyses provide a more detailed understanding of age, gender, race, and ethnicity by primary site for malignant osteosarcoma incidence on a national level in the United States. More importantly, differences between appendicular and axial sites were observed overall by selected demographic characteristics, in particular regional variations. These analyses by subsites are a strength of this study.

Acknowledgements

The authors would like to acknowledge the contribution of hospital and central cancer registry staff who collected and processed the data used in this study.

These data were provided by the statewide central cancer registries participating in either the National Program of Cancer Registries (NPCR) and were submitted to CDC in the November 2010 data submission or to the Surveillance, Epidemiology, and End Results (SEER) Program in the November 2010 submission. The dataset includes data for diagnosis years 1999-2008.

References

Validation of a Large Basal Cell Carcinoma Registry

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Abstract: Background: The epidemiological study of basal cell carcinomas (BCCs) is difficult because BCCs lack distinct disease codes and are excluded from most cancer registries. Objective: To develop and validate a large BCC registry based on electronically assigned Systematized Nomenclature of Medicine (SNOMED) codes and text-string searches of electronic pathology reports from Kaiser Permanente Northern California. Methods and Materials: Potential BCCs were identified from electronic pathology reports (n=39,026) in 2005 and were reviewed by a dermatologist who assigned case/non-case status (gold-standard). A subset of the records (n=9,428) was independently reviewed by a second dermatologist to ascertain reliability of case assignment. In addition, a subset of excluded electronic pathology reports from 2005 (n=2,700) was reviewed to determine whether inclusion criteria had missed potential BCCs. We calculated the positive predictive value (PPV) of 3 different algorithms for identifying BCCs from electronic pathology data. Results: BCC-specific SNOMED codes had the highest PPV for identifying BCCs, 0.992 (95% CI: 0.991-0.993) for identifying BCCs. Inter-rater reliability for case assignment was high (kappa=0.92, 95% CI: 0.91-0.93). Standardized incidence rates were consistent with previously published rates in the United States. Conclusions: We created and validated a large BCC registry to serve as a unique resource for studying BCCs.

Key words: registry, skin cancer, basal cell carcinoma, SNOMED, validation

Introduction

Non-melanoma skin cancer (NMSC), including basal cell carcinoma (BCC) and squamous cell carcinoma (SCC), are the most common malignancies in the United States, afflicting more than 2 million Americans annually.1 Despite the large population affected, NMSC has proven difficult to study, due in part to its exclusion from large national cancer registries such as the Surveillance, Epidemiology and End Results (SEER) program. Epidemiologic estimates of NMSC are often based on periodic surveys and are generally outdated, with the last National Cancer Institute-funded survey performed more than 3 decades ago.2 Studies that rely on disease codes have historically combined BCCs and SCCs, as they share the same International Classification of Diseases (ICD) identifiers. Such data limitations hinder the study of BCC etiology, prevalence, incidence, and disease burden. A BCC registry would be important resource for studying BCC epidemiology and could help identify novel risk factors associated with its increased incidence, more accurately capture its socioeconomic disease burden, and help target screenings and preventative efforts.

We developed and validated a BCC registry at Kaiser Permanente Northern California (KPNC) based on electronic pathology reports. All non-Pap smear pathology reports with relevant Systematized Nomenclature of Medicine (SNOMED) codes or text-strings for skin tissue specimens collected during 2005 (n=39,026) were reviewed by a board-certified dermatologist. Each report was assigned case/non-case status (“gold standard”), and a subset of records was independently reviewed by a second board-certified dermatologist to ascertain intra-rater reliability. In addition, a random sample of approximately 1% of all non-Pap smear pathology records obtained in 2005 that did not meet inclusion criteria for possible BCC (n=2,700) were reviewed to capture BCC specimens potentially missed by the SNOMED code/text-string inclusion criteria. We calculated the positive and negative predictive value of the SNOMED codes in identifying BCCs, the incidence of BCC in our total population by age and gender, and compared standardized incidence rates to other population-based BCC incidence estimates.

Materials and Methods

Study Setting

KPNC is a large, integrated health-care delivery system that provides comprehensive health care and pharmaceutical benefits to a large and diverse community-based population of over 3.2 million members residing in Northern California. KPNC’s membership represents approximately 33% of the insured population and 28% of the total population in its service area. Compared with the underlying insured and uninsured catchment population, the KPNC membership has similar racial diversity (although with fewer Latinos) and slightly lower income and education than the underlying population.3

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In 1997, KPNC implemented a computerized electronic records system for all pathology specimens received for examination. Information in the electronic pathology record includes text fields recording specimen type, anatomic location, gross and microscopic diagnoses, as well as assigned SNOMED codes. SNOMED codes are automatically assigned based on a standardized classification of pathology diagnoses by organ or location (topography code) and morphological alterations (morphology code).4

### Study Population

We first identified all electronic pathology reports of pathology specimens excluding Pap smears collected between January 1, 2005 and December 31, 2005 (n=351,454). We then identified reports containing potential BCC diagnoses as follows: reports assigned a SNOMED code of 809xx, 80003, or 80103 (Table 1) or with pathology report text-strings “basal cell carcinoma,” “BCC,” “basosquam,” “basisquam,” “basal-squam,” “basal squam.”

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This study was approved by the Kaiser Foundation Research Institute Institutional Review Board. The Declaration of Helsinki protocols were followed and a waiver of informed consent was obtained due to the nature of the study.

### Case Assignment

The study dermatologist (MA) reviewed each electronic potential BCC pathology report and assigned a case

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**Table 1. SNOMED Codes Used to Identify BCCs**

<table>
<thead>
<tr>
<th>SNOMED ID</th>
<th>SNOMED Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>M809xx</td>
<td>(Basal cell neoplasms)</td>
</tr>
<tr>
<td>M80901</td>
<td>Basal cell tumor</td>
</tr>
<tr>
<td>M80902</td>
<td>In situ</td>
</tr>
<tr>
<td>M80903</td>
<td>Basal cell carcinoma, NOS</td>
</tr>
<tr>
<td>M809031</td>
<td>Basal cell carcinoma, NOS, well differentiated</td>
</tr>
<tr>
<td>M809032</td>
<td>Basal cell carcinoma, NOS, moderately differentiated</td>
</tr>
<tr>
<td>M809033</td>
<td>Basal cell carcinoma, NOS, poorly differentiated</td>
</tr>
<tr>
<td>M809034</td>
<td>Basal cell carcinoma, NOS, undifferentiated</td>
</tr>
<tr>
<td>M80906</td>
<td>Metastatic</td>
</tr>
<tr>
<td>M809063</td>
<td>Basal cell carcinoma, NOS, poorly differentiated, metastatic</td>
</tr>
<tr>
<td>M80913</td>
<td>Multicentric basal cell carcinoma</td>
</tr>
<tr>
<td>M80922</td>
<td>Basal cell carcinoma, morphea type, in situ</td>
</tr>
<tr>
<td>M80923</td>
<td>Basal cell carcinoma, morphea type</td>
</tr>
<tr>
<td>M80933</td>
<td>Basal cell carcinoma, fibroepithelial type</td>
</tr>
<tr>
<td>M80942</td>
<td>Basosquamous carcinoma, in situ</td>
</tr>
<tr>
<td>M80943</td>
<td>Basosquamous carcinoma</td>
</tr>
<tr>
<td>M809431</td>
<td>Basosquamous carcinoma, well differentiated</td>
</tr>
<tr>
<td>M809432</td>
<td>Basosquamous carcinoma, moderately differentiated</td>
</tr>
<tr>
<td>M809433</td>
<td>Basosquamous carcinoma, poorly differentiated</td>
</tr>
<tr>
<td>M80946</td>
<td>Basosquamous carcinoma, metastatic</td>
</tr>
<tr>
<td>M80953</td>
<td>Metatypical carcinoma</td>
</tr>
<tr>
<td>M80960</td>
<td>Intraepidermal epithelioma of Jadassohn</td>
</tr>
<tr>
<td>M80003:</td>
<td>Neoplasm, malignant</td>
</tr>
<tr>
<td>Neoplasm,</td>
<td></td>
</tr>
<tr>
<td>malignant</td>
<td></td>
</tr>
<tr>
<td>M800031</td>
<td>Neoplasm, malignant, well differentiated</td>
</tr>
<tr>
<td>M800032</td>
<td>Neoplasm, malignant, moderately differentiated</td>
</tr>
<tr>
<td>M800033</td>
<td>Neoplasm, malignant, poorly differentiated</td>
</tr>
<tr>
<td>M800034</td>
<td>Neoplasm, malignant, undifferentiated</td>
</tr>
<tr>
<td>M80103:</td>
<td>Carcinoma, NOS; epithelial tumor, malignant</td>
</tr>
<tr>
<td>Carcinoma,</td>
<td></td>
</tr>
<tr>
<td>NOS</td>
<td></td>
</tr>
<tr>
<td>M801031</td>
<td>Carcinoma, NOS, well differentiated</td>
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<td>M801032</td>
<td>Carcinoma, NOS, moderately differentiated</td>
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<tr>
<td>M801033</td>
<td>Carcinoma, NOS, poorly differentiated</td>
</tr>
<tr>
<td>M801034</td>
<td>Carcinoma, NOS, undifferentiated</td>
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</tbody>
</table>

**Table 2. Validity of Algorithms in Identifying Pathology-proven BCCs**

<table>
<thead>
<tr>
<th>SNOMED codes</th>
<th>Pathology Review PPV</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cancer</td>
</tr>
<tr>
<td>Algorithm 1</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>24,284</td>
</tr>
<tr>
<td>No Cancer</td>
<td>782</td>
</tr>
<tr>
<td>Algorithm 2</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>24,387</td>
</tr>
<tr>
<td>No Cancer</td>
<td>679</td>
</tr>
<tr>
<td>Algorithm 3</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>24,248</td>
</tr>
<tr>
<td>No Cancer</td>
<td>818</td>
</tr>
</tbody>
</table>

*Numbers reported represent unique pathology reports, not individuals. Some individuals have multiple pathology reports in 2005.

†BCC based on SNOMED code M809xx.

‡BCC based on SNOMED codes M809xx, M80003 or M80103.

§BCC based on SNOMED codes M809xx, M80003 OR M80103 and pathology record text-strings “basal cell carcinoma,” “BCC,” “basosquam,” “basisquam,” “basal-squam,” “squamous-basal,” and “basal squam.”
status (binary variable, yes/no) based on whether the pathology report definitively identified at least basal cell carcinoma among the tissue specimens collected (“gold standard”). Pathology reports with no definitive diagnosis, with benign lesions included in the pathologist’s differential, or with excision specimens indicating no residual tumor were not assigned cases status. A subset of potential BCC pathology reports selected by consecutive member medical record number was adjudicated by a second dermatologist reviewer to assess inter-rater reliability.

### Development of Algorithms

We devised 3 algorithms to identify BCCs. The first and simplest algorithm was based solely on the BCC-specific SNOMED codes M809xx. The second, less stringent algorithm, increased the range of SNOMED codes to include SNOMED codes M80003 or M80103 in addition to M809xx. The third algorithm searched for relevant text-strings in addition to the expanded SNOMED code list. We tested these 3 algorithms to assess how different identification algorithms impacted positive predictive value (PPV) (Table 2).

### Statistical Analysis

We calculated positive predictive values comparing electronic identification of BCC based on SNOMED codes and text-strings to pathology record review (gold standard) using the 3 different identification algorithms. We calculated the negative predictive value for the 2,700 reviewed pathology reports with no SNOMED codes or text strings suggestive of BCC. The Wilson score interval method was used to calculate 95% confidence intervals for negative predictive value (NPV) and PPV. We calculated the simple kappa coefficient as a measure of inter-rater agreement. We calculated overall incidence rates (counts of BCC events among KPNC members in 2005) and stratified rates by age and sex. Finally, we applied our 5-year age and sex stratified rates to US 2000 Census population estimates and calculated a directly standardized rate to allow comparison to other study populations.

### Results

A total of 25,066 BCCs were diagnosed among 17,880 KPNC members in 2005, 58.2% of whom were male (n=10,401). The mean age of the cohort as of January 1, 2005 was 66.4 years (+13.7 years). We found that relevant SNOMED codes (Table 1) and text-strings had high PPV in identifying BCCs irrespective of the algorithm used (Table 2). The best identification was achieved with the algorithm using only SNOMED codes specific to BCCs (M809xx codes) with no additional text-string requirements resulting in a PPV of 99.2%. Algorithms using additional information did not improve PPV. As shown in Table 3, inter-rater reliability in case assignment was high between the 2 dermatologists (0.92, 95% CI 0.91-0.93). We observed no BCCs in 2,700 randomly selected non-Pap smear records (of 319,594 potential records) that had been excluded from the initial pool of potential BCC pathology reports chosen for review. The resulting NPV of 100% (95% CI: 99.86%, 100.00%) suggests that our algorithm for selecting pathology records missed very few BCC pathology specimens.

To further validate our methods of capturing BCCs, we calculated the incidence of BCCs by age and sex strata in a total KPNC membership base of 3,094,819 (measured mid-year at June 30, 2005), summarized in Table 4. The overall incidence of BCCs was 5.8 per 1,000 KPNC members. For females, the overall rate was 4.7/1,000, while for males it was 6.9/1,000 members. Rates ranged from 0.003/1,000 in those under age 10 to 40.1/1,000 in those 85 and older (0.003-28.2/1,000 for females; 0.003-61.9/1,000 for males). Incidence rates of BCCs standardized to the US 2000 population census stratified by age categories and gender are also shown in Table 4. BCCs were more common in males, and incidence increased with age across both genders.

### Discussion

The study of NMSC is difficult because, unlike most malignancies, NMSCs are not systematically reported to national cancer registries, such as SEER. While administrative claims can be used to identify NMSC, they cannot be used to distinguish between BCC and SCC as ICD codes for NMSC have historically been non-specific. One method of distinguishing between BCCs and SCCs is use of natural language processing of the electronic medical record, which has shown considerable variation in ascertainment compared to claims-based data. Although population-based BCC registries are available in the Netherlands, Denmark, and Spain, there are no large, validated BCC registries currently available in the United States.

We developed and validated a large registry of 17,888 individuals with at least one biopsy-proven BCC in 2005 in a health-maintenance organization setting. Our data show that BCC-specific SNOMED codes are highly accurate in identifying biopsy-proven BCCs. Inter-rater reliability of case assignment based on pathology records among 2 board-certified dermatologists was high. To examine the possibility that SNOMED codes missed some cases of BCC, we reviewed a random sample of pathology reports excluded by the initial identification algorithm and found no additional cases.

Our 2005 standardized BCC incidence rate is consistent with previously reported BCC incidence rates in the United States, suggesting accurate and comprehensive disease capture. Based on our standardized rates of BCC incidence, we would expect nearly 1.5 million incident BCCs annually in the United States. The most recently published estimate of annual NMSC in the United States, based on claims-based data, approximated the total number.
of persons treated for NMSC in 2006 at 2,152,500 but could not differentiate between BCCs and SCCs. The most recent standardized population-based disease estimates reported specifically for BCCs in the United States, based in north-central New Mexico in 1998-1999 and standardized to the 2000 US population, showed an overall incidence rate for those >25 years of age of 812/100,000 people/year (Athas et al, 2003), nearly identical to our standardized rate for those >25 years of 811/100,000. Furthermore, the pattern of BCC incidence by age in our cohort is similar to those previously reported with the majority of BCCs arising in members >65 years of age. Although males had an overall higher incidence rate for BCCs in our cohort and others, we noted a slightly higher incidence rate in younger (<40 years) women (266/100,000) compared to younger men (216/100,000), supporting data from a previously published report indicating higher incidence rates among women compared to men.

A unique strength of our study was the leveraging of electronic data within a large integrated health care delivery system that included all pathology reports in a diverse, representative population. Among the limitations are that data were collected from a single health-care setting and validation was performed on diagnoses limited to 1 calendar year. Also, inter-rater reliability was performed on only a subset of patients. Furthermore, it is possible that BCCs were diagnosed outside of the KPNP setting and thus not captured in the pathology database. However, seeking care outside of a prepaid health plan and incurring additional out-of-pocket expense is unlikely. Some BCCs may be removed without sending a pathology specimen for definitive diagnosis. However, the KPNP standard of care is to submit specimens suspected for malignancy for histopathologic diagnosis, so such events also are likely to be rare. Finally, BCCs often arise repeatedly and may arise concurrently in susceptible individuals, and SNOMED codes do not distinguish between primary, subsequent, recurrent, or multiple concurrent BCCs, making it difficult to identify true incident disease.

In conclusion, we found that SNOMED codes from the KPNP pathology system accurately and reliably identified BCCs. Having established the validity of SNOMED codes in identifying BCCs, we have used the codes to develop a longitudinal registry spanning a 14-year period from 1997-2010. A total of 136,173 KPNP members had at least 1 BCC diagnosis during this period. This large registry can serve as a resource for important scientific questions including disease incidence and trends over time, patterns of tumor occurrence (location, subtype), disease burden, risk of subsequent disease, and risk factors for recurrence. When used in combination with other readily available KPNP electronic data sources, the registry can also be used to study BCC risk in relation to other factors such as comorbidities and disease associations, environmental exposures,
genetic variations, and novel risk factors such as exposure to certain medication classes. Thus, this registry allows for studies on the etiology, risk factors, and disease burden in a population-based setting of the most common cancer in the United States.

References

Original Article

Establishing Effective Registration Systems in Resource-Limited Settings: Cancer Registration in Kumasi, Ghana

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Abstract: Cancer control programs are needed worldwide to combat the increases in cancer incidence and mortality predicted for sub-Saharan Africa in the next decades. The effective design, implementation, and evaluation of such programs require population-based cancer registries. Ghana’s second largest medical center, the Komfo Anokye Teaching Hospital (KATH) in Kumasi, has made initial progress at developing a cancer registry. This registry, however, is housed in the medical oncology/radiotherapy center at KATH and does not currently include data from other departments that also interact with cancer patients. The aim of this study was to improve KATH cancer registration by compiling cancer data from other major departments that see cancer patients. Using recent population estimates, we calculated crude cancer incidence rates of the “minimally-reported cases” for the Ashanti region. The most common cancers found in this study were breast (12.6 per 100,000), cervix (9.2 per 100,000), and prostate (8.8 per 100,000). These cancers occur at similar crude incidence rates in other West African countries. Females had overall higher incidence rates than males, which is consistent throughout the West African region. This study identified a number of methodological challenges facing cancer registries in Ghana that can be addressed to improve the quality of cancer registries in other resource-limited settings. Such registries should be tailored to the local health system context. A lack of coordination among the sources reporting cancer cases and a lack of understanding of local health-care systems and payment plans may interfere with the quality, completeness, and comparability of data from cancer registries in resource-limited settings. Steps, barriers, and solutions for improving cancer registration in Ghana and countries at similar levels are discussed.

Key words: cancer registration, cancer, epidemiology, Ghana, developing countries

Introduction

More than half of incident cancer cases and two thirds of cancer deaths already occur in developing countries. In sub-Saharan Africa, cancer incidence is expected to increase drastically over the next few decades due to multiple factors, notably increased life expectancy and westernized lifestyles as well as increased quality of diagnostics. Despite the known growing burden of cancer in sub-Saharan Africa, little is known about the incidence and distribution of the different tumor types and few resources are allocated to early detection and disease management in this region. Though cancer registration is indispensable as an accurate and longitudinal measure of the true burden of disease and thus to inform national cancer control programs, only 11% of the population in Africa is covered by a cancer registry and only 1% of African populations are covered by high-quality population-based cancer registries. Where registration systems do exist in these resource-limited settings, major challenges, including the lack of trained personnel, insufficient coordination of reporting sources, and the lack of available census data, threaten the quality and overall effectiveness of the registry. Though Ghana currently lacks a fully functioning population-based cancer registry, there have been earnest attempts to describe the cancer burden in the country. The 2 largest hospitals that diagnose and treat cancer patients in Ghana are the Korle Bu Teaching Hospital (KBTH) in Accra and the Komfo Anokye Teaching Hospital (KATH) in Kumasi. Limited frequency data from these hospitals indicate that the most common cancers are of the cervix, breast, prostate, and liver, with higher proportions of cancer among women than men.

In 2008, GLOBOCAN used a mixture of data from surrounding countries and extrapolations to estimate an age-standardized national cancer rate of 109.5 cases per 100,000 persons per year. GLOBOCAN also identified the same most frequent cancers that were reported by the limited patient data available from KBTH and KATH. Importantly, data from each of 32 sentinel hospitals within the 10 regions of Ghana indicate that cancer is among the top 10 causes of death in the country.

Cancer registration at KATH started with the development of a departmental-based registry in 2004. This

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registry was developed with the aim of reporting all cancer cases diagnosed and treated at the medical oncology/radiotherapy department where most of the patients diagnosed and treated come from the Ashanti region. Although cancer data from other departments exists at KATH, no previous research has tried to link cancer data from different diagnostic and treatment sources at this hospital to arrive at more accurate Ghana-focused estimates of the true incidence of cancer.

Ghana has made initial progress towards the development of cancer registries, yet still lacks the resources and coordination of reporting sources needed for a fully functioning registration system. A lack of coordination of reporting sources within the hospital is a possible source of underestimation and inaccuracy, as cancer cases are not reported in every department. To this end, this study aimed to coordinate cancer data from the surgery, pathology, and medical oncology/radiotherapy departments to estimate the cancer burden seen at KATH from 2008-2010, obtain estimates of cancer incidence for the Ashanti region, and set the groundwork for the development of an effective cancer registry in Ghana.

### Materials and Methods

#### Study Population and Data Sources

The study population consisted of all confirmed or suspected cases of cancer diagnosed in the surgery, pathology, and medical oncology/radiotherapy departments at KATH from 2008-2010. For each department, available information on cancer cases was abstracted from patient logbooks, medical records, or electronic databases into Excel databases.

#### Surgery

The electronic database of all 24,889 cases seen for any surgical procedure in the department of surgery during the period of January 2008-December 2010 was obtained. This database contained the following variables: patient name, age, sex, preoperative diagnosis, and postoperative diagnosis. Postoperative diagnosis data was missing for the majority of cases. Based on the available clinical diagnosis reported for each procedure, cases were reviewed by both Ghanaian and US physicians with more than 30 years of combined expertise in the heterogeneous presentations of cancers. The reviewers categorized the cases into the following 4 categories: definite cancer, likely cancer, unlikely cancer, and not cancer. The first 2 groups (cancer and likely cancer) included a total of 4,304 cases. The judgment call of “likely cancer” or “unlikely cancer” was based on experience for predicting with over or under 50% probability of cancer.

#### Pathology

Logbooks from the pathology department for the same period of 2008-2010 were obtained. Logbook entries included information on patient name, age, sex, site of procedure, and diagnosis. A total of 2,617 cases strongly suggestive of cancer were identified and abstracted.

#### Medical Oncology/Radiotherapy

Data from the medical oncology/radiotherapy department database was obtained for all cases seen during the same period of 2008-2010. This database contained demographic variables, such as name, age, sex, occupation, and town/region of residence and clinical information such as basis of diagnosis, primary site, histology, grade, stage, and treatment. Individual patient medical records were reviewed for this period to supplement and validate the data contained in the database. This process was completed for the data from the medical oncology/radiotherapy department for 2 main reasons: 1) to supplement the minimal diagnostic data included in the database with the complete diagnoses found in the patients’ medical records; 2) to provide a direct link to cases identified from the pathology department using the histopathology report number found in the medical oncology/radiotherapy medical records. A total of 1,936 cases of cancer were obtained from the medical oncology/radiotherapy department.

#### Data Linking/Matching

Once data from all departments were reviewed for accuracy, the following variables were used to link cases between departments: histopathology report number, patient name, patient age, date of diagnosis, and cancer site/site of surgical procedure. After linking the data from the 3 departments and removing duplicates, data was stripped of all identifiers and the final dataset for analysis was defined. Approval for this project was obtained from both the University of Michigan Institutional Review Board and Komfo Anokye Teaching Hospital/Kwame Nkrumah University of Science and Technology Committee on Human Research, Publication, and Ethics.

#### Estimation of Incidence and Statistical Analysis

KATH’s patient population comes largely from the Ashanti region, in which it is located. With a population of 4,725,046, Ashanti is the most populous region in Ghana with one of the fastest growing populations. KATH’s total catchment area covers nearly 50% of the total population in Ghana and also includes the more rural regions north of the Ashanti region, namely the Upper East, Upper West, Northern, and Brong Ahafo regions as well as parts of the Central and Western regions. KATH also sees a majority of the cancer cases in the Ashanti region. As it is estimated that 75% of KATH’s cancer patients are from the Ashanti region, and 25% of cancer cases in the Ashanti region are estimated to receive treatment outside of KATH, 100% of cases from this project were included for the estimation of incidence.

Population data for the Ashanti region was obtained from Ghana’s 2010 Population and Housing Census. Population estimates for 2008 and 2009 were calculated using regression estimate data from Ghana’s 2000 and 2010 census, including data on population growth rates. Age- and sex-specific distributions were obtained from the 2008 Demographic and Health Survey in Ghana and combined with the census data to generate the population distribution for the Ashanti region by 5-year age intervals and sex. KATH provided statistics on its patient catchment area, which
were used to determine the percentage of KATH cancer patients residing in the Ashanti Region. The combined data on cancer diagnosis obtained from the 3 departments were stratified by age groups (5-year intervals), sex, and cancer site for the primary tumor.

Descriptive statistics and rate analyses were conducted using SAS (Version 9.2; SAS Institute, Cary, NC). Crude annual incidence rates for each year were estimated with the number of cases per year as the numerator and the respective population estimate for that year as the denominator. Age-, sex-, and site-specific incidence rates were calculated for each year. Crude incidence rates for the 3-year period were calculated with the total number of cases identified from 2008-2010 as the numerator, and the person-time followed for the period as the denominator. Age-standardized incidence rates were calculated using the World Health Organization (WHO) world standard population estimates.21 Finally, observational comparisons of crude and site-specific incidence rates were made with other West African countries. Côte d’Ivoire, Niger, and Nigeria were chosen for comparison purposes due to availability of incidence data,3 similarities in age structure and distribution,20,22-24 and geographic proximity to Ghana. While we used the term “incidence,” other terms that may reflect the actual situation in Ghana might be “minimally-reported cases” or “working estimates.”

Results

A total of 4,012 individual cancer cases were identified from the 3 departments. Figure 1 provides details on the numbers of unique cases identified in each department and the overlap of cases between departments. The largest numbers of cases were seen in the pathology department only (35.1%), followed by both pathology and oncology departments (20.1%), and surgery only (18.1%). The majority of cases (64.9%) were females. The most frequent cancers identified were breast (22.4%), cervix (16.4%), prostate (14.7%), and head and neck (10.3%).

The total crude incidence rate for the Ashanti region over the 2008-2010 period was 29.5 cases per 100,000. Females had an overall higher total incidence rate (37.0 per 100,000) compared with males (21.3 per 100,000). This was consistent over each of the 3 years as well as the total for the 3-year period.

The total crude incidence rates per year increased slightly over time, from 25.5 per 100,000 in 2008, to 30.8 per 100,000 in 2009, and 31.9 per 100,000 in 2010. The incidence rate per year for females varied similarly to the total, from 32.5 per 100,000 in 2008 to 36.9 per 100,000 in 2009, and 41.5 per 100,000 in 2010. Moreover, the total incidence rate for males increased from 17.9 per 100,000 in 2008 to 24.3 per 100,000 in 2009, and then decreased slightly to 21.5 per 100,000 in 2010.

Table 1 displays the crude age-specific incidence rates for the 3-year period by sex. As expected, the incidence rates increase with increasing age. In this population, however, the incidence rate begins to increase noticeably around age 40-44 for both sexes. For females, incidence rates begin to increase substantially at even younger ages, around age 30-34, whereas for males, incidence rates increase notably starting at older ages, around 55-59 years. Interestingly, there appear to be significant increases in crude incidence rates for both sexes at ages older than 70 years compared to age groups younger than age 70.

Table 2 shows the total incidence rates for the 3-year period.
period by cancer site, revealing that the most common cancers in terms of crude incidence rate were breast, cervix, prostate, and head and neck cancers. Breast cancer was the most frequent cancer overall, with an incidence rate of 12.6 per 100,000 for females. The second most common cancer among females was cervical cancer, with an incidence rate of 9.2 per 100,000. For males, prostate cancer was the most common with an incidence rate of 8.8 per 100,000. Head and neck cancers were common among both sexes. The overall incidence rate for head and neck cancers was 2.9 per 100,000 for both sexes combined, 3.5 per 100,000 for males, and 2.5 per 100,000 for females. Other cancers that occurred at low frequencies include cancers of the corpus uteri, ovary, bladder, colorectum, stomach, thyroid, skin, and lymphomas. Due to unavailability of detailed diagnostic data, many skin cancers and lymphomas were unspecified. Liver cancer is present at low rates (0.20 per 100,000 persons per year for both sexes) and other cancers such as leukemias and multiple myeloma were not found in these departments.

Table 3 and 4 compare the overall crude cancer incidence rates for males and females and by site for the Ashanti region with other countries in West Africa (Côte d’Ivoire, Niger, and Nigeria). As seen in Table 3, the crude total cancer incidence rates for Ghana as estimated for this study (female: 37.0 per 100,000; male: 21.3 per 100,000) fall within ranges seen for the other West African countries. Table 4 indicates that the higher incidence rates estimated for females by this study are consistent across other West African countries. Also, these countries share similar common cancers; in particular, breast, cervix, and prostate cancers are common to all 4 of these West African countries. In contrast, other common cancers seen in Côte d’Ivoire, Niger, and Nigeria were found at lower frequencies or not at all in the 3 KATH departments. These include liver cancer, lung cancer among males, Kaposi sarcoma, non-Hodgkin lymphoma, leukemia, and multiple myeloma.

The total age-standardized incidence rate was 41.9 per 100,000. For females, the age-standardized incidence rate was 50.8 per 100,000. Finally, the age-standardized incidence rate for males was 31.7 per 100,000.

Discussion

This study revealed the following interesting findings. First, this study highlights the importance of developing strategies tailored to the local context in order to enhance

<table>
<thead>
<tr>
<th>Site</th>
<th>Male</th>
<th>Female</th>
<th>CrudeRate/100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head/neck total</td>
<td>3.5</td>
<td>2.5</td>
<td>3.0</td>
</tr>
<tr>
<td>Nasopharynx</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Other pharynx</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Larynx</td>
<td>0.5</td>
<td>0.1</td>
<td>0.3</td>
</tr>
<tr>
<td>Esophagus</td>
<td>0.1</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Lip/oral cavity</td>
<td>1.2</td>
<td>0.8</td>
<td>1.0</td>
</tr>
<tr>
<td>Other head/neck</td>
<td>1.4</td>
<td>1.0</td>
<td>1.2</td>
</tr>
<tr>
<td>Stomach</td>
<td>0.7</td>
<td>0.7</td>
<td>0.7</td>
</tr>
<tr>
<td>Colon/rectum</td>
<td>1.1</td>
<td>1.1</td>
<td>1.1</td>
</tr>
<tr>
<td>Anus</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Liver</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Gallbladder</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Pancreas</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Lung</td>
<td>0.1</td>
<td>0.0</td>
<td>0.1</td>
</tr>
<tr>
<td>Bone</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Skin</td>
<td>0.7</td>
<td>1.2</td>
<td>1.0</td>
</tr>
<tr>
<td>Breast</td>
<td>2.0</td>
<td>12.6</td>
<td>12.6</td>
</tr>
<tr>
<td>Vulva</td>
<td>–</td>
<td>0.4</td>
<td>0.4</td>
</tr>
<tr>
<td>Vagina</td>
<td>–</td>
<td>0.4</td>
<td>0.4</td>
</tr>
<tr>
<td>Cervix uteri</td>
<td>–</td>
<td>9.2</td>
<td>9.2</td>
</tr>
<tr>
<td>Corpus uteri</td>
<td>–</td>
<td>2.3</td>
<td>2.5</td>
</tr>
<tr>
<td>Ovary</td>
<td>–</td>
<td>1.3</td>
<td>1.3</td>
</tr>
<tr>
<td>Penis</td>
<td>0.2</td>
<td>–</td>
<td>0.2</td>
</tr>
<tr>
<td>Prostate</td>
<td>8.8</td>
<td>–</td>
<td>8.8</td>
</tr>
<tr>
<td>Testis</td>
<td>0.2</td>
<td>–</td>
<td>0.2</td>
</tr>
<tr>
<td>Kidney</td>
<td>0.5</td>
<td>0.6</td>
<td>0.5</td>
</tr>
<tr>
<td>Bladder</td>
<td>1.1</td>
<td>1.2</td>
<td>1.1</td>
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<tr>
<td>Eye</td>
<td>0.7</td>
<td>0.5</td>
<td>0.6</td>
</tr>
<tr>
<td>Brain</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Thyroid</td>
<td>0.2</td>
<td>0.7</td>
<td>0.5</td>
</tr>
<tr>
<td>Hodgkin disease</td>
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<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>0.1</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>Lymphoma, unspecified</td>
<td>0.4</td>
<td>0.3</td>
<td>0.4</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>0.2</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Abdomen</td>
<td>0.2</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Small intestine</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Teratoma</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Other/unknown site</td>
<td>1.9</td>
<td>1.7</td>
<td>1.8</td>
</tr>
<tr>
<td>Total</td>
<td>21.3</td>
<td>37.0</td>
<td>29.5</td>
</tr>
</tbody>
</table>

Table 2. Crude Cancer Incidence Rates (per 100,000) in the Ashanti Region (2008-2010) by Site and Sex*

Table 3. Comparison of Crude Total Cancer Incidence Rates (per 100,000) by Sex among West African Countries*


*n=4012.
Not applicable or not available indicated by dash.
Table 4. Comparison of Crude Cancer Incidence Rates (per 100,000) for the Ashanti Region by Site Compared with Other West African Countries*

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Ghana, Ashanti Region</th>
<th>Côte d'Ivoire</th>
<th>Niger</th>
<th>Nigeria</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Mouth</td>
<td>0.9</td>
<td>0.7</td>
<td>0.3</td>
<td>0.3</td>
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<tr>
<td>Salivary gland</td>
<td>0.2</td>
<td>0.2</td>
<td>2.0</td>
<td>–</td>
</tr>
<tr>
<td>Nasopharynx</td>
<td>0.0</td>
<td>0.0</td>
<td>0.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Other pharynx</td>
<td>0.0</td>
<td>0.0</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>Oesophagus</td>
<td>0.1</td>
<td>0.0</td>
<td>0.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Stomach</td>
<td>0.7</td>
<td>0.7</td>
<td>0.8</td>
<td>0.5</td>
</tr>
<tr>
<td>Colon/rectum</td>
<td>1.1</td>
<td>1.1</td>
<td>0.8</td>
<td>0.6</td>
</tr>
<tr>
<td>Liver</td>
<td>0.2</td>
<td>0.2</td>
<td>2.7</td>
<td>1.0</td>
</tr>
<tr>
<td>Gallbladder</td>
<td>0.0</td>
<td>0.0</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Pancreas</td>
<td>0.0</td>
<td>0.0</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>Larynx</td>
<td>0.5</td>
<td>0.1</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Lung</td>
<td>0.1</td>
<td>0.0</td>
<td>1.0</td>
<td>0.2</td>
</tr>
<tr>
<td>Bone</td>
<td>0.2</td>
<td>0.2</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Skin, unspecified</td>
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<td>0.8</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Melanoma of skin</td>
<td>0.1</td>
<td>0.3</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Kaposi sarcoma</td>
<td>0.0</td>
<td>0.0</td>
<td>1.4</td>
<td>0.4</td>
</tr>
<tr>
<td>Breast</td>
<td>–</td>
<td>12.6</td>
<td>0.2</td>
<td>5.9</td>
</tr>
<tr>
<td>Vulva</td>
<td>–</td>
<td>0.4</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Vagina</td>
<td>–</td>
<td>0.4</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Cervix uteri</td>
<td>–</td>
<td>9.2</td>
<td>–</td>
<td>5.5</td>
</tr>
<tr>
<td>Corpus uteri</td>
<td>–</td>
<td>2.3</td>
<td>–</td>
<td>0.3</td>
</tr>
<tr>
<td>Ovary</td>
<td>–</td>
<td>1.3</td>
<td>–</td>
<td>1.1</td>
</tr>
<tr>
<td>Penis</td>
<td>0.2</td>
<td>–</td>
<td>0.1</td>
<td>–</td>
</tr>
<tr>
<td>Prostate</td>
<td>8.8</td>
<td>–</td>
<td>2.8</td>
<td>–</td>
</tr>
<tr>
<td>Testis</td>
<td>0.2</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Kidney</td>
<td>0.5</td>
<td>0.6</td>
<td>0.3</td>
<td>0.2</td>
</tr>
<tr>
<td>Bladder</td>
<td>1.1</td>
<td>1.2</td>
<td>0.5</td>
<td>0.2</td>
</tr>
<tr>
<td>Eye</td>
<td>0.7</td>
<td>0.5</td>
<td>0.1</td>
<td>0.3</td>
</tr>
<tr>
<td>Brain, nervous system</td>
<td>0.1</td>
<td>0.1</td>
<td>0.2</td>
<td>0.3</td>
</tr>
<tr>
<td>Thyroid</td>
<td>0.2</td>
<td>0.7</td>
<td>0.1</td>
<td>0.4</td>
</tr>
<tr>
<td>Lymphoma, unspecified</td>
<td>0.4</td>
<td>0.3</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Hodgkin lymphoma</td>
<td>0.2</td>
<td>0.2</td>
<td>0.5</td>
<td>0.3</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>0.1</td>
<td>0.2</td>
<td>1.9</td>
<td>1.7</td>
</tr>
<tr>
<td>Multiple myeloma</td>
<td>–</td>
<td>–</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>Lymphoid leukemia</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Myeloid leukemia</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Leukemia, unspecified</td>
<td>–</td>
<td>–</td>
<td>0.7</td>
<td>0.7</td>
</tr>
<tr>
<td>Other and unspecified</td>
<td>2.4</td>
<td>2.1</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>All sites‡</td>
<td>21.3</td>
<td>37.0</td>
<td>18.7</td>
<td>23.3</td>
</tr>
</tbody>
</table>


†For Niger, and Nigeria, rate may not reflect total of “other and unspecified” as seen in this table.

‡Excluding non-melanoma skin cancer for Niger and Nigeria.

Not applicable or not available indicated by a dash.
the efficiency of cancer registration starting from earnest local efforts across all departments and identifying the major local registrars and health-care professionals involved in the registry. This is clear in our work, which, for the first time, linked patient records across departments and thus identified many cases of cancer when they were not explicitly diagnosed as such, as from surgical cases only, for example. Second, our results show the need to fully understand the health-care system and structure when developing a cancer registry. This is evidenced by the distribution of cancers by both age and cancer site in this study. In our study, some patients tended to report older ages to utilize health insurance benefits available only to older patients. Also, some cancer sites such as leukemia were under-reported because of lack of diagnostic facilities at the study hospital. Finally, comparison of our results to previous estimates for Ghana and other similar countries provide strong insight into the reasonable nature of our estimates and point to potential gaps in our data.

Linking cancer cases across hospital departments is essential to ensure quality and completeness in a registration system. The departmental-based registry at KATH is common in Africa and in many under-resourced regions, and currently only collects data on cancer cases seen within the medical oncology/radiotherapy department and is therefore unable to accurately describe the cancer burden at the hospital. The process currently in use is based on the assumption that all cancer patients who are seen at the department of surgery and/or diagnosed by the department of pathology will subsequently receive chemotherapy and/or radiotherapy. Our study found 53.2% of cancer cases were seen only in the pathology or surgery departments and thus no further linkage to therapy occurred because the patient declined to receive treatment or a referral was not made. Our results emphasize the importance of capturing cases in all relevant departments based on the dynamics of patient referrals between departments in local health-care systems. This process that we conducted for the first time in Ghana is crucial at least until formal and thorough population-based registries are in place.

The need for locally-tailored strategies for cancer registration is also evidenced by our work in identifying cancer cases that were seen, but not explicitly diagnosed, in the surgery department. Due to the incomplete database of surgery patients and lack of separate databases or logbooks for oncologic surgeries, cancer cases were not easily identified. To abstract cancer cases, we developed a classification strategy to rank cases on their likelihood of being cancer and the coauthors reviewed the data systematically. Without this system, our study would not have captured the 725 (18.1%) patients with suspected cancer who were seen only by the surgery department. Thus, although not without its complexities of design, having identified such a high percentage of cases at surgery alone again points out the diverse nature of the patients’ navigation schemes within the KATH system.

Understanding the intricacies of the local health-care system is essential to effective cancer registration, which was made clear through our attempts to age-standardize our estimated incidence rates. The age-standardized incidence rates reported in the results (total: 41.9 per 100,000; female: 50.8 per 100,000; male: 31.7 per 100,000) are notably low compared to GLOBOCAN’s estimates for Ghana (total: 109.5 per 100,000; female: 125.5 per 100,000; male: 93.8 per 100,000) and age-standardized estimates for other sub-Saharan African countries. Our lower estimate of the age-standardized rates is due to the large proportion of cases aged 70 and older. It is important to note that the National Health Insurance Scheme in Ghana provides free health care without premiums for patients aged 70 and older. Based on one of the coauthors experience in managing cancer patients at KATH (EO-B), patients often report their age as 70 and older to avoid payment of premiums for health care, which is seen in this data. As patients often do not have birth records, it is difficult to validate patients’ age reporting and so the age claimed by the patient is the one reported in the medical records.

Our findings with respect to the distribution and crude cancer incidence rates in the Ashanti region are similar to estimates reported elsewhere for Ghana and other comparable countries. First, our study confirmed previous estimates and observations that cancer incidence rates are higher among females. The International Agency for Research on Cancer (IARC) and other previous studies in Ghana estimated that females have overall greater morbidity and mortality from cancer than males. Our estimated crude incidence rates for Ghana are similar to the estimates for other West African countries and indicate that females have higher rates of cancers in these countries as well. This is likely a real difference, but the magnitude of the differences between sexes could also arise from the available treatment options for cancer in Ghana. Treatment for breast and cervical cancer at KATH are partially covered by the National Health Insurance Scheme whereas other cancers are not covered. This could partly explain the greater representation of women with cancer in treatment at KATH that were captured in this study.

This study found relatively high crude incidence rates for breast, cervix, and prostate cancers. Previous studies are in agreement these cancers are common in Ghana. Furthermore, comparisons with other West African countries indicate that breast, cervix, and prostate cancers are common in similar countries as well. The overall crude rates for males and females as well as the majority of site-specific rates as estimated in this study are quite reasonable when compared with similar West African countries. The crude rates observed in this study fall within ranges reported for other West African countries with similar age distributions to Ghana. Previous results from other West African countries support this observation.

In contrast, such comparisons also show potential gaps in our study. Other estimates for Ghana and other similar sub-Saharan African countries found lung cancer in males and liver cancer among both sexes to be more frequent than indicated in our data. This is likely explained by the fact that this study did not review autopsy records or those in other departments such as internal medicine or laboratory departments. The lower rates of Kaposi sarcoma and
non-Hodgkin lymphoma relative to other West African countries could be explained by the lack of availability of detailed diagnostic data for many skin cancers and lymphomas. Also, Ghana’s HIV prevalence is low relative to both Côte d’Ivoire and Nigeria which could partly explain the lower rates of HIV-related malignancies like Kaposi sarcoma and non-Hodgkin lymphoma, although Niger’s reported HIV prevalence is lower than Ghana’s.26-29 Finally, this study did not identify certain cancers such as leukemia and multiple myeloma that were identified in comparable countries. Again, this is due to incomplete data collection across all relevant departments.

This study has a number of strengths. We built upon existing registration infrastructure at KATH to enhance coordination of case reporting between hospital departments and improve data collection. This study was the first at KATH to provide complete data on all cancer cases seen in 3 departments over a 3-year period. Using the most recent available census data, this study provided the first estimates of incidence based on in-country data.

We also addressed numerous methodological issues in cancer registration that are likely to be highly applicable in other resource-limited settings. For example, KATH lacks a uniform identification system for patients, so there was not one variable common across departments to facilitating case linkages. Instead, we devised a variety of strategies based on the available data to enable these linkages. Also, we identified the most available and efficient data sources available to each department. As these different sources had varying degrees of completeness and quality, we identified other sources in each department for validation purposes. Finally, we devised strategies to identify cases of cancer when they were not explicitly diagnosed in the available data, as evidences by our methods for the surgery department.

This study also had a few limitations. There is the potential for underestimation in the incidence rates provided in this study. We did not review cases in all departments and so may have missed cases of cancer only seen in pediatrics, laboratory medicine or found in death registration and/or autopsy records. In addition, KATH does not see all existing cancer cases in the Ashanti region, so those cases that may have only been seen at private health centers, by traditional or alternative practitioners, or that died before diagnosis were missed by this study. We did, however, attempt to compensate for these missed cases using hospital- and census-based statistics to estimate that we missed 25% of cancer cases in the Ashanti region and used this estimate in our calculations.

There is also a potential for errors in our data or cases that were missed in the 3 departments reviewed. The surgery database did not contain explicit diagnoses of cancer and so each surgery case was categorized by its likelihood of being cancer. These cases were, however, reviewed carefully by medical practitioners and matched to both pathology and oncology to ensure accuracy. We also found data entry errors in the oncology database obtained from the departmental-based registry. We attempted to correct this with a systematic review of patient folders, but could not locate 5.4% of folders for validation purposes. In addition, certain cancer types such as leukemia and multiple myeloma are not reported because of lack of collection from the department of laboratory medicine.

In summary, this study provided the first data on cancer cases seen in multiple departments over multiple years at KATH. We estimated crude cancer incidence rates of the “minimally-reported cases” or “working estimates” for the Ashanti region that are comparable to other West African estimates and we confirmed that breast, cervix, and prostate cancers are common in this population. The methodology and results from this study emphasize the need to tailor strategies for cancer registration to the local context with an in-depth understanding of the overall healthcare system and structure. The next steps in enhancing cancer registration at KATH include expanding data collection to all other relevant departments and collaborating with data sources outside of KATH, such as private treatment centers. Future studies should utilize the insights from this study that may be applicable to other resource-limited settings. Future studies should also consider additional methods to identify the proportion of missing data such as capture-recapture analyses30 and verification of completeness of registries.31 Future studies should also aim to verify the reliability of the census. Methods for inclusion of non-conforming departments into the registration system must consider steps, barriers, and proposed solutions for ensuring participation in the registration process. Periodic utilization of the registry data by senior and junior physicians and faculty of departments could enhance the interest in supporting cancer registration. Utilization of registry data for periodic reports, theses, and dissertation materials could also help in increasing the support of registration by non-conforming departments.

Acknowledgments

We would like to thank the staff of the surgery, pathology, and medical oncology/radiotherapy departments at KATH for their assistance in identifying and retrieving data sources. We would also like to thank David Forman, Director of Cancer Information at IARC, for his thoughtful insights.

References


Prostate Cancer Treatment Modalities and Survival Outcomes: A Comparative Analysis of Falmouth Hospital Versus Massachusetts and Nationwide Hospitals

Sophia Elana Shimer

Abstract: Treatment of clinically localized prostate cancer has been termed a model of “preference-sensitive” health care. Because there is no documented consensus supporting any one of the primary treatment modalities—surgery, external beam radiation, and brachytherapy—over the others, patient and physician preferences can significantly influence treatment approach. This can lead to substantial variation in treatment practices at the level of individual hospitals. In this context, it is informative for individual hospitals, especially small community hospitals that lack substantial quality assurance resources, to compare their prostate cancer care to that provided by cohort groups of hospitals. This study compares prostate cancer treatment modalities at Falmouth Hospital (FH), a 95-bed community hospital located in Falmouth, Massachusetts, to those at hospitals in 3 cohort groups: 1) US hospitals of all types, 2) Massachusetts hospitals of all types, and 3) Massachusetts community hospitals. It also compares survival outcomes for FH prostate cancer patients to national averages. All data for these comparisons were obtained from the National Cancer Data Base (NCDB) Hospital Comparison Benchmark Reports and Survival Reports applications. This study’s main finding is that FH performed markedly less surgery and more radiation, specifically brachytherapy, than the cohort groups of hospitals. This distribution of treatment modalities was not solely attributable to FH’s older than average patient population. Studies similar to this one could be conducted by other community hospitals to inform quality assessment programs for prostate cancer care.

Key words: prostate cancer, Falmouth Hospital, first course treatment, National Cancer Data Base

Introduction

Prostate cancer is the most common type of non-skin cancer diagnosed in American men. One in 6 men will be diagnosed with prostate cancer over the course of his lifetime. Prostate cancer is also the second most common cause of cancer death in men, behind only lung cancer. The National Cancer Institute estimates that there will be 238,590 new cases and 29,720 deaths that are due to prostate cancer in the United States during the year 2013.

Routine screening for early detection of prostate cancer has been widely practiced in the United States since the early 1990s. Screening involves a blood test for prostate-specific antigen (PSA), a protein produced by the prostate. Patients who are found to have high PSA levels usually undergo a biopsy to check for cancerous cells. Diagnosis and staging are primarily determined by the biopsy results.

In recent years, the PSA test’s efficacy as a screening tool has become controversial within the medical community. The controversy intensified in May 2012, when the US Preventive Services Task Force issued a strong recommendation against routine PSA screening. After analyzing recently released results from 2 clinical trials that compared mortality rates of men who were screened and men who were not screened, the Task Force determined that PSA screening could prevent prostate cancer mortality in 0 to 1 man for every 1,000 men screened over a decade. The task force concluded that saving so few lives does not justify the known harms of screening. These harms include 1) false-positive PSA results in 100-120 out of 1,000 men screened, which can lead to unnecessary biopsies and negative psychological effects, 2) biopsy-related complications such as pain and infection, and 3) treatment-related complications such as urinary incontinence and erectile dysfunction in 50 out of 1,000 men screened. The task force also found that 17%-50% of tumors detected by PSA screening are so slow-growing that they would have remained asymptomatic for the patient’s lifetime. This high overdiagnosis rate is particularly concerning because nearly 90% of men who receive a diagnosis undergo treatment and are thus subject to the risk of treatment-related complications.

There is no documented consensus about the optimal treatment for prostate cancers that are clinically localized, which constitute the vast majority (93%) of cases at diagnosis. Management strategies include watchful waiting (observation with palliative treatment of symptoms) and active surveillance (periodic monitoring with PSA tests and repeated biopsies), which are switched to active treatment if signs of disease progression are discovered. The most common active treatment modalities are surgery (radical prostatectomy), external beam radiation, and brachytherapy (radioactive seed implants). No contemporary clinical trials have compared outcomes among men randomly assigned to these active treatment modalities. The Surgical Prostatectomy vs Interstitial Radiation Intervention Trial...
(SPIRIT) closed due to inadequate accrual. The Prostate Testing for Cancer and Treatment (ProtecT) trial successfully randomized men in the United Kingdom to surgery, radiation, or active surveillance, but it has just begun the follow-up phase and mortality results will not be available for several years. In the meantime, a systematic review commissioned by the Agency for Healthcare Research and Quality found insufficient evidence to recommend any of the primary active treatment modalities over the others. The American Urological Association does not support one modality over another in its clinical practice guidelines.

In the absence of conclusive evidence or clinical guidelines regarding the comparative efficacy of treatment options, patient and physician preferences can significantly influence treatment approach. In fact, treatment of localized prostate cancer has been termed a model of “preference-sensitive” health care, in which treatment choice involves trade-offs and thus patient and clinician preferences, beliefs, and values drive decision making.

Several studies have reported substantial local variation in treatment practices. One older study, using Medicare data from the mid-1990s, found that among the 10 most commonly performed surgical procedures in the United States, radical prostatectomy exhibited the greatest degree of local variation. A more recent and comprehensive study by Cooperberg et al analyzed data from a large national registry of men with prostate cancer to quantify variation in treatment at the level of individual clinical practice sites. This study found that a substantial proportion of treatment variation was attributable to practice site, even after controlling for differences in case mix and patient demographics, including clinical stage, Charlson comorbidity score, age, race, and income. The authors speculated that the observed variation by practice site reflected the impact of local culture on patient preferences, the uneven spread of new technologies, and differences in physician training, experience, personal outcomes, and financial incentives.

In this context of widespread treatment variation, it would be informative for individual hospitals to ascertain how their prostate cancer care measures up to the care provided by cohort groups of hospitals. This type of analysis is especially practical in small community hospitals, which may lack the resources of larger teaching/research hospitals, to ensure that the care they provide is current and competitive in terms of both treatment approach and outcome. The present study is such a comparative analysis of the prostate cancer care at Falmouth Hospital (FH), a 95-bed community hospital located in Falmouth, Massachusetts, about an hour and a half away from Boston, the nearest metropolitan center. This study compares prostate cancer treatment modalities at FH to those at hospitals in 3 cohort groups: 1) US hospitals of all types, 2) Massachusetts hospitals of all types, and 3) Massachusetts community hospitals. It also compares prostate cancer survival outcomes at FH to those at a cohort group of US hospitals of all types.

**Methods**

This study analyzed data from the National Cancer Data Base (NCDB). The NCDB was created through a collaboration of the American College of Surgeons’ Commission on Cancer (CoC) and the American Cancer Society. It consists of records from approximately 70% of all invasive cancer cases diagnosed in the United States annually. Certified tumor registrars at CoC-accredited cancer programs collect and submit data to the NCDB using nationally standardized data item and coding definitions. The NCDB maintains several Web-based data applications intended for individual hospitals to evaluate the care they provide. These applications are accessible to the more than 1,500 hospitals nationwide that have CoC-accredited cancer programs.

**Comparison of Treatment Modalities**

Comparison of treatment modalities was carried out using the NCDB Hospital Comparison Benchmark Reports application, which allows individual hospitals to compare themselves to hospitals in a cohort. Users can customize the cohort by geographic region (for example, to include reporting hospitals across the United States or only in one state) and by hospital type (for example, to include all types of hospitals, only community hospitals, or only teaching/research hospitals). This application contains data from all reported cancer cases diagnosed between 2000 and 2010.

First course treatment modalities for prostate cancer at FH were compared to those at hospitals in 3 cohort groups. The first cohort group consisted of CoC-accredited US hospitals of all types (1,389 hospitals). The second cohort group consisted of CoC-accredited Massachusetts hospitals of all types (37 hospitals). The third cohort group consisted of CoC-accredited Massachusetts community hospitals (12 hospitals). FH was excluded from the composition of each cohort group. Only cases diagnosed and receiving all or part of the first course treatment at the reporting hospital were included. This amounted to a total of 443 cases at FH: 869,047 cases in the US hospitals cohort; 26,367 cases in the Massachusetts hospitals cohort; and 2,893 cases in the Massachusetts community hospitals cohort. First course treatment modalities were categorized as surgery only, radiation only, radiation and hormones, hormones only, other specified therapy, or no first course treatment. For FH and each cohort group, the percent of prostate cancer cases receiving each treatment modality was determined.

Because surgery is less often a viable option for elderly patients than it is for younger patients, the distribution of patient ages at a particular hospital may affect the distribution of treatment modalities. To investigate this possibility, the distribution of age at diagnosis for prostate cancer patients was determined for FH and each cohort group.

Next, the following first course treatment modalities were individually stratified by patient age group: surgery only, radiation only, and radiation and hormones. The age groups were 40-49, 50-59, 60-69, 70-79, 80-89, and 90+ years. For FH and each cohort group, the percent of cases in each age group receiving each treatment modality was determined.

To further investigate the particular treatment modality of radiation therapy, this modality was broken down into the subcategories of external beam radiation and brachytherapy.
For FH and each cohort group, the percent of cases receiving each subcategory of radiation was determined.

Comparison of Survival Outcomes

The NCDB’s Survival Reports application was used to generate unadjusted 5-year observed survival rates for prostate cancer patients at FH and at a cohort group of all CoC-accredited US hospitals. The application displayed both overall survival rates and 95% confidence intervals, which were calculated as +/- 1.96 standard deviations from the overall survival rate. The displayed survival rates were stratified by clinical stage at diagnosis. However, FH did not have enough cases to yield specific survival rates for stages I, III, or IV, as the application did not display a rate when fewer than 30 cases were available within a stage group. Therefore, only overall (all stages combined) and stage II-specific survival rates were generated. Separate survival rates were generated for patients diagnosed in 1998-2002 (the time period covered by the fifth edition of the AJCC Cancer Staging Manual) and patients diagnosed in 2003-2005 (the time period covered by the sixth edition of the AJCC Cancer Staging Manual).

Results

Comparison of Treatment Modalities

Figure 1 displays the distribution of first course treatment modalities for prostate cancer cases diagnosed between 2000 and 2010 at FH compared to those at hospitals in 3 cohort groups: 1) US hospitals of all types, 2) Massachusetts hospitals of all types, and 3) Massachusetts community hospitals. The result that stands out most clearly from this graph is that FH performed markedly less surgery and more radiation than all 3 cohort groups. Only 23% of cases were treated with surgery at FH, compared to 42% at US hospitals of all types, 38% at Massachusetts hospitals of all types, and 48% at Massachusetts community hospitals. On the other hand, 33% of cases at FH were treated with radiation only, compared to 18% at US hospitals of all types, 17% at Massachusetts hospitals of all types, and 9% at Massachusetts community hospitals. FH also treated more patients with a combination of radiation and hormones than all 3 cohort groups. The discrepancy in surgery vs radiation rates was biggest between FH and the cohort group consisting of other Massachusetts community hospitals.

In the analysis of patient age at diagnosis, FH was found to have an older-than-average prostate cancer patient population: 49% of FH patients were diagnosed at age 70 or older, compared to 40% of patients at US hospitals of all types, 41% of patients at Massachusetts hospitals of all types, and 39% of patients at Massachusetts community hospitals. In the analysis of first course treatment modalities stratified by age group, it became apparent that FH’s low surgery rate and high radiation rate cannot be solely attributed to its older patient population. Figure 2 shows that, compared to the cohort groups, FH performed surgery less often even on younger patients in their forties, fifties, and sixties. Figure 3 shows that FH used radiation at higher rates than all 3 cohort groups on patients in their forties, fifties, sixties, and seventies. Furthermore, on more elderly patients in their eighties and nineties, FH used radiation alone at lower rates than the cohort groups, but as Figure 4 reveals, in these age groups it used a combination therapy consisting of both radiation and hormones at much higher rates than the cohort groups. Taken together, Figures 2, 3, and 4 suggest that factors other than patient age have influenced FH’s distribution of treatment modalities.
When the radiation therapy treatment modality was broken down into subcategories, as displayed in Figure 5, it became apparent that FH’s higher than average radiation rates were almost entirely due to more patients being treated with brachytherapy, not external beam radiation. Approximately the same percentage of cases at FH and at hospitals nationwide were treated with external beam radiation: 21% of cases at FH and 22% of cases at US hospitals of all types. However, FH patients underwent brachytherapy at more than 3 times the rate of patients nationwide and more than 7 times the rate of patients in the Massachusetts community hospital cohort: 39% of patients at FH underwent brachytherapy vs 11% of patients at US hospitals of all types and 5% of patients at Massachusetts community hospitals.

**Comparison of Survival Outcomes**

The NCDB Survival Reports application generated unadjusted 5-year observed survival rates for prostate cancer cases diagnosed and treated at FH compared to those diagnosed and treated at a cohort group of all CoC-accredited hospitals in the United States. Table 1 displays these survival rates both for all stages combined and for stage II only. Separate survival rates are displayed for patients diagnosed in 1998-2002 and patients diagnosed in 2003-2005. As evidenced by the overlapping 95% confidence intervals, there was no statistically significant difference in stage II-specific survival between FH and the cohort group for either diagnosis period. There was also no statistically significant difference in survival for all stages combined in the 1998-2002 diagnosis period. On the other hand, in the 2003-2005 diagnosis period, FH’s survival rate for all stages combined (77.5%) was lower than the national average (87.6%) by a statistically significant amount, as evidenced by the non-overlapping confidence intervals.

**Discussion**

**Comparison of Treatment Modalities**

This study compared prostate cancer first course treatment modalities at FH to those at hospitals in 3 cohort groups: 1) US hospitals of all types, 2) Massachusetts hospitals of all types, and 3) Massachusetts community hospitals. The most salient result was that FH performed markedly less surgery and more radiation, specifically brachytherapy, than all 3 cohort groups. The discrepancy in surgery vs radiation rates was biggest between FH and the cohort group consisting of other Massachusetts community hospitals, which on average had even higher surgery rates and lower radiation rates than the state and national cohort groups that included teaching/research hospitals. This finding was surprising given that the other Massachusetts community hospitals are FH’s peers in terms of having similar resources and case volumes.

Because surgery is less often a viable option for elderly patients than it is for younger patients,20 it was hypothesized that FH’s low surgery rates and high radiation rates might be attributable solely to its older than average patient population. FH’s older patient population is consistent with its location in Barnstable County on Cape Cod, a popular retirement destination. According to US census data, Barnstable County has the highest proportion of elderly people of any county in the state: 25.4% of the Barnstable population is over 65 years old, compared to 14.0% of the overall Massachusetts population and 13.3% of the US population.22,23 However, the analysis of first course treatment modalities stratified by age group revealed that, compared to the cohort groups, FH performed surgery less often and radiation more often even on younger patients.

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**Table 1. Unadjusted 5-Year Observed Survival for Prostate Cancer Patients at Falmouth Hospital Versus CoC-Accredited Hospitals Nationwide**

<table>
<thead>
<tr>
<th>Diagnosis Year</th>
<th>FH</th>
<th>US Hospitals</th>
<th>Stage II Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998-2002</td>
<td>87.9 (83.4 - 92.4)</td>
<td>85.9 (85.8 - 86.0)</td>
<td>92.1 (88.0 - 96.1)</td>
</tr>
<tr>
<td>2003-2005</td>
<td>77.5 (70.6 - 84.4)</td>
<td>87.6 (87.4 - 87.7)</td>
<td>84 (77.5 - 90.5)</td>
</tr>
</tbody>
</table>

- Overlapping confidence intervals
- Non-overlapping confidence intervals
This finding indicates that factors other than patient age have affected FH’s distribution of treatment modalities. This result is consistent with a previous study by Cooperberg et al., which found substantial variation in prostate cancer treatment practices across practice sites. This variation was not explained by differences in patient demographics.

Further research would be needed to pinpoint the factors that have contributed to FH’s particular distribution of prostate cancer treatment modalities. These factors likely include local patient and physician preferences. Speculatively, FH’s propensity for brachytherapy may reflect the area of expertise of FH’s radiation oncologists, one of whom was a pioneer in the brachytherapy field.24 Notably, given the lack of conclusive evidence supporting one treatment modality as optimal, it may be justified for preferences to play a major role in determining treatment practices.

Comparison of Survival Outcomes

The NCDB Survival Reports application was used to determine unadjusted 5-year observed survival rates for prostate cancer cases at FH compared to those at a cohort group of all CoC-accredited hospitals in the United States. Unlike the Hospital Comparison Benchmark Reports application, the Survival Reports application does not allow users to refine the cohort by geographic region or hospital type. Therefore, comparison to more restricted cohorts consisting of Massachusetts hospitals of all types or Massachusetts community hospitals was not possible.

There was no statistically significant difference in stage II-specific survival between FH and the national cohort group. On the other hand, the survival rate for all stages combined at FH was lower than the national average by a statistically significant amount for patients diagnosed in 2003-2005. However, it is important to bear in mind that these observed survival rates were computed with death from any cause as the endpoint. They were not adjusted for patient age or hospital case-mix, so they did not take into account that some hospitals care for older or sicker patients. This limitation of unadjusted survival rates is particularly relevant for this study, given that FH was found to care for an older than average patient population. For these reasons, the unadjusted survival rates provided by the NCDB Survival Reports application were insufficient to support robust conclusions about the relative quality of FH’s prostate cancer care.

To test whether FH’s lower 5-year observed survival rate is attributable to its older patient population, the observed survival rates could be stratified by patient age group. However, the NCDB Survival Reports application does not allow stratification by age, despite the availability of this data. The addition of this capability would allow more meaningful comparison of individual hospitals’ survival outcomes to national averages.

A rigorous evaluation of FH’s quality of prostate cancer care would require analysis of both relative survival rates and performance measures, neither of which are provided by the NCDB. Relative survival rates are adjusted for the expected survival of people in the general population who do not have prostate cancer. The national 5-year relative survival rate is 28% for patients diagnosed with malignant prostate cancer, but 100% for those with localized cancer, which constitute the vast majority of cases.2 For all stages combined, national 10-year and 15-year relative survival rates are 98% and 93%, respectively.3 These high relative survival rates illustrate prostate cancer’s characteristically long time course.

Performance measures assess adherence to best practices in treatment. The NCDB maintains an application dedicated to disease-specific performance measures: the Cancer Program Practice Profile Reports.25 However, this application currently only compiles data for breast and colorectal cancers. It allows individual hospitals to view performance rates that give the proportion of their breast and colorectal cancer patients that were treated according to recognized standards of care. An example of a best practice is that at least 12 regional lymph nodes should be pathologically examined for accurate staging of resected colon cancer.26 A performance measures program for prostate cancer would allow hospitals to better assess and improve their prostate cancer care. Given the lack of conclusive evidence supporting one optimal treatment modality for localized prostate cancer, these performance measures would be especially helpful in ensuring that whichever treatment modality a patient elects is executed according to best practices.

Conclusions and Future Directions

This study’s main finding is that FH performed markedly less surgery and more radiation, specifically brachytherapy, than the cohort groups of hospitals. Furthermore, this distribution of treatment modalities was not solely attributable to FH’s older than average patient population. These preliminary insights provide a potential starting point for further internal evaluation of FH’s prostate cancer care.

This study was conducted using NCDB Web-based data applications that are available to the more than 1,500 hospitals nationwide that have CoC-accredited cancer programs.19 The ease of access to these applications allows this type of study to be replicable at other community hospitals that lack substantial quality assurance resources and personnel. Similar studies could easily be carried out by a small community hospital’s tumor registrar or other cancer program staff. The results of these studies could inform quality assessment programs aimed at improving prostate cancer care.

References


Abstract: **Objective:** To characterize population-level surgical treatment patterns for cervical carcinoma in situ (CIS) reported to the Michigan Cancer Surveillance Program (MCSP), and to inform data collection strategies. **Methods:** All cases of cervical carcinoma in situ (CIS) (including cervical intraepithelial neoplasia grade 3 and adenocarcinoma in situ [AIS]) reported to the MCSP during 1998–2003 were identified. First course of treatment (ablative procedure, cone biopsy, loop electrosurgical excisional procedure [LEEP], hysterectomy, unspecified surgical treatment, no surgical treatment, unknown if surgically treated) was described by histology, race, and age at diagnosis. **Results:** Of 17,022 cases of cervical CIS, 82.8% were squamous CIS, 3% AIS/adenosquamous CIS, and 14.2% unspecified or other CIS. Over half (54.7%) of cases were diagnosed in women under age 30. Excisional treatments (LEEP, 32.3% and cone biopsy, 17.3%) were most common, though substantial proportions had no reported treatment (17.8%) or unknown treatment (21.1%). Less common were hysterectomy (7.2%) and ablative procedures (2.6%). LEEP was the most common treatment for squamous cases, while hysterectomy was the most treatment for AIS/adenosquamous CIS cases. Across histologic types, a sizeable proportion of women diagnosed ≤30 years of age underwent excision, either LEEP (20%-38.7%) or cone biopsy (13.7%-44%). **Conclusion:** Despite evidence suggesting it may be safer and equally effective as excision, ablation was rarely used for treating cervical squamous CIS. These population-based data indicate some notable differences in treatment by histology and age at diagnosis, with observed patterns appearing consistent with consensus guidelines in place at the time of study, but favoring more aggressive procedures. Future data collection strategies may need to validate treatment information, including the large proportion of no or unknown treatment.

Key words: adenocarcinoma, cervical carcinoma in situ, cervical intraepithelial neoplasia, hysterectomy, squamous cell carcinoma

Introduction

Despite dramatic declines in cervical cancer in the United States concurrent with widespread screening, about 12,280 women are diagnosed with invasive cervical cancer each year.1 Cervical cancer is preceded by dysplastic changes of the cervical epithelium, known as cervical intraepithelial neoplasia (CIN). These CIN lesions are graded based on histological severity from 1 to 3, the latter including carcinoma in situ (CIS), a pre-invasive carcinomatous change of the cervix. High-grade CIN lesions (CIN 3) and CIS, often synonymous, are considered the most relevant cervical cancer precursors for diagnosis and treatment due to their heightened invasive potential.2 Most cervical cancers (70%) are squamous cell carcinomas.3 While adenocarcinomas account for a smaller proportion (20%-25%) of all cervical cancers,3,4 registry-based studies indicate their incidence may be increasing.5 Adenocarcinoma in situ (AIS) is the most proximate precursor of cervical adenocarcinoma.

The systematic collection of data on high-grade CIN lesions could serve an important role in monitoring the impact of preventive measures such as newer cervical cancer screening guidelines and prophylactic human papillomavirus (HPV) vaccine on future disease burden.6,7 However, cervical cancer precursors are currently not routinely reported throughout the United States.8 Routine collection of CIS did occur by US cancer registries for several decades in the 1970s, 1980s, and early 1990s. In 1996, US cancer registries discontinued this practice due to concerns over the burden to reporting facilities; the quality of data, in light of changing diagnostic terminology for cervical cancer precursors;9 and loss of comparability in incidence data over time and across registries.9

Despite the national decision in 1996 to stop collection of high-grade cervical cancer precursors, the Michigan...
Cancer Surveillance Program (MCSP) continued collection of cervical CIS/AIS data, with minimal additional resources, due to the increasing use of electronic case reporting. Because the Michigan program is the only population-based data source for high-grade cervical cancer precursors that has been continuously collected since 1985, it provides a unique resource for the long-term systematic monitoring of cervical cancer control efforts. Analysis of MCSP data found increasing rates of cervical carcinoma in situ (CIS) in Michigan that nearly doubled in less than 2 decades, increasing from 31.7 per 100,000 in 1985 to 59.2 per 100,000 in 2003. Furthermore, for every invasive cervical cancer diagnosis reported during the same period, there were 7 in situ cases in white women and 4 in situ cases in black women.

In women with a histological diagnosis of CIN, appropriate management is a critical component of cervical cancer prevention. However, very few population-based data exist on patterns of management for cervical cancer precursors. Surgical management options for CIN include ablative procedures that destroy the affected tissue in vivo (eg, cryotherapy, laser ablation), excisional procedures that remove the affected tissue (eg, loop electrosurgical excisional procedure [LEEP], laser conization, cold knife conization), and hysterectomy. A Cochrane review of the evidence through July 2004, from 28 randomized controlled trials of alternative surgical treatments for CIN, found no overwhelmingly superior technique for eradicating CIN. The authors concluded that the choice of treatment should therefore be based on cost, morbidity, and the value of obtaining biopsy specimens.

Excisional procedures are more widely used to treat CIN in the United States, largely due to its provision of a tissue specimen for assessment of histopathology and surgical margins, and perhaps because it is believed by clinicians to more effective than ablation, despite evidence to the contrary. In contrast to these potential benefits, there is now evidence from meta-analyses of observational studies indicating potential increased risks for adverse pregnancy outcomes (ie, premature rupture of membranes, preterm delivery, low birth weight infant, and even perinatal mortality) among women treated with cold knife conization, LEEP, or laser conization.

The objectives of this study were to characterize population-level treatment patterns for cervical CIS by histology, age, and race in the MCSP, and to inform future data collection strategies.

Materials and Methods

Data Source and Case Selection

This study was approved as exempt by the Michigan Department of Community Health’s Institutional Review Board. We used data collected by the MCSP, a statewide population-based registry which has been in operation since 1981, with legally mandated cancer reporting and statewide population coverage since 1985. Methods for collection of cervical CIS cases through the MCSP have been described in detail. Briefly, the MCSP covers a state population of approximately 10 million, consisting of 81.2% whites, 14.2% blacks, 2.4% Asians, 0.6% American Indians/Alaska Natives, and approximately 4.2% Hispanics. All in situ and invasive cancers (other than basal or squamous cell carcinoma of nongenital skin) have been reportable to the MCSP as defined by the Michigan Administrative Code under the authority of Public Act 82 of 1984.

Cervical CIS is collected by MSCP in either of 2 diagnostic categories: carcinoma in situ, or grade 3 cervical intraepithelial neoplasia (CIN 3) without any qualifier. During the study period, a diagnosis of CIN 3 qualified with the term “severe dysplasia” was not reportable, an exclusion criterion intended to increase the specificity of cervical CIS cases. For our analysis, all cervical CIS cases reported between 1998 and 2003 were included. Cases were limited to ICD-O-3 topography code C53 (cervix uteri), histology codes 8010–8560, and behavior code 2 (in situ neoplasms). The majority of cases (63.6%) were ICD-O-3 histology code 8077, corresponding to squamous intraepithelial neoplasia grade III. The remaining cases included histology codes 8070 (squamous cell carcinoma in situ, not otherwise specified (NOS); 19%), 8010 (carcinoma in situ, NOS; 14.2%), 8140 (adenocarcinoma in situ, NOS; 2.8%), and other, less common codes.

Classification of Variables

Histology, demographic information (race and age at diagnosis), and first course of treatment were collected and reported according to SEER standards. Histologic subtypes were classified according to ICD-O-3 morphology codes, and categorized as squamous CIS, AIS/adenosquamous CIS, unspecified CIS, or other specified CIS. For analysis purposes, unspecified CIS and other specified CIS were grouped, so that the final categories for histologic subtype were as follows: squamous CIS, AIS/adenosquamous CIS, and unspecified CIS/other CIS. Race was categorized as white, black, other, or unknown. Age at diagnosis was categorized as <21, 21–30, 31–45, or >45 years.

Surgical procedures were classified according to SEER variable codes for first course of cancer-directed surgery, and categorized as ablative procedure, cone biopsy, LEEP, hysterectomy, unspecified surgical treatment, no surgical treatment, and unknown if surgically treated. Details of the surgical procedure classification, including SEER codes, procedure descriptions and frequencies, are shown in a supplemental table.

Ablative procedures included surgical techniques that destroy the affected tissue in vivo. The two most widely used excisional modalities that remove the affected tissue, LEEP and cone biopsy, were kept as separate categories. Hysterectomy included total, radical, modified radical, and extended hysterectomy. Trachelectomy, or surgical removal of the cervix, is a fertility-preserving surgical alternative to a radical hysterectomy. This procedure was reported in only a small number of cases (n=3) and was classified as
hysterectomy because it may be viewed as having similar severity (though, unlike hysterectomy, trachelectomy does not preclude future childbearing). Unspecified surgical treatment included instances where it was assumed a surgical treatment occurred, but the procedure could not be readily classified with other surgical treatments on the basis of its limited description (i.e., surgery, NOS [n=4]; local tumor excision, NOS [n=287]). The category of “no surgical treatment” was kept separate from “unspecified surgical treatment” and “unknown if surgically treated” since some women may have had contraindications to surgery.

Statistical Analysis

The distribution of age at diagnosis was tested for normality using the Shapiro-Wilk test, and because the resultant p-value was <0.05, age at diagnosis was compared across histologic subtypes using the non-parametric Kruskal-Wallis test. First course of treatment was described overall and by histologic subtype, and was further stratified by race and age at diagnosis. Analyses by race were limited to white and black women, and excluded 109 (0.6%) women with other race due to small numbers as well as 1,865 (11%) women with unknown race. Analyses by age at diagnosis excluded 18 (0.1%) women for whom age at diagnosis was missing. The exact Cochran-Armitage trend test was used to evaluate trends in hysterectomy by age, stratified by histologic subtype. These trend tests compared the distribution of women undergoing hysterectomy with all individuals who did not undergo that treatment across age groups. Two-sided p-values <0.05 were considered statistically significant. All analyses were conducted using SAS version 9.2 (SAS Institute, Inc., Cary, NC).

Results

Characteristics of the Study Population

For the period 1998 through 2003, there were 17,022 cases of cervical CIS reported to the MSCP (Table 1). Median age at diagnosis was 29 years. Over half (54.7%) of cases were diagnosed under 30 years of age and 10.3% of cases were diagnosed under age 21. Most women were white (73.7%). The majority of cases diagnosed during this period were squamous CIS (82.8%). The distribution of age at diagnosis differed significantly across histologic subtypes (Kruskal-Wallis p-value <0.0001; data not shown); women with AIS/adenosquamous CIS were diagnosed at later ages (median: 33 years) than women with squamous CIS (median: 29 years) or unspecified/other CIS (median: 30 years). Overall, LEEP (32.3%) and cone biopsy (17.3%) were the most commonly used treatments. Fewer women underwent hysterectomy (7.2%), ablative procedures (2.6%) or unspecified surgical treatments (1.7%). In addition, a substantial proportion of women had no surgical treatment (17.8%), and for approximately one fifth of women (21.1%), it was unknown if they were surgically treated.

Table 1. Characteristics of Cervical Carcinoma In Situ (CIS) Cases* in Michigan, 1998-2003 (n=17,022)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis (years)</td>
<td></td>
</tr>
<tr>
<td>&lt;21</td>
<td>1,749 (10.3)</td>
</tr>
<tr>
<td>21-30</td>
<td>7,552 (44.4)</td>
</tr>
<tr>
<td>31-45</td>
<td>59,92 (35.2)</td>
</tr>
<tr>
<td>&gt;45</td>
<td>1,711 (10.1)</td>
</tr>
<tr>
<td>Missing</td>
<td>18 (0.1)</td>
</tr>
<tr>
<td>Median (range)</td>
<td>29 (8-103)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>12,540 (73.7)</td>
</tr>
<tr>
<td>Black</td>
<td>2,508 (14.7)</td>
</tr>
<tr>
<td>Other</td>
<td>109 (0.6)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1,865 (11.0)</td>
</tr>
<tr>
<td>Histologic subtype</td>
<td></td>
</tr>
<tr>
<td>Squamous CIS</td>
<td>14,096 (82.8)</td>
</tr>
<tr>
<td>AIS or adenosquamous CIS</td>
<td>514 (3.0)</td>
</tr>
<tr>
<td>Unspecified or other CIS</td>
<td>2,412 (14.2)</td>
</tr>
<tr>
<td>First course of cancer-directed surgery</td>
<td></td>
</tr>
<tr>
<td>Ablative procedure</td>
<td>446 (2.6)</td>
</tr>
<tr>
<td>Cone biopsy</td>
<td>2,942 (17.3)</td>
</tr>
<tr>
<td>LEEP</td>
<td>5,504 (32.3)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>1,221 (7.2)</td>
</tr>
<tr>
<td>Unspecified surgical treatment</td>
<td>291 (1.7)</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>3,032 (17.8)</td>
</tr>
<tr>
<td>Unknown if surgically treated</td>
<td>3,586 (21.1)</td>
</tr>
</tbody>
</table>

*All cases reported to the Michigan Cancer Surveillance Program during 1998-2003 and limited to ICD-O-3 topography code C53 (cervix uteri), histology codes 8010-8560, and behavior code 2 (in situ neoplasms). The majority of cases (63.6%) were ICD-O-3 histology code 8077, corresponding to squamous intraepithelial neoplasia grade III.

AIS = adenocarcinoma in situ, LEEP = loop electrosurgical excisional procedure.

First Course of Surgical Treatment Stratified by Histologic Subtype

There were some notable differences in treatment across histologic subtypes (Table 2). LEEP was the most common treatment for women with squamous (33.6%) and unspecified/other CIS (29.2%). However, the most common form of treatment among women with AIS/adenosquamous CIS was hysterectomy (29.6%), a treatment received by only 6% of those with squamous CIS and 9% of those with unspecified/other CIS. Fewer women with AIS/
adenosquamous CIS received no surgical treatment (9.5%), compared to 17.9% of those with squamous CIS and 19.3% of those with unspecified/other CIS. Ablation was the least common treatment across all histologic types (0.4%–2.7%).

First Course of Surgical Treatment Stratified by Race

Treatment patterns by race and histologic subtype, limited to 15,048 (88.4%) black and white women, are shown in Table 3. Among women with squamous CIS, treatments were similar by race, with the majority of white and black women undergoing LEEP (33.6% and 37.4%, respectively) and cone biopsy (17.8% and 17.3%, respectively). Treatments for unspecified/other CIS were also similar by race, with the majority of white and black women also undergoing LEEP (30.2% and 28%, respectively) and cone biopsy (19% and 20.5%, respectively). Some racial differences in treatment types were observed among women with AIS/adenosquamous CIS. White women had a higher proportion of hysterectomies (31.3%) than black women (34.8%), while black women had a higher proportion of cone biopsies (34.8%) than white women (23.3%). Among women with AIS/adenosquamous CIS, a larger proportion of black women (21.7%) underwent LEEP compared with white women (11.7%). Of note, because there were only 23 black women with AIS/adenosquamous CIS in this study population, these percentages and comparisons should be interpreted with caution.

First Course of Surgical Treatment Stratified by Age at Diagnosis

Treatment patterns by age at diagnosis and histologic subtype, among women for whom age at diagnosis was known (n=17,044; 99.9%), are shown in Table 4. For all histologic subtypes, the proportion of women undergoing hysterectomy increased significantly with increasing age at diagnosis (Cochran-Armitage trend test p-value <0.05 for each histologic subtype). Ablative procedures were performed in small proportions of women (<3.3%) regardless of age at diagnosis, and were used the least among those with AIS/adenosquamous CIS. Treatment patterns by age at diagnosis were similar for those with squamous CIS and unspecified/other CIS, with the majority of women with these histologic subtypes undergoing LEEP. However, treatment patterns were more variable among women with AIS/adenosquamous CIS. Among women diagnosed with this histologic subtype at <21 and 21–30 years of age, cone biopsy was the most common surgical treatment (44% and 35%, respectively). Among women diagnosed with this histologic subtype at later ages, hysterectomy was the predominant form of surgical treatment (42.2% for those diagnosed at age 31–45 years and 44.6% for those diagnosed at age >45 years), with substantially fewer women diagnosed in these age groups undergoing cone biopsy or LEEP.

Notably, across histologic subtypes, a sizeable proportion of women diagnosed ≤30 years of age underwent an excisional procedure, either a LEEP (20%–38.7%) or cone biopsy (13.7%–44%). In the subgroup of 1,749 (10.3%) women diagnosed at the youngest ages (<21 years), approximately one fourth (23.2%) received no surgical treatment. Excisional procedures were common among women diagnosed <21 years of age, for squamous CIS (36.1% LEEP, 13.7% cone biopsy), AIS/adenosquamous CIS (20% LEEP, 44% cone biopsy), and unspecified/other CIS (38.7% LEEP, 17% cone biopsy).

Discussion

In this population-based study of 17,022 women diagnosed with cervical CIS in Michigan during 1998–2003, excisional procedures (LEEP and cone biopsy) were the most commonly used treatments. Cervical ablation was rarely performed, with less than 3.3% of women across all histological subtypes treated with these procedures. Consensus guidelines in place during the time frame of our study recommended both excision or ablation of the
### Table 3. First Course of Treatment for Cervical Carcinoma In Situ (CIS) Cases* by Histologic Subtype, Overall and by Race, Michigan, 1998-2003 (n=15,048)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>White (n=12,540; 83.3%)</th>
<th>Black (n=2,508; 16.7%)</th>
<th>Overall (n=15,048)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ablative procedure</td>
<td>313 (3.0)</td>
<td>38 (1.9)</td>
<td>351 (2.3)</td>
</tr>
<tr>
<td>Cone biopsy</td>
<td>1862 (17.8)</td>
<td>342 (17.3)</td>
<td>2204 (17.8)</td>
</tr>
<tr>
<td>LEEP</td>
<td>3509 (33.6)</td>
<td>741 (37.4)</td>
<td>4250 (34.2)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>714 (6.8)</td>
<td>109 (5.5)</td>
<td>823 (6.6)</td>
</tr>
<tr>
<td>Unspecified surgical treatment</td>
<td>200 (1.9)</td>
<td>25 (1.3)</td>
<td>225 (1.8)</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>1744 (16.7)</td>
<td>276 (13.9)</td>
<td>2020 (16.3)</td>
</tr>
<tr>
<td>Unknown if surgically treated</td>
<td>2096 (20.1)</td>
<td>451 (22.8)</td>
<td>2547 (20.5)</td>
</tr>
<tr>
<td>AIS or adenosquamous CIS (n=483)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ablative procedure</td>
<td>2 (0.4)</td>
<td>0 (0)</td>
<td>2 (0.4)</td>
</tr>
<tr>
<td>Cone biopsy</td>
<td>107 (23.3)</td>
<td>8 (34.8)</td>
<td>115 (23.8)</td>
</tr>
<tr>
<td>LEEP</td>
<td>54 (11.7)</td>
<td>5 (21.7)</td>
<td>59 (12.2)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>144 (31.3)</td>
<td>5 (21.7)</td>
<td>149 (30.9)</td>
</tr>
<tr>
<td>Unspecified surgical treatment</td>
<td>16 (3.5)</td>
<td>0 (0)</td>
<td>16 (3.3)</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>41 (8.9)</td>
<td>0 (0)</td>
<td>41 (8.5)</td>
</tr>
<tr>
<td>Unknown if surgically treated</td>
<td>96 (20.9)</td>
<td>5 (21.7)</td>
<td>101 (20.9)</td>
</tr>
<tr>
<td>Unspecified or other CIS (n=2,145)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ablative procedure</td>
<td>49 (3.0)</td>
<td>8 (1.6)</td>
<td>57 (2.7)</td>
</tr>
<tr>
<td>Cone biopsy</td>
<td>312 (19.0)</td>
<td>103 (20.5)</td>
<td>415 (19.4)</td>
</tr>
<tr>
<td>LEEP</td>
<td>496 (30.2)</td>
<td>141 (28.0)</td>
<td>637 (29.7)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>174 (10.6)</td>
<td>39 (7.8)</td>
<td>213 (9.9)</td>
</tr>
<tr>
<td>Unspecified surgical treatment</td>
<td>38 (2.3)</td>
<td>1 (0.2)</td>
<td>39 (1.8)</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>261 (15.9)</td>
<td>111 (22.1)</td>
<td>372 (17.3)</td>
</tr>
<tr>
<td>Unknown if surgically treated</td>
<td>312 (19.0)</td>
<td>100 (19.9)</td>
<td>412 (19.2)</td>
</tr>
</tbody>
</table>

*All cases reported to the Michigan Cancer Surveillance Program during 1998-2003 and limited to ICD-O-3 topography code C53 (cervix uteri), histology codes 8010-8560, and behavior code 2 (in situ neoplasms). The majority of cases (63.6%) were ICD-O-3 histology code 8077, corresponding to squamous intraepithelial neoplasia grade III. †Does not include 109 (0.6%) women of other race and 1865 (11.0%) women with unknown race.

LEEP = loop electrosurgical excisional procedure, AIS = adenocarcinoma in situ.

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transformation zone as acceptable treatment options for women with biopsy-confirmed CIN and a satisfactory colposcopy. In women with recurrent CIN, excisional treatment modalities were recommended. We also found that hysterectomies increased significantly with age, and were most commonly performed for AIS/adenosquamous CIS, in line with the existing recommendations against hysterectomy as primary therapy for CIN but the recommended treatment for women with AIS who have completed childbearing. We observed some potential differences in treatment for AIS/adenosquamous CIS by race, which may be due in part to confounding by differences in desires for future childbearing and/or preferences for definitive risk-eliminating surgery compared to continued surveillance.

There are several other population-based registry studies with which to compare the treatment patterns observed in our study. A small study conducted by the Romagna Cancer Registry in northern Italy found that, among 264 women with biopsy-confirmed CIN 3, the first course of treatment involved conization (59%), hysterectomy (35%), and local destructive therapy (6%). The authors attributed the limited role of conservative therapy and high prevalence of hysterectomy to a lack of ensuring follow-up with repeat smears and/or colposcopy. We observed similar proportions of women undergoing LEEP or conization (49.6%), but fewer women undergoing hysterectomy (7.2%) and ablative therapy (2.6%). The lower percentage of hysterectomies and ablative therapy could reflect misclassification or the preferred and popular choice of treatment during the study period.

A study linking the British Columbia Cancer Agency cytology database with cancer registry and vital statistics data found women with CIN 3 most often underwent cone biopsy; however, as the purpose of their study was to examine rates of CIN and invasive cervical cancer following treatment, their exclusion criteria precludes direct comparison with our findings. Perhaps the most methodologically comparable study is an analysis published in 1990 of the Surveillance, Epidemiology, and End Results (SEER) Program’s New Mexico Tumor Registry. Overall, of the 4,585 women diagnosed with cervical CIS during 1969-1985, 31.1% underwent conservative treatment (conization, laser treatment, cryosurgery or trachelectomy), while 65.5% underwent hysterectomy. By the end of the 17-year period, the proportion of women undergoing hysterectomy had declined to 45.8% while the proportion of women who underwent more conservative treatments had increased to 50.3%. The use of conservative treatments increased in all age groups with the largest increase in women under age 30. Interestingly, these dramatic shifts in surgical practice occurred in the absence of any consensus guidelines for the management of women with CIN, but may have reflected the advent of LEEP which could be easily performed in an outpatient setting.

In our study, the median age at diagnosis was 29 years, coinciding with peak childbearing age among American women. The few available registry-based studies have reported later ages at diagnosis, both in areas with organized cervical cancer screening such as in Romagna, Italy...
(median: 38.5 years) and in areas with opportunistic cervical cancer screening such as in Israel (mean: 38.4 years), which may reflect differences in risk factors for CIN, socioeconomic characteristics, access to cervical cancer screening, and management of abnormal screening test results. In our study, a small proportion (10.3%) of cervical CIS cases was diagnosed at ages under 21 years. However, newer guidelines for screening start age combined with HPV vaccine initiatives are likely to affect diagnoses among the youngest women. Recent cervical cancer screening guidelines issued by both the American Cancer Society and the US Preventive Services Task Force recommend that screening start at age 21, regardless of sexual history. Typically, CIN 3 lesions grow slowly over many years before invasion and less than half (30%-50%) of CIN 3 lesions will progress to cancer; treatment of lesions which may ultimately regress could put women at unnecessary risk for treatment-related side effects as well as for potential adverse outcomes in future pregnancies. Ongoing surveillance data are needed to inform our understanding of the epidemiology of cervical CIS, and registry-based studies may be helpful in evaluating the population-level impact of evolving screening guidelines and of HPV vaccination on the burden of disease, particularly among young women.

Table 4. First Course of Treatment for Cervical Carcinoma In Situ (CIS) Cases* by Age at Diagnosis and Histologic Subtype, Michigan, 1998-2003 (n=17,004†)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Age at diagnosis (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;21 (n=1,749; 10.3%)</td>
</tr>
<tr>
<td></td>
<td>21-30 (n=7,552; 44.4%)</td>
</tr>
<tr>
<td></td>
<td>31-45 (n=5,992; 35.2%)</td>
</tr>
<tr>
<td></td>
<td>&gt;45 (n=1,711; 10.1%)</td>
</tr>
<tr>
<td>Squamous CIS</td>
<td></td>
</tr>
<tr>
<td>Ablative procedure</td>
<td>47 (3.1)</td>
</tr>
<tr>
<td>Cone biopsy</td>
<td>209 (13.7)</td>
</tr>
<tr>
<td>LEEP</td>
<td>552 (36.1)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>1 (0.1)</td>
</tr>
<tr>
<td>Unspecified surgical treatment</td>
<td>20 (1.3)</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>351 (22.9)</td>
</tr>
<tr>
<td>Unknown if surgically treated</td>
<td>350 (22.9)</td>
</tr>
<tr>
<td>AIS or adenosquamous CIS</td>
<td></td>
</tr>
<tr>
<td>Ablative procedure</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Cone biopsy</td>
<td>11 (44.0)</td>
</tr>
<tr>
<td>LEEP</td>
<td>5 (20.0)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>1 (4.0)</td>
</tr>
<tr>
<td>Unspecified surgical treatment</td>
<td>0 (0)</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>1 (4.0)</td>
</tr>
<tr>
<td>Unknown if surgically treated</td>
<td>7 (28.0)</td>
</tr>
<tr>
<td>Unspecified or other CIS</td>
<td></td>
</tr>
<tr>
<td>Ablative procedure</td>
<td>5 (2.6)</td>
</tr>
<tr>
<td>Cone biopsy</td>
<td>33 (17.0)</td>
</tr>
<tr>
<td>LEEP</td>
<td>75 (38.7)</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Unspecified surgical treatment</td>
<td>3 (1.6)</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>53 (27.3)</td>
</tr>
<tr>
<td>Unknown if surgically treated</td>
<td>25 (12.9)</td>
</tr>
</tbody>
</table>

*All cases reported to the Michigan Cancer Surveillance Program during 1998-2003 and limited to ICD-O-3 topography code C53 (cervix uteri), histology codes 8010–8560, and behavior code 2 (in situ neoplasms). The majority of cases (63.6%) were ICD-O-3 histology code 8077, corresponding to squamous intraepithelial neoplasia grade III. †Does not include 18 (0.1%) women with missing age at diagnosis.

LEEP = loop electrosurgical excisional procedure, AIS = adenocarcinoma in situ.
### Supplemental Table. Classification and Frequency of Surgical Treatments for Cervical Carcinoma In Situ Cases,* Michigan, 1998-2003 (n=17,022)

<table>
<thead>
<tr>
<th>Category</th>
<th>SEER site-specific surgery codes for first course of cancer-directed surgery</th>
<th>Description (SEER coding manual)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ablative procedure</td>
<td>10 Local tumor destruction, NOS</td>
<td>10</td>
<td>66</td>
</tr>
<tr>
<td></td>
<td>13 Cryosurgery, no specimen sent to pathology</td>
<td>13</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>14 Laser</td>
<td>14</td>
<td>108</td>
</tr>
<tr>
<td></td>
<td>16 Laser ablation</td>
<td>16</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>17 Thermal ablation</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>21 Electrocautery</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>22 Cryosurgery</td>
<td>22</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>23 Laser ablation or excision</td>
<td>23</td>
<td>158</td>
</tr>
<tr>
<td>Cone biopsy</td>
<td>24 Cone biopsy with gross excision of lesion</td>
<td>24</td>
<td>2,286</td>
</tr>
<tr>
<td></td>
<td>27 Cone biopsy</td>
<td>27</td>
<td>656</td>
</tr>
<tr>
<td>LEEP</td>
<td>15 Loop electrocautery excision procedure, no specimen sent to pathology</td>
<td>15</td>
<td>157</td>
</tr>
<tr>
<td></td>
<td>28 Loop electrocautery excision procedure</td>
<td>28</td>
<td>5,347</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>29 Trachelectomy; removal of cervical stump; cervicectomy</td>
<td>29</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>30 Total hysterectomy (simple, pan-) without removal of tubes and ovaries</td>
<td>30</td>
<td>517</td>
</tr>
<tr>
<td></td>
<td>40 Total hysterectomy (simple, pan-) with removal of tubes and/or ovary</td>
<td>40</td>
<td>495</td>
</tr>
<tr>
<td></td>
<td>50 Modified radical or extended hysterectomy; radical hysterectomy; extended radical hysterectomy</td>
<td>50</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>51 Modified radical hysterectomy</td>
<td>51</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>53 Radical hysterectomy; Wertheim procedure</td>
<td>53</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>60 Hysterectomy, NOS, with or without removal of tubes and ovaries</td>
<td>60</td>
<td>126</td>
</tr>
<tr>
<td></td>
<td>61 Hysterectomy, NOS, without removal of tubes and ovaries</td>
<td>61</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>62 Hysterectomy, NOS, with removal of tubes and ovaries</td>
<td>62</td>
<td>37</td>
</tr>
<tr>
<td>Unspecified surgical treatment</td>
<td>20 Local tumor excision, NOS</td>
<td>20</td>
<td>287</td>
</tr>
<tr>
<td></td>
<td>90 Surgery, NOS</td>
<td>90</td>
<td>4</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>0 None; no surgery of primary site; autopsy only</td>
<td>0</td>
<td>3,032</td>
</tr>
<tr>
<td>Unknown if surgically treated</td>
<td>25 Dilation and curettage; endocervical curettage</td>
<td>25</td>
<td>1,685</td>
</tr>
<tr>
<td></td>
<td>26 Excisional biopsy, NOS</td>
<td>26</td>
<td>275</td>
</tr>
<tr>
<td></td>
<td>99 Unknown if surgery performed; death certificate only</td>
<td>99</td>
<td>1,626</td>
</tr>
</tbody>
</table>

*All cases reported to the Michigan Cancer Surveillance Program during 1998-2003 and limited to ICD-O-3 topography code C53 (cervix uteri), histology codes 8010-8560, and behavior code 2 (in situ neoplasms). The majority of cases (63.6%) were ICD-O-3 histology code 8077, corresponding to squamous intraepithelial neoplasia grade III.

NOS = not otherwise specified; LEEP = loop electrosurgical excisional procedure.
years of age underwent either LEEP (20%–39%) or cone biopsy (14%–44%). Even in the youngest subgroup of women (diagnosed under age 21), excisional procedures were common. It is conceivable that these young women may have undergone repeat excisional procedures over their reproductive life span, potentially further increasing their risk of adverse outcomes in future pregnancies. A meta-analysis showing consistent evidence linking excisional treatments for CIN and adverse outcomes in future pregnancies, with risks of preterm delivery, low birth weight, and preterm premature rupture of membranes increased approximately twofold, was published after the time frame of our study (2006).\textsuperscript{29} Risks of adverse pregnancy outcomes were not shown for women undergoing ablative treatment.\textsuperscript{30} In the United States, practitioners may choose more aggressive management options even for the youngest women due to concerns about access to care and compliance with follow-up.

While the MCSP represents some of the best available population-level data for cervical CIS, several limitations must be considered. The current study likely underestimates the true burden of cervical CIS because CIN 3 qualified with “severe dysplasia” was not reportable in Michigan during the study period. As the MCSP began collecting “severe dysplasia” in 2009, additional studies using more recent data could be useful for evaluating the sensitivity and specificity of the reporting definition for cervical CIS and the potential need for modifying or standardizing the definition. We were not able to evaluate the observed racial differences in surgical treatment for AIS/adenosquamous CIS for potential confounding (eg, by age at diagnosis) due to the small number of black women with this histological subtype (n=23) in our study population. As management guidelines in place at the time of study recommended cryotherapy, laser ablation, and LEEP as acceptable treatment modalities even for biopsy-confirmed CIN 1,\textsuperscript{24} reasons for the high proportion of women (17.8%) with CIS that had no surgical treatment or unknown treatment (21.1%) warrant further investigation.

There is potential misclassification of some diagnostic procedures as treatment in the registry. For example, in this study, dilation and curettage or endocervical curettage was recorded in the registry as the first course of treatment for 1,685 (9.9%) women; for the purposes of our analyses, these women were included in the “unknown if surgically treated” category, as these procedures are generally considered part of the diagnostic workup rather than treatment. Data collection and coding manuals should be reviewed and, if needed, modified to distinguish between procedures used for diagnostic workup and those used therapeutically, taking into account the sequence of treatments. This process will also involve efforts to train the medical chart abstraction staff to improve data quality. Finally, choice of treatment may have been influenced by medical history (eg, remote history of treated CIN) that we could not capture in our analysis.

Looking forward, future changes being proposed by pathology organizations to standardize classification of HPV-related neoplasia of the lower genital tract\textsuperscript{35} may impact the interpretation of data from long-standing surveillance systems like the MCSP. Further, with our improving understanding of treatment-associated outcomes, the collection of relevant treatment details (eg, cone excised depth) could be considered. While it may be prohibitively burdensome to add this to existing cancer registries, newer population-based cancer registries and sentinel surveillance systems that begin collecting cervical cancer precursors to monitor the effects of HPV vaccination may be able to enhance their overall impact by also collecting data on relevant treatment characteristics and clinical outcomes.

References


Abstract: Background: The Vaccine Adverse Event Reporting System (VAERS) is a US surveillance program that collects information on adverse events that occur after the use of vaccines. Poison centers also receive calls about potentially adverse exposures to vaccines. Since the same vaccine exposure might be reported to both VAERS and a poison center, this study examined the feasibility of matching publicly available VAERS records to poison center records. Methods: All VAERS records reported from Texas during 2000-2011 were downloaded from the VAERS database. All vaccine exposures reported to Texas poison centers during 2000-2011 were identified. Since no unique identifiers (e.g., names, dates-of-birth, etc.) were available in the public VAERS database, matches had to be made using other, non-unique data fields that both databases had in common. Matches were made using the following 4 data fields: vaccine, sex or gender, age, and date. The match rate was determined for total poison center records and for selected poison center variables. Results: There were 13,630 VAERS and 738 poison center records in the investigation. Twenty-nine percent (213) of the poison center records were matched to VAERS records. The match rate by 3-year period was 2000-2002 (21%), 2003-2005 (27%), 2006-2008 (20%), and 2009-2011 (41%). The rate for the most common vaccines was influenza (42%), pneumococcal (39%), diphtheria-pertussis-tetanus (49%), hepatitis B (14%), and diphtheria-tetanus (29%). The match rate was 35% for adverse reactions and 32% for therapeutic errors. The rate was 28% for non-serious outcomes and 33% for serious outcomes. The match rate was 29% for patients managed on site and 28% for patients already at or referred to a health-care facility. Conclusion: Matching between public VAERS and poison center records can be performed. However, these matches might be considered tentative because unique identifiers are not available. The match rate was highest during the most recent 3-year period. The match rate varied by vaccine but not by the exposure reason, management site, or medical outcome.

Key words: vaccine, Vaccine Adverse Event Reporting System (VAERS), poison center, match, link

Introduction

The Vaccine Adverse Event Reporting System (VAERS) is a US surveillance program sponsored by the Centers for Disease Control and Prevention and Food and Drug Administration that collects information on suspected adverse events (health problems or possible side effects) that occur after the use of vaccines licensed in the United States.1 VAERS is a passive surveillance system where reports are voluntarily submitted by the persons who receive the vaccines, their family or friends, health-care providers, public health organizations, and others. The law requires that all personal identifiers are kept confidential. VAERS data are useful for studying the safety of vaccines, identifying and understanding rare adverse events that might not have been observed in clinical trials, and evaluating vaccines used in unique populations, such as travelers and the military.

US poison centers are free telephone consultation services that provide information on and assist in the management of potentially adverse exposures to a variety of substances such as medications, illegal drugs, household and industrial chemicals, food, plants, and animals. Poison centers are usually available 24 hours a day, 365 days a year. They receive calls from health-care providers, law enforcement, and the public. Each poison center uses an electronic database to collect demographic and clinical information on all calls handled by the poison center’s agents. The data fields and allowable field options are standardized by the American Association of Poison Control Centers (AAPCC). A subset of the data fields collected by every poison center is submitted to the AAPCC and combined into a single National Poison Data System (NPDS).2 Reporting exposures to poison centers is usually not mandatory. Their databases and the NPDS could be considered passive surveillance programs.

Among the types of calls poison centers receive are potentially adverse exposures to vaccines. During 2011, US poison centers received calls about 2,151 exposures to vaccines, serums, and toxoids, at least 457 of which were due to adverse reactions and 110 resulted in moderate or major effects.2

This suggests that poison centers might serve as a potentially useful source of adverse vaccine exposures for VAERS. In fact, an unknown portion of those vaccine exposures currently reported to poison centers might already be reported to VAERS by the poison centers or others. To
determine the extent to which this is already occurring, it would be useful to match poison center records of vaccine exposures to VAERS records. This study examined the feasibility of matching publicly available VAERS records to the records of the Texas Poison Center Network (TPCN). The TPCN is comprised of 6 poison centers that cover the entire state, a population of more than 25 million. The 6 poison centers use a single, common electronic database.

**Methods**

All VAERS records reported from Texas during 2000-2011 were downloaded from the VAERS database (https://vaers.hhs.gov/data/index). All of the publicly available data were obtained. The data were imported into a Microsoft Access database.

All vaccine exposures reported to the TPCN during 2000-2011 were identified. Exposures to vaccines not intended for humans were subsequently excluded from the poison center cases since they were not likely to be reported to VAERS. The poison center data were imported into the same Microsoft Access database as the VAERS data.

No unique identifiers (eg, names, dates of birth, etc) were available in the public VAERS data set. Moreover, date of birth is not typically collected by Texas poison centers. Thus, matches had to be made using other, non-unique data fields that both data sets had in common. As a result, any matches that were made should be considered probable at best and not definite. However, other studies have reported using similar non-unique data for successful matching of records in different databases. Matches were made using the following 4 data fields: vaccine, sex or gender, age, and date. For poison center records, the date used in the matching process was the date the call was received; this is likely to be the date the vaccine was received or shortly afterward. For VAERS records, 4 different dates were used in the matching process: the vaccination date, symptom onset date, report completed date, and report received date. Since the dates in the 2 databases were not equivalent, a match was considered possible if the dates in the 2 databases were within 5 days of one another. Likewise, the ages were considered a match if they were within 3 years of one another.

A deterministic multi-pass match algorithm was used to perform the matching between the 2 data sets. Both the VAERS and TPCN tables containing record identification numbers and the variables of interest were added to a Microsoft Access query, and all the variables of interest were designated to be included in the query output. In a query, if an exact match was desired for a given variable, the variable in the VAERS table was linked to the corresponding variable in the TPCN table; if no exact match was desired for a given variable, the corresponding variables in the 2 tables were not linked. First, a query was run where an automated match (link) was made between all 4 fields (vaccine, sex, age, date). Next, queries were run where automated matches were made using combinations of 3 of the fields, with the data in the fourth field compared between the 2 data sets to rule out any obvious non-matches (eg, exact matches between vaccine, sex, and age but not date; exact matches between vaccine, sex, and date but not age; etc). Then queries were run where automated matches were made using combinations of 2 of the fields with the data in the other 2 fields compared between the 2 data sets to rule out any obvious non-matches (eg, exact matches between vaccine and sex but not age and date, etc). Records that were matched in a given query were excluded from subsequent queries.

The match rate (poison center records matched to VAERS records/total poison center records) was calculated for total cases, the variables used to make the matches, and the poison center data variables of year, circumstances of the exposure, management site, and medical outcome (severity). Differences in match rates between the subgroups were evaluated for statistical significance by calculating the rate ratio (RR) and 95% confidence interval (CI) by the Newcombe-Wilson method without continuity correction. The RRs were considered statistically significant if the 95% CI excluded 1.00. P-values were not calculated.

For the analysis by year, the 12-year period was divided into four 3-year periods. The circumstances of, or reason for, the exposure were grouped into adverse reaction (the vaccine was given as directed but the person reported adverse effects), therapeutic error (the vaccine was given incorrectly, such as the patient receiving a double dose), and all other/unknown reasons (other unintentional and intentional exposures, etc).

The medical outcome or severity of an exposure is assigned by the poison center staff and is based on the observed or anticipated adverse clinical effects. In the AAPCC coding system, the medical outcome is classified by the following criteria: no effect (no symptoms due to exposure), minor effect (some minimally troublesome symptoms), moderate effect (more pronounced, prolonged symptoms), major effect (symptoms that are life threatening or cause significant disability or disfigurement), and death. A portion of exposures are not followed to a final medical outcome because of resource constraints or the

### Table 1. Exact Match Rate of Texas Poison Center Network (TPCN) Records and Vaccine Adverse Event Reporting System (VAERS) Records by Variable Used in the Matches

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaccine type</td>
<td>231</td>
<td>90</td>
</tr>
<tr>
<td>Sex</td>
<td>200</td>
<td>78</td>
</tr>
<tr>
<td>Age</td>
<td>117</td>
<td>46</td>
</tr>
<tr>
<td>Report completed date*</td>
<td>159</td>
<td>62</td>
</tr>
<tr>
<td>Vaccination date*</td>
<td>109</td>
<td>43</td>
</tr>
<tr>
<td>Report received date*</td>
<td>91</td>
<td>36</td>
</tr>
<tr>
<td>Symptom onset date*</td>
<td>86</td>
<td>34</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>256</strong></td>
<td></td>
</tr>
</tbody>
</table>

213 TPCN records were matched to 256 VAERS records.

*For TPCN records, the date used in the matching process was the date the call was received, which was matched to the 4 different VAERS dates.
inability to obtain subsequent information on the patient. In these instances, the poison center staff record the expected outcome of the exposure. These expected outcomes are grouped into the following categories: not followed but judged as nontoxic exposure (symptoms not expected); not followed but minimal symptoms possible (no more than minor symptoms possible); and unable to follow but judged as a potentially toxic exposure. Another medical outcome category is unrelated effect where the exposure was probably not responsible for the symptoms. For this analysis, the medical outcomes were grouped into those exposures known or expected not to be serious (no effect, minor effect, not followed but judged as nontoxic, not followed but minimal symptoms possible) vs those exposures known or expected to be serious (moderate effect, major effect, death, unable to follow but judged as potentially toxic).

Results

There were 13,630 VAERS and 738 poison center records included in the investigation. Twenty-nine percent (213) of the poison center records were matched to 256 VAERS records. Of the 213 poison center records, 189 (89%) were matched to one VAERS record and 24 (11%) were matched to more than one (range 2-8).

Table 1 presents the exact match rates by the 4 types of variables used to make the match. The highest exact match rate occurred with the vaccine type followed by patient sex. The exact match rate varied among the 4 different VAERS dates used.

Table 2 shows the match rate for selected poison center variables from the TPCN database. The match rate was higher during 2009-2011 than during the previous three 3-year periods with the difference being statistically
significant. The match rate varied among the types of vaccine most commonly reported in the TPCN database, being highest for diphtheria-pertussis-tetanus vaccine and lowest for hepatitis B vaccine. Exposures due to adverse reactions and therapeutic errors had similar match rates but the rate for other or unknown exposures was significantly lower. The match rates also were similar for the different management sites and medical outcomes.

**Discussion**

This study demonstrates that matching between poison center records and VAERS records can be performed, even without unique identifiers such as name and date of birth. However, considering the variables available to be used to make the matches are not unique identifiers, the matches that are made should be considered tentative at best. Nevertheless, of those TPCN records that were matched, 89% were matched to only one VAERS record.

Only 29% of the TPCN vaccine exposures were matched to VAERS records, i.e., the majority (525) of TPCN vaccine exposures likely were not reported to VAERS. This may be because many of the TPCN vaccine exposures were not classified as adverse reactions but due to other circumstances such as therapeutic errors and thus possibly not considered suitable for reporting to VAERS. The number of poison center records that were not reported might be considered rather small when compared to the total number of VAERS records (525 vs 13,360). Still, poison centers could serve as an additional data source for VAERS. When the H1N1 influenza vaccine was first introduced in 2009, there was concern about its safety. The Texas Department of State Health Services (DSHS) Immunization Branch approached the TPCN and asked whether it would be possible for the TPCN to report all H1N1 influenza vaccine exposures to them. A system was set up where all H1N1 influenza exposures reported to the TPCN would be forwarded to DSHS. As a consequence, DSHS asked if a system could be created where all vaccine exposures received by the TPCN could be reported to the DSHS. Such a system was created and has been in operation since January 2010. Thus, although the TPCN does not currently report vaccine exposures directly to VAERS, a portion may be indirectly reported through DSHS.

The match rate was substantially higher during 2009-2011 than during the 9 years prior to this time period. Moreover, more vaccine exposures were reported to the TPCN during 2009-2011 than during the previous three 3-year periods. The H1N1 influenza pandemic and the introduction of the H1N1 vaccine occurred in 2009. The number of TPCN influenza vaccine reports in 2009 were higher than in previous years. As a consequence, the collaboration between the TPCN and the DSHS that started in 2009 might have led to the DSHS submitting a portion of these TPCN exposures to VAERS, which then contributed to a higher match rate during 2009-2011. The match rate varied by the type of vaccine, being highest for diphtheria-pertussis-tetanus vaccine and lowest for hepatitis B vaccine. The differences in match rates possibly may be due to different concerns about potentially adverse effects depending on the type of vaccine.

The match rate did not vary greatly with respect to the circumstances of the exposure, management site, or medical outcome. It might be expected that the match rate would be higher for adverse reactions than for therapeutic errors, since VAERS is for reporting “adverse events.” However, poison centers and VAERS and those individuals who submit information to them might have different definitions of what qualifies as an “adverse event” or “adverse reaction.”

In addition, it might be presumed that those poison center exposures managed at a health-care facility would be more likely to be matched to VAERS records, since health-care providers might be expected to report adverse vaccine exposures to VAERS. Patients and family members would be less likely to know about the existence of VAERS. However, some of the TPCN exposures that were managed on site also might have been reported to health-care providers without the TPCN staff being made aware of the fact.

Likewise, it might be anticipated that more serious exposures, which had more serious adverse effects, would be more likely to be matched to VAERS records. However, the severity of the exposure was based on the symptoms reported to TPCN agents. The agents might not have been notified of all symptoms. Moreover, the TPCN and VAERS might differ in what they consider serious exposures.

The exact match rate varied greatly between the 4 types of variables used to make the matches. This knowledge might help to prioritize which variables to use or have confidence in when making matches. Nevertheless, these exact match rates might be an artifact of the matching methodology. For example, if a TPCN and VAERS record matched by age, sex, and date but not by vaccine, then the 2 records would not be considered a match. But if sex did not match, date did not match but was close, and age and vaccine matched, the 2 records would be considered a potential match.

**Conclusions**

Matching between public VAERS and poison center records can be performed. However, these matches might be considered tentative because unique identifiers are not available. The match rate was highest during the most recent 3-year period, possibly because in 2010 the poison center system in this study began to report all vaccine exposures to the state health department, which in turn might have reported a portion of these exposures to VAERS. The match rate varied by vaccine but not by the exposure reason, management site, or medical outcome.

**References**


Birth Defect Registries: the Vagaries of Management—The British Columbia and Alberta Case Histories

R. Brian Lowry\textsuperscript{a,b,c,d}; Tanya Bedard\textsuperscript{a,c}

Abstract: Birth defect surveillance is of increasing interest and importance, especially since the discovery that folic acid fortification or supplementation can prevent a large proportion of neural tube defects. Funding is a constant problem, but management or policy can also lead to changes in ascertainment and quality, and even to the threat of actual closure. This is a case study of 2 Canadian registries—British Columbia and Alberta—from an historical point of view. The lessons here are applicable to many registries or surveillance systems. To succeed, 4 things must be in place—stated objectives of the program, funding (preferably government, but may start with a grant or foundation), support from public health departments, and someone to champion the cause. The importance of medical consultants cannot be overstated.

Key words: birth defects, congenital anomalies, surveillance, registry, British Columbia, Alberta

Introduction

The discovery that thalidomide produced an epidemic of limb and other congenital malformations resulted in the development of many birth defects surveillance systems or registries in the 1960s or even later. While many health departments and vital statistics sections of government started collecting information on live and still births with congenital malformations (eg, New York State Department of Health—1940\textsuperscript{1}; Birmingham, England, 1949\textsuperscript{2}), the first formal comprehensive surveillance registry for congenital malformations was in British Columbia, Canada, which opened in 1952. Ascertainment also included handicapped persons to age 21. Alberta, Canada followed with a Handicapped and Birth Defects Register in 1963. Many other countries or areas started congenital malformation surveillance in the 1960s, eg, Czechoslovakia in 1961, Hungary in 1962, Finland in 1963, and Sweden, England and Wales in 1964. The Centers for Disease Control and Prevention birth defects program started in Atlanta in 1967.

This report is a case study of British Columbia and Alberta and is designed to examine historical events to demonstrate how government decisions and reorganizations affect the quality of congenital anomaly surveillance. Although funding is a constant challenge, poor management and ineffective policy can contribute to the decline of a surveillance system.

British Columbia (BC)

The Establishment of the British Columbia Health Status Registry

In 1948, the Canadian government made a major announcement of a policy shift and assigned grants to the provinces, including national health grants (which included a crippled children’s grant).\textsuperscript{3} In British Columbia, a subcommittee was established to advise the British Columbia Ministry of Health of a plan to deal with crippling diseases of children. Dr. Donald Paterson (Figure 1) was the most active member of this subcommittee. Paterson was a Canadian who graduated from Edinburgh University and rapidly became the most prominent pediatrician in the United Kingdom.\textsuperscript{4} He developed pediatrics both as a professional specialty and as an independent academic subject, with one of his greatest achievements being the founding of the British Pediatric Association. He retired to Canada in 1947 and was immediately appointed as consultant in child health to the Metropolitan Health Committee of Vancouver, and head of the pediatric section of the Vancouver General Hospital. He recognized that there were many handicapped children who were not getting appropriate services. A report was submitted to the deputy minister of health, Dr. Gregoire Amyot, based on the results of a provincial survey begun in 1948 and completed in 1950 that recommended the establishment of a voluntary register of handicapped children. Thus the Health Status Registry, initially called the Crippled Children’s Registry, formally opened in January 1952. Administratively, it was placed in the Division of Vital Statistics within the Ministry of Health. There were many subsequent name changes: the Registry for Handicapped Children, the Registry of Handicapped Children, the Registry of Handicapped Persons, the Registry of Handicapped Children and Adults, the Registry for Handicapped Persons, the Registry of Handicapped Persons and Children, the Registry of Handicapped Persons, the Registry of Handicapped Persons and Children, the Registry of Handicapped Persons, and the Registry of Handicapped Persons.

Figure 1. Dr. Donald Paterson


\textsuperscript{a}Alberta Congenital Anomalies Surveillance System, Alberta Health and Wellness, Calgary, Alberta, Canada. \textsuperscript{b}Departments of Medical Genetics and Pediatrics, University of Calgary, Alberta, Canada. \textsuperscript{c}Alberta Children’s Hospital, Alberta Health Services, Calgary, Alberta, Canada. \textsuperscript{d}Alberta Children’s Hospital Research Institute, Calgary, Alberta, Canada.

Address correspondence to Dr. R. Brian Lowry, ACASS/Clinical Genetics, Alberta Children’s Hospital, 2888 Shaganappi Tr NW, Calgary, Alberta, Canada T3B 6A8. Telephone: (403) 955-7370. Fax: (403) 955-2870. Email: brian.lowry@albertahealthservices.ca.
Baird.7 Table 1 provides a brief summary of HSR.

There was an increase in academic and scientific activity, clarifying or verifying diagnoses or offering advice. Dr. Patricia or physicians were written by the medical consultant to input. Letters to the registering agency, public health unit, and agencies could see the value of their visits always served to improve ascertainment, whereby conditions or diagnoses were looked at rigorously only of value in itself but also served to clean the data, helping to overcome ascertainment deficits but also providing knowledge about diagnosis or other handicaps. HSR provided a liaison between physicians, institutions and agencies for child care and rehabilitation. The public health units were actively involved and there was excellent communication between HSR and the health units. HSR instituted a follow-up of cohorts when children became 7 years and 14 years of age, known as the 7 and 14 Follow Up. These were invaluable and provided information that could be used for planning with respect to future resources, and information about who would later require assistance regarding possible employment.

Dr. Jim Miller was appointed in 1962 as genetic consultant to HSR and Dr. Brian Lowry replaced Dr. Paterson in 1965 as the medical consultant. This was the era in which scientific or academic publications began to be produced using the extensive HSR data banks.8 Each study was not only of value in itself but also served to clean the data whereby conditions or diagnoses were looked at rigorously and either changed if necessary or discarded if inappropriate or unreliable.

There were further increases in activities between HSR and the public health units in the 1970s. Many in-service visits were made by Drs. Miller and Lowry to the public health units. The visits always served to improve ascertainment as registering agencies could see the value of their input. Letters to the registering agency, public health unit or physicians were written by the medical consultant to clarify or verify diagnoses or to offer advice. Dr. Patricia Baird replaced Dr. Lowry as the medical consultant in 1977. There was an increase in academic and scientific activity with many theses and papers being produced. Between 1961 and 2011, there were 127 scientific reports published in peer reviewed journals and authored by the medical and genetic consultants, University of British Columbia graduate students or residents in the pediatrics or medical genetics programs, and BC Ministry of Health staff including research officers, data personnel and administrators (a list of publications based on British Columbia registry data is available from the authors of this article). Figure 2 shows the level of productivity, which peaked from 1981-1985.

Reports were issued by HSR and provided information on the methodology of the registry, prevalence rates by time in years and by geographical units (provincial, health authority, health service delivery areas), and a description of the different activities of the registry. There were 4 reports issued by HSR prior to 1958 and from 1958 to 1972 they were produced annually. There was no report in 1973, but annual reports from 1974 to 1981 were produced. Thereafter the reports appear to be approximately every 2 to 4 years, with the last report in 2005 which deals with data up to 2002. There are 3 reports using HSR data by BC Ministry of Health personnel and/or medical genetic consultants published in the now defunct Canadian Congenital Anomalies Surveillance Network (CCASN) publications online 2003-2005 (http://www.phac-aspc.gc.ca/ccasn-rccas/).

HSR became a member of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) in 2001 supplying annual data to them up to 2006. It continued to send quarterly data up to the first quarter of 2010 on selected malformations and on a multimalformed project and also supplied data for an international study on the prevalence of cleft lip/palate.

The Challenges of the British Columbia Health Status Registry

Towards the end of the 1980s, the BC Ministry of Health indicated a desire to withdraw support for HSR. Negotiations for the HSR takeover were held with members of the Department of Health Care and Epidemiology (HCE) at the University of British Columbia (UBC). When it was realized that the Ministry of Health would not be transferring the funding to run HSR, and since UBC could not afford it, the plans were dropped. At this time, the ministry also made a decision to discontinue the services of the medical consultant (Dr. Baird) who had also fulfilled the duties of genetic consultant as well after Dr. Miller’s retirement. HSR was then moved in 1990 from Vancouver to Victoria, which is the capital of British Columbia.

The move to Victoria, together with the loss of a medical consultant, resulted in a decline in ascertainment of congenital anomalies. The decision to accept the discharge notices from BC Children’s Hospital (the second largest ascertainment source) in ICD-9 codes instead of text diagnoses resulted in a serious loss of detail. No permanent medical consultant was appointed, but one of the medical geneticists from UBC traveled from Vancouver to Victoria 3 or 4 times a year for 2 to 3 years, but then ceased. As a result, there was no medical supervision of the coders.
or any attempt to verify complex or uncertain diagnoses. There was an excellent administrator, Nancy Scott, who was succeeded by another capable administrator, Helen Colls, but on her death, the Ministry chose not to appoint another dedicated administrator for HSR. Subsequent managers had many additional duties, and administration functions were parceled out to various parts of the BC Ministry of Health in vital statistics and knowledge management technology. Thus, there was no overall guiding hand. Additionally, there was failure to appoint a research officer when the previous one retired. Due to the lack of feedback to the reporting agencies, they were less inclined to report cases.

An outside consultant firm (Coopers and Lybrand) was commissioned in 1990 to evaluate HSR. Unfortunately, this report cannot be found, but a summary was published which identified problems and made future recommendations including the formation of a 14-member health advisory committee. It is not clear how long this committee functioned or how often it met, but by the middle of the decade they had ceased, and there was further decline in activities including ascertainment.

In 2002, there was a rejuvenation of interest in HSR and Dr. Lowry was appointed chair of a newly formed medical advisory committee. Also on the committee were 2 Victoria Medical geneticists, the provincial epidemiologist, and members of the BC Ministry of Health representing HSR including the research officer, data management specialist, and the 2 coders. The health advisory committee, realizing that ascertainment was deficient, attempted to make improvements and did manage to get BC Children’s Hospital to agree to send the diagnosis in text rather than ICD codes. At one time, prenatally diagnosed cases of congenital anomalies that underwent termination of pregnancy (ToP) were received but no data on ToP for malformations has been received since 2006. Lowry was replaced as chair of this committee in 2006 and shortly thereafter the committee disappeared completely.

HSR was probably the first birth defects and handicapped registry in the world and at one time enjoyed a very high level and quality of ascertainment, function, utilization, and scientific importance. The decline of HSR’s acquisition of cases for accurate statistics, research, interaction with registering agencies, and reduced funding cannot be attributed to the staff, coders, clerks, research officers, and data management personnel. The responsibility resides in the hands of BC Ministry of Health officials from the

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### Table 1. Characteristics of the British Columbia Health Status Registry and the Alberta Registry/System

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>British Columbia Health Status Registry</th>
<th>Alberta Registry for Handicapped Children and Adults</th>
<th>Alberta Congenital Anomalies Surveillance System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date established</td>
<td>1952 to date</td>
<td>1963-1979</td>
<td>1980 to date</td>
</tr>
<tr>
<td>Administration</td>
<td>Division of Vital Statistics, Ministry of Health Knowledge Management Technology</td>
<td>Department of Social Services and Community Health-Vital Statistics</td>
<td>Vital Statistics, Ministry of Health Ministry of Registries</td>
</tr>
<tr>
<td>Objectives</td>
<td>Record and classify congenital abnormalities, genetic conditions and selected handicapping conditions Assist in health care planning and other appropriate services Undertake statistical analysis for medical and genetic research Keep public informed with timely and accurate information while maintaining confidentiality Respond to research requests Be a useful tool for health care and social service systems</td>
<td>Record and classify congenital abnormalities, genetic conditions and selected handicapping conditions Assist in health care planning and other appropriate services Undertake statistical analysis for medical and genetic research Keep public informed with timely and accurate information while maintaining confidentiality Respond to research requests Be a useful tool for health care and social service systems</td>
<td>Provide baseline data Investigate temporal or geographic changes Measure trends Assess effectiveness of prevention Assist in health program planning Participate in related research Offer advice regarding congenital anomalies</td>
</tr>
<tr>
<td>Sources of ascertainment</td>
<td>Multiple &gt; 50 reporting sources Physicians’ Notice of Birth Still birth and Death Registrations Public Health Units (e.g. well baby clinics, immunization, special schools for the mentally handicapped, blind, deaf). Hospital Discharge Abstracts</td>
<td>Physicians’ Notice of Birth Still birth and Death Registrations Health Units Specialty clinics Hospital admissions</td>
<td>Physicians’ Notice of Birth Still birth and Death Registrations Delivery hospitals Pediatric and tertiary care hospitals Specialty clinics</td>
</tr>
</tbody>
</table>
Table 1, cont. Characteristics of the British Columbia Health Status Registry and the Alberta Registry/System

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>British Columbia Health Status Registry</th>
<th>Alberta Registry for Handicapped Children and Adults</th>
<th>Alberta Congenital Anomalies Surveillance System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registration Criteria</td>
<td>Person of any age diagnosed with genetic condition or congenital anomaly that is not necessarily disabling Person &lt;19 years diagnosed with a physical, mental, and/or emotional problem with long-term disabling effects that interferes with education or prevents full and open functional employment</td>
<td>Person of any age diagnosed with genetic condition or congenital anomaly that is not necessarily disabling Person &lt;19 years diagnosed with a physical, mental, and/or emotional problem with long-term disabling effects that interferes with education or prevents full and open functional employment</td>
<td>Persons up to 1 year of age diagnosed with a congenital anomaly</td>
</tr>
<tr>
<td>Follow up</td>
<td>Yes-assist local authorities with obtaining specialist services by contacting the reporting agency or registering physician, thus maintaining confidentiality. Follow-up cohorts when children were 7 and 14 years to determine if condition was resolved or further care was needed, and used for resource allocation and planning</td>
<td>Yes if suspicious increases or clusters To verify diagnoses</td>
<td></td>
</tr>
<tr>
<td>Legislation</td>
<td>Evidence Act of 1970-protects reporting agency from liability Amendment to Health Act of 1992 established legislative mandate for submission of data</td>
<td>None</td>
<td>Health Information Act 2001-allows disclosure by reporting agencies for purpose of public health surveillance and allows ACASS to legally request documents and reports</td>
</tr>
<tr>
<td>Advisory Committee</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

assistant deputy minister level right up to ministers of health and indeed the premiers, all of whom were made fully aware in this recent decade of what was necessary to restore HSR back to its former strength.10

Alberta (AB)
The Establishment of the Alberta Congenital Anomalies Surveillance System

In 1963, the Alberta Department of Health started the Registry for Handicapped Children and Adults (RHCA) as a result of the thalidomide problem. It was modeled entirely on the British Columbia HSR and used the same criteria for registering cases (Table 1). With multiple government reorganizations, RHCA was ultimately placed in the Department of Social Services and Community Health (SSCH) together with Vital Statistics (VS). The RHCA director was a physician. Annual reports were not published but statistical data on specific topics were available on request. There was only 1 scientific publication.11

Because of the impending retirement of the medical director, Dr. Charlotte Dafoe, the government commissioned a review of RHCA in 1976. The report, known as the Kaegi Report, was never given general release, though copies were sent to all health unit directors and some selected individuals. It raised issues such as lack of interest and commitment, and underascertainment. Although the minister and deputy minister of SSCH said that a decision had been made to revitalize RHCA, no action ensued and the medical director was not replaced. In December 1979, an administrator was appointed. In January 1980 he, together with the pediatric consultant from SSCH, set up a birth defects monitoring system, which later became the Alberta Congenital Anomalies Surveillance System (ACASS).12 Unfortunately, the system did not use ICD codes but developed a sequential numerical code starting at 1. The cases had to be recoded to ICD later.

A parallel development occurred in the province with the start of the Alberta Hereditary Diseases Program (AHDP) in 1979.13 A subcommittee on birth defects was formed together with the administrator and pediatric consultant from SSCH. The first meeting occurred in May 1981. In November 1981, the RHCA administrator resigned and was not replaced. In April 1982, the new VS Director, William Gilroy, supported by the Birth Defects Monitoring Subcommittee, sent in a new proposal for restoring the
RHCA which had been inactive since 1977 with loss of the early data. This was turned down on financial grounds and furthermore funds for birth defects monitoring would cease as well the following year. The Alberta Ministry of Health did agree to transfer the congenital anomalies surveillance component to the department of medical genetics at the Alberta Children’s Hospital in Calgary whose director (Dr. Lowry) undertook to find funding which was successful. Table 1 provides a brief summary of ACASS.

Annual grants were obtained from foundations such as Medical Services Incorporated and the Alberta Children’s Hospital Foundation. In 1986, a federal national health grant was obtained for a pilot project to incorporate controls into congenital anomaly surveillance and this was followed by a 3-year grant (1988-1991) to implement a case-control system for the 12 congenital anomalies in the ICBDSR surveillance reports. Mothers were interviewed using the services of genetic nurses in all 27 health units. When the grant ended, interviews and inclusion of controls were discontinued because of time and expense. From 1992-1996, ACASS was totally supported by the Alberta Children’s Hospital Foundation but subsequently the Alberta Ministry of Health (Dr. Stefan Gabos) restored funding and since that time, the surveillance branch of the Alberta Ministry of Health has provided financial support and been a very active participant, although the office remains at the Alberta Children’s Hospital.

In 2001, the Health Information Act was passed by the Alberta government, which allows disclosure by agencies or health personnel of any health information for the purposes of public health surveillance. ACASS is legally entitled to request such data.

Activities of the Alberta Congenital Anomalies Surveillance System

The first ACASS report for the 1980-1986 data was issued in 1989 with subsequent reports every 3 years (www.health.alberta.ca/documents/congenitalanomalies-Report9-2012pdf). Between 1988 and 2012, 40 publications used ACASS data plus 3 articles in the now defunct CCASN system (http://www.phac-aspc.gc.ca/ccasn-rscas/index.html). A list of these publications is available from the authors of this article.

ACASS became a member of ICBDSR in 1996 and continues to supply annual data for ICBDSR reports and has supplied data for the 8 very rare defects reported in the American Journal of Medical Genetics15; for a cleft lip/palate study and a recent study on esophageal atresia.

Conclusion

Reorganization of the health-care system is usually done to improve efficiency and reduce costs. In both British Columbia and Alberta, these steps have not necessarily aided the registry or surveillance systems. For example, in Alberta, ACASS was moved from the Ministry of Health to a Ministry of Registries and thus was grouped with land titles and motor vehicle registrations. Fortunately, this was short-lived and ACASS returned to the Ministry of Health. In both BC and AB, health unit districts and areas were changed to regions with loss of contact between public health units and the registry/surveillance systems as well as hampering geographic investigation of clusters.

Some of the methods which governments use to deal with problems are to invite outside consultants or to set up their own investigative commission. The results are often disappointing, as was seen with the Coopers-Lybrand report in BC where very little sustained action occurred, with the exception of improving computer technology. There was little, if anything, done towards improving ascertainment, contact with stakeholders, or verification of diagnoses. AB had similar experiences (see previous reference to Kaegi report). The AB government also set up a task force to look at services for disabled persons. The report (known as the Klufas report) was submitted to the minister of SSCH in 1983 and made a large number of recommendations, one of which was that the provincial government establish a committee to assess the feasibility of an Alberta Health Surveillance Registry similar to that of British Columbia. There was no action on this recommendation.

There are lessons here not just for British Columbia and Alberta but for all congenital anomaly and/or birth defects registries. Consistent funding is essential; many systems in Canada and the United States and indeed in the British Isles Network of Congenital Anomaly Registers as well as ICBDSR constantly admit to financial difficulties. However, policy changes should not be implemented without having discussions with all the major stakeholders of the system in question.

While major congenital anomalies occur in approximately 3%-5% percent of newborn infants and in 8%-10% of stillbirths, the World Health Assembly at their 2010 meeting made a number of statements, including the fact that they were “deeply concerned that birth defects are still not recognized as priorities in Public Health.” Item 1 urges member states “to raise awareness among all relevant stakeholders, including government officials, health professionals, civil society and the public about the importance of birth defects as the cause of child morbidity and mortality.”15

As stated in the Beijing manifesto, “We must continue to collaborate to establish and maintain birth defects surveillance and monitoring systems, foster research on the causes and prevention of birth defects and genetic diseases and establish sustainable technologically appropriate interventions for the prevention and care of these conditions including the provision of genetic services.”16 Thus, it is apparent that the British Columbia HSR is no longer meeting its objectives, as outlined in Table 1. The Alberta Congenital Anomalies Surveillance System was evaluated by Dr. Andrew Czeizel (Hungary) in 2005, who noted that while the existing level of functioning was excellent and was meeting its objectives, there were 2 major shortcomings: lack of maternal risk factors and no controls. Negotiations are presently underway to link ACASS with the Alberta Perinatal Program to ascertain maternal histories and risk factors. Because of privacy and ethical concerns, it will be very difficult to have routine controls. The age of ascertainment needs to be increased. The thrust in congenital anomaly surveillance is now in prevention as exemplified.
by the folic acid fortification studies with a 46% reduction of neural tube defects in Canada17 and confirmed elsewhere. However, if we are to assess preventive measures, it is essential that we have good quality surveillance data.

The take-home message for all registries is that in order to remain viable, there must be well-written objectives, funding, and an engaged provincial, state or federal government as well as medical, epidemiological, data management and scientific support. The importance of a leader or champion cannot be overstated.

Acknowledgements

This paper is dedicated to the memory of Dr. Jim Miller (AJMG, 2001:98;289).

ACASS is supported by the Surveillance and Assessment Branch of the Ministry of Alberta Health. The help of Michael Sanderson and Larry Svenson is appreciated. The Alberta Children’s Hospital Foundation supported ACASS for many years prior to Alberta Ministry of Health support and without the foundation’s help, ACASS would have closed in 1983. We thank Barbara Sibbald for critical reading of the manuscript and Judy Anderson for transcription.

References

Much talk and attention is being given to pay-for-performance, Meaningful Use 2, incentive payments, cancer quality initiatives, and the like. As I sat at my desk to write this quarter’s article for Raising the Bar, I could not help but wonder if there was a hint of Chicken Little announcing that “the sky is falling” in all the flurry of activities.

As I continued to ponder the future of cancer registry and what it will look like in a new era of accountability, quality control, and rapid reporting, I gave in to the need to play and offer to you the cancer registrar’s version of The Story of Chicken Little.¹ Here’s how it goes.

CHARACTERS
- CANCER LIAISON PHYSICIAN (CLP), the narrator
- SHARLEE CHICKEN, granddaughter of Chicken Little
- HENNIE WINNY, niece of Henny Penny
- LUCKY DUCKY, identical twin brother of Ducky Lucky
- GUMMY LUMMY, maternal aunt to Goosey Loosey
- TURKEY MURKEY, married name of Turkey Lurkey
- The villain, FUDDY DUDDY, the nerdy, bow-tie wearing nephew of Foxy Loxy

THE STORY OF SHARLEE CHICKEN
CLP: Sharlee Chicken was in the registry one day when a light bulb fell on her head. It scared her so much she trembled all over. In fact, she shook so hard her hair extensions started to fall out.

SHARLEE CHICKEN: “Help! Help! The sky is falling! I have to go tell the CEO!”

CLP: So she ran in great fear to tell the CEO. Down the hall and past the water fountain she met Hennie Winny.

HENNIE WINNY: “Where are you going, Sharlee Chicken?”

SHARLEE CHICKEN: “Oh, help! The sky is falling!”

HENNIE WINNY: “How do you know?”

SHARLEE CHICKEN: “I saw it with my own eyes, heard it with my very own ears, and part of it fell on my head!”

HENNIE WINNY: “This is terrible, just terrible! We’d better run.”

CLP: So they both ran down the hall as fast as they could. In front of the cafeteria they met Lucky Ducky.

LUCKY DUCKY: “Where are you going, Sharlee Chicken and Hennie Winny?”

SHARLEE CHICKEN: “I saw it with my own eyes, heard it with my very own ears, and part of it fell on my head!”

HENNIE WINNY: “Help! Help! The sky is falling! We’re going to tell the CEO!”

LUCKY DUCKY: “And we’re running to tell the CEO!”

GUMMY LUMMY: “How do you know the sky is falling?”

SHARLEE CHICKEN: “I saw it with my own eyes, and heard it with my very own ears, and part of it fell on my head!”

GUMMY LUMMY: “Wicked cool! Then I’d better run with you.”

CLP: And they all ran in great fear across the crowded main lobby. There they met Turkey Murkey strutting back and forth in front of the gift shop.

TURKEY MURKEY: “Hello there, Sharlee Chicken, Hennie Winny, Lucky Ducky, and Gummy Lummy. Where are you all going in such a hurry?”

SHARLEE CHICKEN: “Help! Help!”

HENNIE WINNY: “We’re running for our lives!”

LUCKY DUCKY: “The sky is falling!”

GUMMY LUMMY: “And we’re running to tell the CEO!”

TURKEY MURKEY: “How do you know the sky is falling?”

SHARLEE CHICKEN: “I saw it with my own eyes, and heard it with my very own ears, and part of it fell on my head!”

TURKEY MURKEY: “Good grief! I always suspected the sky would fall someday. I’d better run to the CEO with you.”

CLP: So, they picked up their clogs and ran as fast they could, until they met up with Fuddy Duddy in the CEO’s doorway.

FUDDY DUDDY: “Hello there. Where are you rushing to on such a beautiful day?”

SHARLEE CHICKEN, HENNIE WINNY, LUCKY DUCKY, GUMMY LUMMY, TURKEY MURKEY (together): “Help! Help! It’s not a beautiful day at all. The sky is falling, and we’re here to tell the CEO!”

LUCKY DUCKY: “Uh oh, freakin’ scary! We’d better run!”

CLP: So they all ran down the hall at fast as they could. Soon they met Gummy Lummy coming out of the elevator.

GUMMY LUMMY: “Whassup? Where are you all going in such a hurry?”

SHARLEE CHICKEN: “We’re running for our lives!”

HENNIE WINNY: “The sky is falling!”

LUCKY DUCKY: “And we’re running to tell the CEO!”

GUMMY LUMMY: “How do you know the sky is falling?”

SHARLEE CHICKEN: “I saw it with my own eyes, and heard it with my very own ears, and part of it fell on my head!”

GUMMY LUMMY: “Hey! Whassup? Where are you all going in such a hurry?”

SHARLEE CHICKEN: “Help! Help!”

HENNIE WINNY: “We’re running for our lives!”

LUCKY DUCKY: “The sky is falling!”

GUMMY LUMMY: “And we’re running to tell the CEO!”

TURKEY MURKEY: “How do you know the sky is falling?”

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Michele Webb, CTR
FUDDY DUDDY: “How do you know the sky is falling?”
SHARLEE CHICKEN: “I saw it with my own eyes, and heard it with my very own ears, and part of it fell on my head!”
FUDDY DUDDY “I see. Well then, follow me, and I’ll take you to the CEO right away.”
CLP: So Fuddy Duddy led Sharlee Chicken, Hennie Winny, Lucky Ducky, Gummy Lummy and Turkey Murkey through a side door and down a long dark hallway. He led them straight to his office in human resources, and they never saw the CEO to tell him that the sky was falling.

And that is the story of how 5 cancer registrars quietly disappeared from the workforce on that fateful day! Was Sharlee Chicken a cancer registrar? What do you think?

Is this a silly story? Perhaps. But, we know that the landscape of oncology healthcare is changing and that quality control initiatives, Rapid Quality Reporting System (RQRS), workforce shortages and all the new scientific and clinical discoveries in medicine are directly impacting the cancer registrar’s work. We know that how we complete our tasks, what we say about our work, what others see in our attitudes and philosophies about service, and their perceived value of our work is directly related to our future.

We, meaning cancer registrars worldwide, have to make an important and life-changing decision. We can be like Sharlee Chicken and predict the sky is falling, talk about lack of support, poor salaries, or increasing job demands and fail to meet the workforce expectations.

Or, we can grow individual and workforce competencies, collaborate and serve our health-care teams to provide data and services that meet their growing needs, volunteer and serve our associations to reinvent the perceived value of the cancer registry profession, and, ultimately, bring value and quality outcomes to patient care.

These are not changes that will come about quickly or easily. They require hard work, dedication and vision. But, we can accomplish this with a united workforce if we choose to abandon reactive behaviors in favor of leadership and service that focuses on new and enhanced competences and knowledge to promote the value of the cancer registry.

Reference

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.
Introduction
Trends in Cancer Registration/EHRs

From one perspective, the move toward electronic hospital and medical office records and related events have incorporated cancer registration almost completely into the world of computerized medical information, or health informatics. Accordingly, cancer registrars have become accepting users of personal computers (PCs). In 2 short decades, cancer registration has moved from no computers, to 1 computer in the supervisor’s office, to now a PC at virtually every registrar’s workstation. Inertia, fear, or unwillingness to operate computers has given way to the routine widespread use of computers by registry staff. This is not to claim universal computer competence. There still remain many competency and technical literacy issues within cancer registration.

Dealing with Personal Change

For many, the dramatic move to computerization has come at significant emotional cost and been a source of day-to-day stress. Broad changes in previous core cancer registration tasks such as abstracting, staging, casefinding, and follow-up have occurred concurrently with the advent of the electronic age in medical records. Busy registrars have had to become masters of change and new learning in the core certified tumor registrar (CTR) functions at the same time that information technology (IT) is significantly increasing. This necessary acceptance has largely been achieved and deserves celebration. In effect, expert usage of computers has also become one of the necessary core competencies of cancer registrars.

Opportunity

Harnessing Opportunities in Computerization

1. Increasing IT (computer) knowledge.
2. Establishing an IT personal profile and perception within your organization.
3. Collaborating/networking with others on organizational IT projects.
4. Being alert and open to promotional possibilities.

Because computerization has become universal within organizations, this tidal change has inherently increased the value of the computer-savvy registrar within registries and elsewhere within organizations. This major change has had 2 positive effects: 1) increasing the organizational versatility and value of registrars, and 2) the potential for increased personal satisfaction in doing one’s work. It can be more fun, and result in a sense of pride of accomplishment. In addition, an opportunity arises for the registrar to become not only an experienced user of computers, but an expert on cancer registration automation in total. Harnessing this opportunity is summarized in the inset.

Increasing IT (Computer) Knowledge

A straightforward learning path is to read introductory and intermediate IT books, or to take classes on IT subjects. There are numerous journal and magazine articles that will also be helpful. Topics might include:

- Computer resources: Hardware and operating systems, local area networks, firewalls, remote network access, use of desktops, laptops and servers, Web servers, the Web and cancer registry.
- Evolution of medical records: Electronic medical record (EMR)/electronic health record (EHR) environment, meaningful use, interfaces to other clinical records and systems.
- Cancer registry software functionality/applications: Data collection, database management systems, structured query language (SQL), consolidating records, data editing/quality control (QC) software, linkage with external sources, health information exchange/transfer, record linkage, follow-up software, information security, statistical, geographic information systems (GIS) software, vendors/sources of registry software. A detailed discussion of what such subjects as QC, SQL and information exchange are and why they frequently involve registrars, and not just IT personnel, is beyond the scope of this article, but their relevance to registrars is noted.
- Selected IT/registration subjects: Clinical trials, working from home (remotely), cancer registration, informatics summary.

A comprehensive bibliography of these subjects is available from the National Cancer Registrars Association Web site. Also see the selective bibliography below (1-3). Because of the completeness of this bibliographic information, it may be best to take one bibliography subject at a time.

Also, become familiar with your software vendor’s manual and the vendor’s representative. Get to know people in your IT department and learn in collaboration with IT personnel how to install, back up, and restore your cancer registry software. Further, the registrar should make sure IT is aware of all of the registry system requirements.

Special Feature

On Using Health Informatics to Advance Your Career

Herman R. Menck, BS, MBA, CPhil, FACE; Michele Webb, CTR; Kim Watson, CTR; Sue Koering, MEd, RHIT, CTR; Annette Hurlbut, RHIT, CTR; Suzan Naam, MD, CTR; Judy Williams, RHIT, CTR
Establishing an IT Personal Profile and Perception within Your Organization

Helpful advice from several registrars is offered.

Susan Koering suggests, “Approaches include showing data from the registry, offering a data search for physicians, administrative staff or researchers, and showing them report options (departments such as dermatology). Also, Cancer Registry Week is a good time to display data at cancer conferences, cancer committee meetings, facility/cancer center libraries and using hallway displays. I have also asked to be present at department meetings to show data on our organization. These include our annual reports, (general) statistics and those with a cancer-site focus. The cancer program newsletter is another option to share our resources.”

Kim Watson says, “I came to the cancer registry field with a degree in computer software support, so my journey has been different than what most registrars may have experienced. People tend to notice that my computer skills are greater than theirs (usually), and then I end up being the person they come to for quick answers, usually about word processing or spreadsheet applications. We’ve recently changed software vendors and the process would have been much more difficult had I not had the computer background that I have. I’ve just always tried to be available to help. I also always try to make instructions clear and make sense to the learner, rather than just telling them what to do. You have to make them understand why you do something the way you do. This helps them retain the information.”

Michele Webb suggests, “Learning about your registry software, how it works and what the registrar can do to get optimal performance as a result is a key to maintaining your system. Many years ago, I found it simpler and faster to install and maintain my registry software on my own. But, as technology increases and the workload of the registrar increases, it has been more successful, and even a relief, to let IT do what they do best and to focus my efforts in partnering with them to understand what the registry is accountable for, and to be willing to listen, learn, and grow my skills from what IT is almost always willing to give. It’s like free education if we are willing to collaborate.”

Collaborating/Networking with Others on Organizational IT Projects

Volunteer for or ask to be included in automation or IT planning projects within your organization. Also initiate other IT projects, such as additional data reporting, and submitting outcomes data for Meaningful Use Phase 2 (MU2) as part of the Centers for Medicare and Medicaid Services/National Quality Forum (CMS/NQF) activities.

Suzan Naam suggests, “Step up and volunteer to help in many of the tasks that used to be performed by IT in the registry. Participate in many cooperative projects with other databases in our organization. Take every opportunity to present registry data and analysis in advanced and impressive format.”

Michele Webb says, “Get involved in your organization’s efforts to maintain compliance with all quality control measures, many undertaken through the quality control department. IT is often a part of this effort and this is a chance to have a voice in both sides of the picture and still promote the activities of the cancer registry independent of both groups.”

Being Alert and Open to Promotional Possibilities

Let your supervisor and human resources know you are interested in job growth and promotion. Ask for their advice on career advancement pathways, and what you can do to help your organization. Be open to new opportunities, even if they are somewhat different.

Your approach to registry informatics may be colored by whether you are a central registrar, hospital based, independent contractor, or whatever. It is believed that these core suggestions can be usefully adapted, whatever the case.

Summary

For personal satisfaction and possible promotion, increased IT (health informatics) familiarization can be a positive step. This article outlines self-help steps toward making that goal possible. The authors and many of their peer leaders believe that IT familiarization is a valuable career goal, and is possible following the steps discussed above.

References
DESCRIPTIVE EPIDEMIOLOGY OF MALIGNANT PRIMARY OSTEOSARCOMA USING POPULATION-BASED REGISTRIES, UNITED STATES, 1999-2008

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:
• Compare the national incidence of osteosarcoma by age and sub-site
• Identify the source data used in this study
• Describe how the incidence of malignant primary osteosarcoma differs according to age, gender, race, ethnicity, region, grade, and stage

1. Osteosarcoma:
   a) is a common bone tumor
   b) incidence peaks during adolescence
   c) is most frequently diagnosed among individuals in the fourth decade of life
   d) occurs only in very young children
2. Among 15 to 29 year olds, osteosarcomas are more likely to occur in the:
   a) axial skeleton
   b) proximal femur
   c) metaphyses of long bones
   d) distal tibia
3. Osteosarcoma affects males more frequently than females across all age categories.
   a) True
   b) False
4. Incidence data for this study include:
   a) radiographically confirmed cases of primary osteosarcoma
   b) cases diagnosed between 2000 and 2010
   c) data from 44 states and the District of Columbia
   d) data from the National Program of Cancer Registries (NPCR) and the Surveillance, Epidemiology, and End Results (SEER) Program
5. According to Table 1, Topography Codes Used to Define Malignant Primary Osteosarcomas by Appendicular and Axial Sites, United States, 1999–2008, axial subsites include:
   a) bone, NOS
   b) bone of limb, NOS
   c) overlapping lesion of bones, joints, and articular cartilage of limbs
   d) scapula
6. Cancer stage was assigned according to:
   a) SEER summary stage 1977
   b) SEER summary stage 2000
   c) derived summary stage
   d) the year of diagnosis
7. Ethnicity was categorized as Hispanic or non-Hispanic based on:
   a) race/ethnicity information taken from the face-sheet
   b) patient self-disclosure of ethnicity
   c) North American Association of Central Cancer Registries’ (NAACCR) Hispanic/Latino Identification Algorithm (NHIA)
   d) random assignment of the Hispanic ethnicity when Hispanic status was unknown
8. This study considered race and ethnicity to be mutually exclusive.
   a) True
   b) False
9. According to Table 3. Description of Primary Osteosarcoma Incidence by Selected Characteristics, United States, 1999–2008:
   a) 37% of the grade IV osteosarcomas were appendicular
   b) axial sarcomas occur most commonly in the 70–79 age group
   c) among appendicular and axial cases, the predominant race group was black
   d) the majority of axial osteosarcomas were diagnosed at distant stage
10. Limitations in this study include:
    a) possibility of misclassification or miscoding in the registry data
    b) data were not available from some central registries because they did not meet case ascertainment and quality criteria
    c) race and/or ethnicity misclassification
    d) all of the above
Instructions: Mark your answers clearly by filling in the correct answer, like this ■ not like this ◯. Passing score of 70% entitles one (1) CE clock hour per quiz. Please use black ballpoint pen.

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4. **“How I Do It” Articles** describe tips, techniques, or procedures for an aspect of registry operations that the author does particularly well. The “How I Do It” feature in the *Journal* provides registrars with an informal forum for sharing strategies with colleagues in all types of registries.
5. **Opinion papers/editorials** including position papers, commentaries, essays, and interviews that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management.
6. **Bibliographies** which are specifically targeted and of significant interest will be considered.
7. **Letters to the Editor** are also invited.


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

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

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

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

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