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Contents

Letter from the Editor
Vonetta L. Williams, PhD, MPH, CTR ................................................................. 129

Original Articles
Use of Population-Based Cancer Registry Data to Determine the Effect of Timely Treatment on the Survival of Colorectal Cancer Patients ...................... 130
Moe Sandar, MB, BS, MMedSc, MA, CTR; Lim Gek Hsiang, BSc, MSc; Chow Khuan Yew, MBBch, FRACGP, MMed; Lee Bee Guat, RN, CTR

Current Status of Brain Tumor Surveillance in Canada and Why it Matters .......... 139
Faith Davis, PhD; Chenthila Nagamuthu, MPH; Jordan Ross, MPH(c); Joseph Megyesi, MD, PhD

Analysis of the National Cancer Data Base to Describe Treatment Trends in Stage IV Oral Cavity and Pharyngeal Cancers in the United States, 1998–2012 ........................................................................ 146
Shai White-Gilbertson, PhD, MSCR, Dipl Ac, CTR; Sybil Nelson, MS; Kevin Zhan, MD; Christopher Xiao, BA; Linda Cope, CTR; Terry Day, MD

Features and Other Journal Departments
Remote Abstracting: A Home Guide ................................................................. 152
Danillie Clark, RMA, AAS, CTR; Danette Clark, BS, RMA, AAS, CTR

Update from the American Joint Committee on Cancer TNM Edits Task Force ... 155
North American Association of Central Cancer Registries (NAACCR) Edits Workgroup

Winter 2015 Continuing Education Quiz ....................................................... 156
Deborah C. Roberson, MSM, CTR; Denise Harrison, BS, CTR

Index ............................................................................................................. 158

Call for Papers ........................................................................................... 169

Information for Authors ............................................................................. 170
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**Indexing**
The *Journal of Registry Management* is indexed in the National Library of Medicine’s MEDLINE database. Citations from the articles indexed, the indexing terms (key words), and the English abstract printed in *JRM* are included and searchable using PubMed.

For your convenience, the *Journal of Registry Management* is indexed in the 4th issue of each year and on the Web (under “Resources” at [http://www.ncra-usa.org/jrm](http://www.ncra-usa.org/jrm)).

The 4th issue indexes all articles for that particular year.

The Web index is a cumulative index of all *JRM* articles ever published.
I was listening to the radio the other day and the gentleman speaking stated that we need to have an “attitude of gratitude.” My first thought was, *what does he mean?* I always carry a notepad and pencil or pen with me (I haven’t fully transitioned to using the notes app on my phone or tablet), so I quickly wrote down “attitude of gratitude” on a piece of paper so I could reflect on what that statement means to me. After thinking about this for a few minutes, I wrote down what having an attitude of gratitude means to me. First, being grateful for health and life speaks volumes. Every morning that we wake up, we have the opportunity to do better than we did yesterday. Second, I’m grateful for my family, friends, colleagues, and you. Having a support system is vital; none of us can make it along this journey alone. Finally, I’m grateful to have an opportunity to wake up every day and do something that I love and am passionate about. The passion and love for what we do lightens the load a bit during difficult times. I challenge and encourage each of you to create a “thank you list.” I started working on my thank you list and, as I write this letter, I have more than 50 thank yous. Put copies of this list in places you frequent daily (phone or computer screen saver, office desk, bathroom mirror, back of your front door, garage door, etc). This will allow you to focus on what you have and worry less about what you do not have.

In this issue, we highlight a special article from the American Joint Committee on Cancer TNM Edits Task Force and a *How I Do It* article from Danillie Clark, RMA, AAS, CTR, and Danette Clark, BS, RMA, AAS, CTR, on a home guide to remote abstracting. In addition to the featured articles, we have an original manuscript from Moe Sandar, MB, BS, MMedSc, MA, CTR, and colleagues evaluating the relationship between timely treatment and survival among colorectal cancer patients using a study population of Singaporean patients. Also, Dr. Faith Davis and team evaluated brain tumor surveillance in Canada and why this is important. Finally, Dr. Shai White-Gilbertson and colleagues completed a secondary data analysis evaluating treatment trends using data from the National Cancer Data Base on patients diagnosed with stage IV oral cavity and pharyngeal cancer.

We are excited about the opportunity to highlight birth defects registries in our spring 2016 issue. You will hear more from our guest editors, Kirby Russell, PhD, and Wendy Nemhhard, PhD, MPH, in our spring 2016 issue. We are highlighting trauma registries in our fall 2016 issue (see page 169 for the call for trauma registry articles/manuscripts).

We thank you for your continued support of the *Journal of Registry Management* and look forward to making 2016 a great year.

Respectfully,

Vonetta L. Williams, PhD, MPH, CTR
Editor-in-Chief, *Journal of Registry Management*
National Cancer Registrars Association
Use of Population-Based Cancer Registry Data to Determine the Effect of Timely Treatment on the Survival of Colorectal Cancer Patients

Moe Sandar, MB, BS, MMedSc, MA, CTR; Lim Gek Hsiang, BSc, MSc; Chow Khuan Yew, MBBch, FRACGP, MMed; Lee Bee Guat, RN, CTR

Abstract: Introduction: Colorectal cancer is the third most common cancer in the world. In Singapore, it was the most common cancer in males and second most common cancer in females from 2009 to 2013. The incidence for colorectal cancer is declining, but the mortality remains high. Cancer of the colon is a highly treatable and curable disease when it is localized to the bowel. Timely treatment of cancer, which is defined as the interval between date of diagnosis and starting date of treatment within an assigned time frame, plays an important role for the survival of patients. This is the first study in Southeast Asia looking at multiethnic groups. The study attempts to determine the effect of timely treatment on survival of colorectal cancer patients by using the Singapore cancer registry data. Methods: Histologically proven colorectal cancer cases of the residents in Singapore diagnosed in 2008–2012 were included. Exclusion criteria for the study were neuro-endocrine carcinomas, soft tissue sarcoma, and lymphoma of the bowel. Bivariate analysis was used to describe patient demographic and disease characteristics by survival status of patient as well as by treatment types and stage group. Timely surgery, adjuvant therapy, and neoadjuvant treatment modalities were defined. Cox regression analysis was used to determine the effect of timely treatment on survival of patients by controlling other independent variables of age, sex, the stage of disease, and ethnicity. Results: A total of 7,739 patients were included in this study. Colorectal cancer was more common in males (55.8%) than in females (44.2%), with a median age of 65.5 years for males and 67.1 years for females. It was more common in Chinese ethnicity (87.7%) followed by Malay (7.4%) and Indian (3.2%). About 40% of patients were diagnosed in early stage and 54.3% in late stage. Primary subsites in order of frequency were sigmoid colon (29%) and rectum (24.4%), followed by rectosigmoid colon (11.4%). About 86% of patients had surgery, of which 47% were treated by surgery alone. More than 75% of patients received timely treatment. Cox regression analysis produced a hazard ratio (HR) of 1.18 (95% CI, 1.02–1.36) for patients who did not receive any type of timely first treatment, an HR of 1.35 (95% CI, 1.17–1.57) for patients with no timely surgery, an HR of 1.4 (95% CI, 1.21–1.62) for patients with no timely adjuvant chemotherapy, and an HR of 2.05 (95% CI, 1.23–3.41) for patients with no timely neoadjuvant therapy. Conclusion: The study shows that there were significant effects of timely treatment on survival. Information on the timely treatment modalities and its benefits should be included in the public education and emphasized during the treatment planning with patients for better compliance and improved outcomes. Some delays are avoidable and perhaps the causes of these avoidable delays should be identified and resolved to further enhance quality of service in health care.

Key words: colorectal cancer, Singapore Cancer Registry, survival, timely treatment

Introduction

Colorectal cancer is the third most common cancer in the world. In Singapore, it was the most common cancer in males and second most common cancer in females from 2009 to 2013, and the second- and third-leading cause of cancer-related death in males and females, respectively. The incidence trend for colorectal cancer is declining, but the age-standardized mortality rates for colorectal cancer still remain high.

Surgery is the standard of care for colorectal cancer. The current evidence-based standard of care for surgery is colectomy with removal of at least 12 lymph nodes for stage II and III disease. Adjuvant chemotherapy is recommended for those patients with stage II A, II B, II C with high risk, and stage III disease. Surgery can sometimes be done for stage IV cancer to remove metastasis. Randomized studies have shown that adjuvant chemotherapy can improve overall survival by 25% to 30%. For advanced rectal cancer, preoperative chemoradiation with optimal surgery is considered the standard treatment.

Early initiation of treatment plays an essential role to reduce the mortality of patients. It is accepted that surgery should begin within 4 weeks after diagnosis and most clinical trials mandate that chemotherapy should be started within 6 to 8 weeks after surgery. A meta-analysis conducted in 2009 suggested that colorectal cancer patients with chemotherapy performed more than 8 weeks after surgery had worse survival than those with timely chemotherapy.

Recent studies reported that an interval of more than 8 weeks between neoadjuvant and surgery resulted in a higher rate of tumor down-staging and pathologic complete response than a shorter interval of 6 to 8 weeks to surgery. Tumor down-staging and pathological complete response may improve overall survival.

A systematic review and meta-analysis study was conducted by Biagi et al in 2011 to determine if an association existed between the timing of the initiation of chemotherapy and the survival in colorectal cancer patients. In that study, relevant articles through MEDLINE from 1975...
to January 2011, EMBASE, Cochrane Database of Systemic Reviews, and Cochrane Central Register of Controlled trials were identified. The study included 10 eligible studies (7 published and 3 abstracts) with 15,410 patients. The authors used bivariate analyses and looked at overall and disease-free survival. The study demonstrated that a 4-week increase in delay of starting adjuvant chemotherapy was associated with a significant decrease in both overall and disease-free survival by 14%.12

Purpose of Study
This study aimed to compare survival between patients who received timely initiation of treatment and those who did not. In our study, the cutoff point for timely treatment was 30 days between the date of diagnosis to the date of surgery (all stages) or start date of neoadjuvant treatment. For patients who received neoadjuvant treatment, 60 days was the cutoff for the time interval between start of neoadjuvant treatment and initiation of surgery. The interval between the date of surgery and the start date of adjuvant treatment (usually stage II disease onwards) was considered 60 days.

Theoretical Framework
From the previous studies and literature reviews,8-11 a theoretical conceptual framework was constructed for this study (Figure 1).

Figure 1. Theoretical Conceptual Framework for the Study

For Stage I and II colorectal cancer cases, surgery should be done within 30 days of diagnosis.

For stage II and III cases with adjuvant therapy, adjuvant therapy should be started within 60 days after surgery.

For stage II and III cases with neo-adjuvant therapy, neo-adjuvant treatment should be started within 30 days after diagnosis and surgery should be followed after 60 days of neo-adjuvant therapy.

Materials and Methods

Study Population
The study population comprised of Singapore residents who were primarily diagnosed with colorectal cancer from 2008 to 2012, and followed with the death registry until December 31, 2013. Patients who were still alive on December 31, 2013 were censored. All patients with histologically proven colorectal cancers were included in the study. Histology proved neuroendocrine carcinomas, soft-tissue sarcoma, and lymphoma cases were excluded from the study.

The Singapore Cancer Registry receives notification from multiple sources: medical practitioners, pathology records, and hospital records. Cancer notification was made mandatory in 2009 when cancer became a reportable disease under the National Registry of Diseases Act. The Registry ensures that notifications are as complete as possible by checking all pathology reports from restructured hospitals, private laboratories, and death certificates issued in Singapore as well as discharge records from all restructured hospitals. Restructured hospitals are privately run health care institutions which are wholly owned by the government through the Ministry of Health, Singapore. The hospitals receive government subsidy for the provision of subsidised medical services to their patients.13

Cancer cases identified from these sources are checked against registered cases. The Registry captures patient details such as age, date of birth, gender, ethnicity, and disease characteristics including date of diagnosis and treatment. The start dates of all treatment modalities received by patients within 6 months were recorded in the cancer registry data base. Completeness and accuracy of data are checked using a sample of records in the annual quality audit.

Statistical Methods
Bivariate analysis was used to determine 2 variables simultaneously to show distribution of age group, gender, and ethnicity, stage at diagnosis, primary subsites by survival status of patient, as well as by treatment and stage of disease.

Timely treatment refers to any type of treatment (surgery/neoadjuvant treatment) initiated within 30 days from date of diagnosis. Timely adjuvant treatment (chemotherapy or radiation therapy or combination of chemoradiation) was defined as within 60 days after surgery. The interval between surgery and neoadjuvant treatment was considered “timely surgery” if it was done after 60 days from the start date of neoadjuvant treatment (chemotherapy/radiotherapy). The interval between date of diagnosis and treatment date was calculated and recorded as timely if it fell within the assigned time frame.

Cox regression (or proportional hazards regression) is a method for investigating the effect of variables upon the timeframe during which a specific event occurs. This analysis was used to determine the effect of timely treatment on the survival of patients, while adjusting for potential confounders such as age, gender, ethnicity, and stage. Within the study defined population, colorectal cancers with unknown stage and unknown treatment modalities were excluded in Cox regression analysis. Analysis was carried out using Stata statistical software (version 10)14 and P < .05 was considered significant.

Results
The total number of patients included in the study was 7,739 after exclusion of 430 patients according to exclusion criteria. Four hundred thirty-eight patients were recorded as unknown stage and 605 observations grouped under no treatment were not included in the Cox regression analysis. Colorectal cancer was slightly higher among males (55.8%) than among females (44.2%). The median
Age at diagnosis was 65.5 years for males and 67.1 years for females. Colorectal cancer was also more common in Chinese patients (87.7%) than in Malay patients (7.4%) and Indian patients (3.2%) (Table 1).

Nearly 40% of the patients were diagnosed with early-stage disease (stage I and II) whereas 54.5% of the patients were diagnosed with late-stage disease (stage III and IV). Twenty-nine percent of the cases were found to be in sigmoid colon; 24.4% were in the rectum followed by 11.4% in the rectosigmoid colon.

There was significant association between age group, ethnicity, stage, and primary subsite with survival status.

The total number of patients who had surgery combined with other treatment in this study was 6,621 (85.6%). It was observed that less than half of patients were treated by surgery alone (47.1%) followed by surgery with adjuvant chemotherapy (29.2%), and surgery with adjuvant chemoradiation (4.9%) (Figure 2).

More than three-fourths of patients had timely surgical treatment (84.2%), chemotherapy (82.4%), timely radiation (83.2%), and neoadjuvant therapy (76.6%) in this study (Table 2). Out of the 7,739 patients, 438 (5.7%) patients had unknown stage and 7.8% had not taken any treatment (Tables 3 and 4).

| Table 1. Profile of Patients' Demographic and Disease Characteristics with Survival Status |
|---------------------------------|---------|-----------------|-----------------|---------|
| Variable                        | Number  | Percent         | Survival        | P Value |
|                                 |         |                 | Alive | Death |
| Gender                          |         |                 |       |       |
| Male                            | 4315    | 55.8            | 2724  | 1591  | (0.13) |
| Female                          | 3424    | 44.2            | 2218  | 1206  |       |
| Age group (in years)            |         |                 |       |       |
| <50                             | 688     | 8.9             | 497   | 191   | (<.001) |
| 50–69                           | 3761    | 48.6            | 2660  | 1101  |       |
| ≥70                             | 3290    | 42.5            | 1785  | 1505  |       |
| Ethnicity                       |         |                 |       |       |
| Chinese                         | 6789    | 87.7            | 4348  | 2441  |       |
| Malay                           | 573     | 7.4             | 329   | 244   | (<.001) |
| Indian                          | 244     | 3.2             | 169   | 75    |       |
| Others                          | 90      | 1.2             | 66    | 28    |       |
| Unknown                         | 38      | 0.5             | 30    | 9     |       |
| Stage at Diagnosis              |         |                 |       |       |
| Stage I                         | 1077    | 13.9            | 968   | 109   | (<.001) |
| Stage II                        | 2010    | 25.9            | 1625  | 385   |       |
| Stage III                       | 2530    | 32.7            | 1811  | 719   |       |
| Stage IV                        | 1684    | 21.8            | 363   | 1321  |       |
| Unknown                         | 438     | 5.7             | 175   | 263   |       |
| Primary site                    |         |                 |       |       |
| Caecum                          | 499     | 5.8             | 268   | 181   | (<.001) |
| Appendix                        | 44      | 0.6             | 26    | 18    |       |
| Ascending colon                 | 533     | 6.9             | 330   | 203   |       |
| Hepatic flexure                 | 274     | 3.5             | 163   | 111   |       |
| Transverse colon                | 460     | 5.9             | 286   | 174   |       |
| Splenic flexure                 | 221     | 2.9             | 133   | 88    |       |
| Descending colon                | 405     | 5.2             | 280   | 125   |       |
| Sigmoid colon                   | 2243    | 29.0            | 1527  | 716   |       |
| Overlapping lesion              | 247     | 3.2             | 136   | 111   |       |
| Colon, NOS                      | 86      | 1.1             | 35    | 51    |       |
| Recto-sigmoid                   | 886     | 11.4            | 578   | 308   |       |
| Rectum                          | 1891    | 24.4            | 1180  | 711   |       |
Timely initiation with any type of first treatment had a significant effect on survival of patients. Patients who did not receive timely treatment were 18% more likely to die than those who had timely treatment (HR, 1.18; 95% CI, 1.02–1.36; P < .05), after adjusting for all potential confounders: age, sex, ethnicity, and stage of disease (Table 5). Specifically, timely initiation of surgery had a significant effect on survival of colorectal cancer patients after controlling age, sex, ethnicity, and stage (Table 6). The patients who did not have timely surgical treatment were 35% more likely to die than those who had timely surgery within 30 days of diagnosis (HR, 1.35; 95% CI, 1.17–1.56; P < .001). On the other hand, timely initiation of radiotherapy had no significant effect (P = .99) on survival of colorectal cancer patients after controlling for all potential confounders (Table 8).

There was a significant impact of timely adjuvant chemotherapy on the survival of patients in this study. Patients who did not receive timely adjuvant treatment were 40% more likely to die than patients who received early initiation (HR, 1.40; 95% CI, 1.21–1.62; P < .001), after adjusting for all potential confounders (Table 7).

There was significant association between timely neo-adjuvant treatment and the survival of colorectal cancer patients after controlling for all potential confounders. Patients who did not receive timely neo-adjuvant were 2 times more likely to die than those who received timely neo-adjuvant treatment (Table 9).

**Discussion**

Our study showed that more than 75% of patients received timely treatment modalities. Early initiation of adjuvant chemotherapy is crucial to patient survival in colorectal cancer patients. There is theoretical rationale to initiate adjuvant chemotherapy promptly after curative surgery. The studies in animal models suggested that surgery may increase the numbers of circulating tumor cells and may accelerate growth of metastasis. These were associated with reduction of angiogenesis inhibitors. Surgery has been shown to enhance production of oncogenic growth factor that may promote tumor growth. The rationale of early chemotherapy in that study is that after surgery, the cell cycle metastatic foci was rapid due to effect of several cytokines that could be a good target for chemotherapeutic action. The chemotherapeutic agent can penetrate into tumor cells.15,16 The fact that timely adjuvant chemotherapy had significant effects on the survival outcome was also shown in a Swedish study by Berglund et al.18 The study was done in stage III colon cancer patients to assess the overall survival with start of adjuvant therapy. They compared overall survival between 3 groups: patients starting chemotherapy within 56 days, patients starting...
Table 3. Distribution of Characteristics of Eligible Patients According to Stage Group in Colorectal Cancer Diagnosed in 2008–2012

<table>
<thead>
<tr>
<th>Variables</th>
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<th>Stage III</th>
<th>Stage IV</th>
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<td>181</td>
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<td>95</td>
<td>32</td>
<td>(0.7%)</td>
</tr>
<tr>
<td></td>
<td>(2.3%)</td>
<td>(2.1%)</td>
<td>(1.2%)</td>
<td>(0.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatic Flexure</td>
<td>27</td>
<td>98</td>
<td>88</td>
<td>46</td>
<td>15</td>
<td>(0.3%)</td>
</tr>
<tr>
<td></td>
<td>(1.3%)</td>
<td>(1.1%)</td>
<td>(0.6%)</td>
<td>(0.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transverse colon</td>
<td>54</td>
<td>151</td>
<td>136</td>
<td>103</td>
<td>16</td>
<td>(0.7%)</td>
</tr>
<tr>
<td></td>
<td>(2.0%)</td>
<td>(1.8%)</td>
<td>(1.3%)</td>
<td>(0.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Splenic Flexure</td>
<td>16</td>
<td>72</td>
<td>73</td>
<td>56</td>
<td>4</td>
<td>(0.2%)</td>
</tr>
<tr>
<td></td>
<td>(0.9%)</td>
<td>(0.9%)</td>
<td>(0.7%)</td>
<td>(0.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Descending colon</td>
<td>31</td>
<td>127</td>
<td>144</td>
<td>87</td>
<td>16</td>
<td>(0.4%)</td>
</tr>
<tr>
<td></td>
<td>(1.6%)</td>
<td>(1.9%)</td>
<td>(1.1%)</td>
<td>(0.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sigmoid colon</td>
<td>367</td>
<td>578</td>
<td>690</td>
<td>495</td>
<td>113</td>
<td>(4.7%)</td>
</tr>
<tr>
<td></td>
<td>(7.5%)</td>
<td>(1.1%)</td>
<td>(6.4%)</td>
<td>(1.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overlapping lesion</td>
<td>27</td>
<td>75</td>
<td>80</td>
<td>53</td>
<td>12</td>
<td>(0.3%)</td>
</tr>
<tr>
<td></td>
<td>(1.0%)</td>
<td>(1.0%)</td>
<td>(0.7%)</td>
<td>(0.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon, NOS</td>
<td>5</td>
<td>12</td>
<td>15</td>
<td>38</td>
<td>16</td>
<td>(0.1%)</td>
</tr>
<tr>
<td>Recto-sigmoid</td>
<td>140</td>
<td>209</td>
<td>281</td>
<td>203</td>
<td>53</td>
<td>(1.8%)</td>
</tr>
<tr>
<td></td>
<td>(0.2%)</td>
<td>(0.2%)</td>
<td>(0.5%)</td>
<td>(0.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rectum</td>
<td>303</td>
<td>367</td>
<td>701</td>
<td>379</td>
<td>141</td>
<td>(3.9%)</td>
</tr>
<tr>
<td></td>
<td>(4.7%)</td>
<td>(9.1%)</td>
<td>(4.9%)</td>
<td>(1.8%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
chemotherapy after 56 days, and those receiving surgery alone. The overall survival was higher in adjuvant chemotherapy groups (whether within 56 days or not) than patients treated with surgery alone. The study showed that the patients who had their treatment initiated beyond 8 weeks appeared to have no benefit from chemotherapy.17 Our finding was comparable with previous studies on timely adjuvant chemotherapy on improved survival.

A Korean study was conducted in 2 centers of Seoul National University Hospital (NUH) and Samsung Medical Center (SMC) on patients with postoperative chemoradiation therapy for rectal cancer diagnosed between 1999 and 2007, to compare the impact on locoregional control of radiochemotherapeutic sequence and time to initiation of adjuvant treatment in stage II/III rectal cancer patients. At Seoul NUH, pelvic radiotherapy was administered concurrently with first chemotherapy after surgery (concurrent early chemotherapy group) whereas at SMC group, pelvic radiotherapy was conducted at the third chemotherapy cycle (late concurrent chemotherapy group). It was determined that delayed initiation of adjuvant treatment for more than 5 weeks was associated with a lower rate of locoregional free survival (79% vs 91%, \( P < .01 \)), but there was no significant difference in sequencing of treatment. The overall survival and disease free survival were not affected by radiochemotherapeutic sequence or delay of adjuvant treatment.18 Researchers from Yonsei University College of Medicine, Seoul analyzed data retrospectively for locally advanced rectal cancer patients who underwent preoperative chemoradiation therapy followed by radical resection from 2005 to 2009. The study showed that a delay in the interval of surgery ≥8 weeks after chemoradiation resulted in better nodal down-staging than early surgery within 8 weeks (46.7% vs 66.7%; \( P = .021 \)). There was no significant difference in local recurrence, distant recurrence, disease-free survival and overall survival between the 2 groups.19 The finding was comparable with our study that there was no significant relation between timely radiation therapy and survival of patients with an HR of 0.99 (95% CI, 0.81–1.03, \( P = .99 \)). The patients who received radiation therapy in this study were a small number of cases compared to total patients. There were no data available for end date of radiation and chemotherapy to calculate the interval between neoadjuvant treatment and surgery. Our study took the start date of treatment as proxy to calculate the timing of treatment. We selected all patients with radiation therapy (radiotherapy, chemoradiation, adjuvant radiotherapy). We did not analyze separately rectal cancer patients who received timely chemoradiation that might have had an effect on survival.

There was no comparable study to assess the interval between date of diagnosis and start date of neoadjuvant
therapy. Our finding showed that there was a significant relationship with timely neoadjuvant treatment and survival with an HR of 2.05 (95% CI, 1.23–3.41, \( P < .05 \)). Our study could identify the significant relationship between early initiation of adjuvant chemotherapy and survival in colorectal cancer patients. In this study, individuals receiving late initiation of chemotherapy had a 40% greater mortality than those with early initiation. Timely initiation of any treatment and timely surgery had a significant effect in improving survival by 18% and 35%, respectively.

**Limitations and Strengths**

The study had good coverage of residents in Singapore as the data was taken from the National Cancer Registry of Singapore. All the cases were histologically proven and maintained data accuracy of above 95% by annual audit. Other variables such as disease characteristics (surgical resection margins, histology types, grade/differentiation, specific lymph node staging) and comorbid conditions that may have had an effect on survival of patients were unavailable in this study.
Table 5. Cox Regression on Timely Initiation of Any Type of Treatment on the Survival of Patients

<table>
<thead>
<tr>
<th>Variable</th>
<th>HR</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timely treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1 (Reference)</td>
<td>0.03</td>
</tr>
<tr>
<td>No</td>
<td>1.18 (1.02, 1.36)</td>
<td>0.03</td>
</tr>
<tr>
<td>Age</td>
<td>1.02</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>(1.01, 1.02)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (Reference)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Female</td>
<td>0.85 (0.78, 0.93)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early stage</td>
<td>1 (Reference)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Late stage</td>
<td>3.05 (2.74, 3.40)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>1 (Reference)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Indian</td>
<td>0.92 (0.69, 1.21)</td>
<td>0.53</td>
</tr>
<tr>
<td>Malay</td>
<td>1.27 (1.08, 1.5)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Others</td>
<td>0.70 (0.45, 1.08)</td>
<td>0.11</td>
</tr>
</tbody>
</table>

Early stage = stage I, II. Late stage = stage III, IV with sample size of 7,134.

Table 6. Cox Regression on Timely Surgery on the Survival of Patients

<table>
<thead>
<tr>
<th>Variable</th>
<th>HR</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timely treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1 (Reference)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>No</td>
<td>1.35 (1.17, 1.56)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age</td>
<td>1.02</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>(1.01, 1.02)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (Reference)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Female</td>
<td>0.87 (0.79, 0.96)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early stage</td>
<td>1 (Reference)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Late stage</td>
<td>2.85 (2.54, 3.19)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>1 (Reference)</td>
<td>0.81</td>
</tr>
<tr>
<td>Indian</td>
<td>0.92 (0.67, 1.25)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Malay</td>
<td>1.24 (1.03, 1.49)</td>
<td>0.81</td>
</tr>
<tr>
<td>Others</td>
<td>0.69 (0.42, 1.12)</td>
<td>0.09</td>
</tr>
</tbody>
</table>

Early stage = stage I, II. Late stage = stage III, IV with Sample size of 6,621.

Table 7. Cox Regression on Timely Adjuvant Chemotherapy after Surgery on Survival of Patients

<table>
<thead>
<tr>
<th>Variable</th>
<th>HR</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timely adjuvant chemotherapy</td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1 (Reference)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>No</td>
<td>1.4 (1.21, 1.62)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Age</td>
<td>1.00</td>
<td>.34</td>
</tr>
<tr>
<td></td>
<td>(1.0, 1.01)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (Reference)</td>
<td>.05</td>
</tr>
<tr>
<td>Female</td>
<td>0.88 (0.78, 0.99)</td>
<td>.05</td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early stage</td>
<td>1 (Reference)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Late stage</td>
<td>2.9 (2.19, 3.67)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>1 (Reference)</td>
<td>.41</td>
</tr>
<tr>
<td>Indian</td>
<td>1.0 (0.7, 1.4)</td>
<td>.99</td>
</tr>
<tr>
<td>Malay</td>
<td>1.14 (0.90, 1.44)</td>
<td>.28</td>
</tr>
<tr>
<td>Others</td>
<td>0.65 (0.34, 1.26)</td>
<td>.20</td>
</tr>
</tbody>
</table>

Early stage = stage I, II. Late stage = stage III, IV with sample size of 3,373.

Regarding study limitations, the registry data did not include name of drugs, dosage, and duration of treatment. In our data, the date of the first course of treatment was available and treatment was captured within 6 months from the date of diagnosis. In addition, our study could not determine the factors related to delay in treatment such as postoperative complications, patient compliance, comorbid conditions, and other health service factors on the referral system and waiting time at specialist clinics.

**Conclusion**

Timely treatment of colorectal cancer patients had a significant effect on survival in this study. But there were some reasons for delay in receiving treatment of surgery, adjuvant chemotherapy, and neoadjuvant therapy. Postoperative complications and comorbid conditions may be factors in delays in receiving timely adjuvant therapy. Delays related to pathology reporting and waiting time for oncologic referral could be other factors that affect timely treatment. Clinicians may need to emphasize timing when discussing adjuvant chemotherapy with patients. Timely treatment should be considered as one of the quality indicators for treatment of colorectal cancer patients.

Further study needs to be focused on barriers in receiving timely treatment. Health service factors (timeliness in diagnosis and appropriate treatment) and the feasibility of a standard protocol for management of disease are other research areas to improve survival and quality care for patients. Public education should include information to increase awareness on improved survival with timely treatment.
Table 8. Cox Regression on Timely Adjuvant Radiotherapy after Surgery on Survival of Patients

<table>
<thead>
<tr>
<th>Variable</th>
<th>HR</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timely adjuvant radiotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1 (Reference)</td>
<td>.99</td>
</tr>
<tr>
<td>No</td>
<td>0.99 (0.81,1.03)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1.02 (1.01,1.03)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (Reference)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>0.70 (0.56,0.87)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early stage</td>
<td>1 (Reference)</td>
<td></td>
</tr>
<tr>
<td>Late stage</td>
<td>2.19 (1.73,2.76)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>1 (Reference)</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Indian</td>
<td>0.83 (0.39,1.75)</td>
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</tr>
<tr>
<td>Malay</td>
<td>1.38 (1.04,1.85)</td>
<td>.03</td>
</tr>
<tr>
<td>Others</td>
<td>0.38 (0.12,1.19)</td>
<td>.10</td>
</tr>
</tbody>
</table>

Early stage = stage I, II. Late stage = stage III, IV with sample size of 857.

Table 9. Cox Regression on Timely Neo-adjuvant Treatment on Survival of Patients

<table>
<thead>
<tr>
<th>Variable</th>
<th>HR</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
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<td>Timely adjuvant radiotherapy</td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1 (Reference)</td>
<td>.95</td>
</tr>
<tr>
<td>No</td>
<td>2.05 (1.23,3.41)</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Age</td>
<td>1 (Reference)</td>
<td>.46</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (Reference)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>0.88 (0.54,1.43)</td>
<td>.62</td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early stage</td>
<td>1 (Reference)</td>
<td></td>
</tr>
<tr>
<td>Late stage</td>
<td>1.43 (0.81,2.53)</td>
<td>.22</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>1 (Reference)</td>
<td>.58</td>
</tr>
<tr>
<td>Indian</td>
<td>0.91 (0.38,2.16)</td>
<td>.83</td>
</tr>
<tr>
<td>Malay</td>
<td>0.07 (0.64,6.75)</td>
<td>.22</td>
</tr>
<tr>
<td>Others</td>
<td>4.37</td>
<td>1</td>
</tr>
</tbody>
</table>

Early stage = stage I, II. Late stage = stage III, IV with sample size of 857.

Acknowledgements
The authors gratefully acknowledge the Singapore Cancer Registry and National Registry of Diseases Office for providing data for analysis.

References
13. Phua KH. Privatization and restructuring of health services in Singapore.
Abstract: The Brain Tumor Foundation of Canada has identified developing a pan-Canadian report on all primary brain tumors as a priority. The objective of this report is to present the history and rationale underlying reporting of brain tumors and to summarize the current status of brain tumor data collection and reporting in Canadian registries. We reviewed the literature on reporting history and rationale, conducted a survey of cancer registries across Canada, and reviewed cancer registry websites and Canadian Cancer Statistics Reports for publicly available descriptive statistics. A brain tumor surveillance system that includes data on both malignant and benign brain tumors is feasible within Canada and will include approximately twice the number of malignant cases currently reported. Once patterns of brain tumors become available, clinicians, researchers, and policy makers will have a clearer understanding of disease burden and how Canadian survival outcomes fare across regions and against other nations. Collaborative efforts on the part of cancer registry and neuro-oncology stakeholders will serve to enhance the quality and utility of this information for improving the overall patient experience.

Key words: benign, brain tumor, Canada, cancer registry, data quality

Introduction

In Canada, brain cancer accounts for 2% of all cancers, with a population-based 5-year relative survival rate for brain cancer of 22.5% reported in the literature for 1967–1986 in Saskatchewan.1 Approximately 9,855 cases of brain cancer are diagnosed each year, with an estimated 55,000 individuals living with a brain tumor.2 While these tumors are often dismissed as rare, their impact on patients, their families, and the health care system is substantial, but largely undocumented in Canada.3–5 A scan of the brain tumor data families, and the health care system is substantial, but largely are often dismissed as rare, their impact on patients, their individuals living with a brain tumor.2 While these tumors cancer are diagnosed each year, with an estimated 55,000

The Brain Tumor Foundation of Canada has identified developing a pan-Canadian report on all primary brain tumors as a priority. The objective of this report is to present the history and rationale underlying reporting of brain tumors and to summarize the current status of brain tumor data collection and reporting in Canadian registries. We reviewed the literature on reporting history and rationale, conducted a survey of cancer registries across Canada, and reviewed cancer registry websites and Canadian Cancer Statistics Reports for publicly available descriptive statistics. A brain tumor surveillance system that includes data on both malignant and benign brain tumors is feasible within Canada and will include approximately twice the number of malignant cases currently reported. Once patterns of brain tumors become available, clinicians, researchers, and policy makers will have a clearer understanding of disease burden and how Canadian survival outcomes fare across regions and against other nations. Collaborative efforts on the part of cancer registry and neuro-oncology stakeholders will serve to enhance the quality and utility of this information for improving the overall patient experience.

Key words: benign, brain tumor, Canada, cancer registry, data quality

Methods

We administered a survey (either in person or by telephone) with key personnel from 8 provincial/territorial (P/T) cancer registries (Nova Scotia and Newfoundland and Labrador did not participate) to obtain further insights on the changes in nonmalignant brain tumor case ascertainment (see Appendix for survey). All 10 provinces have centralized population-based cancer registries. The contiguous provinces of British Columbia, Alberta, and Ontario are responsible for collecting data for the 3 territories (northern regions with sparse populations currently under federal government jurisdiction): Yukon Territory, Northwest Territories, and Nunavut, respectively (Figure 1). Questions posed were related to the specifics of what benign tumor data are collected by each registry and about known barriers associated with their reporting. We designed the survey in consultation with the director of the Alberta Cancer Registry to address the following components of data collection: the availability and quality of data on malignant and nonmalignant brain tumors, the legislation governing this data collection, the status of nonmalignant brain tumor reporting, and the data sharing processes within each province. These surveys were initiated by contacting the registry directors who then delegated the response to registry staff and/or joined us in a team conversation. All provinces except Newfoundland and
Statistics Canada provides a data repository for each P/T registry, under the supervision of the CCR, and data are compiled into the equivalent of a national cancer surveillance system. A model for national brain tumor data reporting does exist. During 2002, legislation in the United States through the Benign Brain Tumor Cancer Registries Amendment Act (Public Law 107-260) was passed, requiring collection of all primary nonmalignant brain and central nervous system (CNS) tumors by the Centers for Disease Control and Prevention National Program of Cancer Registries. All other surveillance stakeholders then agreed to voluntarily collect nonmalignant brain tumors starting in 2004. Federal dollars flow through this program to central (state) cancer registries. The requirements of this legislation were also mirrored in recommendations by the International Agency for Research on Cancer (IARC) to the international cancer registry community and voluntarily adopted in many counties.

In Canada, data on benign brain tumors are not collected by all regional cancer registries, nor are they systematically reported to the CCR. This leads to a recognized underestimation of the burden of brain tumors for Canadians. In response to advocacy efforts, the Canadian House of Commons passed Bill M235 in February 2007 to create national guidelines for the surveillance of all malignant and benign brain tumors. However, like many private member bills, funds were not aligned to accomplish this task.

The Public Health Agency of Canada (PHAC) subsequently explored the underlying issues regarding the collection and reporting of benign brain tumor data, and identified several barriers experienced by regional cancer registries: 1) technological challenges in coding benign tumor data (Quebec); 2) lack of administrative data linkage (Ontario); and 3) lack of legislation (Northwest Territories). At the time of this evaluation, 4 of 13 P/T registries (Quebec, Ontario, the Northwest Territories, and Yukon) did not report information on benign brain and CNS tumors.

In 2011, the Brain Tumor Foundation of Canada (BTFC) identified this gap in available information on Canadian brain tumor patients and prioritized development of a pan-Canadian report on brain tumors, similar to that periodically published by the Central Brain Tumor Registry of the United States (CBTRUS) as an institutional goal.

Evolution of Brain Tumor Surveillance in North America

Tumors of the brain and CNS are initially classified as malignant, benign, or of uncertain behavior, depending on their cellular traits. They are also classified by tumor subtype (or histology) and some subtypes include all 3 of these behavior classifications. Unlike traditional cancer diagnoses, a substantial portion of these tumors may be diagnosed radiologically rather than through a biopsy procedure. As such, these are complex tumors that are challenging to diagnose, treat, and record in existing surveillance systems. Accurate classification is important in guiding appropriate treatment decisions, but is also relevant in understanding the patterns of disease and the etiology (or causes) of disease and in assessing progress in
the diagnosis and outcomes of treatment of tumors at the population level.

The rationale for reporting all primary brain tumors has been discussed for nearly half a century.15,16 Arguments for collecting data on all brain tumors include the fact that: (1) both malignant and nonmalignant tumors have outcomes which may be devastating; (2) tumor prognosis is dependent on histology, location, and behavior; and (3) unique occurrence patterns by tumor type suggest differing etiologies which can only be understood if accurate data by tumor type are available.15 It was also recognized during the 1990s that tumors could progress from low to high grade, making data on low-grade tumors essential in efforts to understand the natural history of this biologic process.16 During the 1990s, there was a collaborative effort spearheaded by the American Brain Tumor Association to implement the collection of all primary brain tumors which used this additional rationale of grade progression to support feasibility studies. This resulted in the development of CBTRUS.17

CBTRUS is now a nonprofit corporation whose database makes up the largest collection of population-based data on the incidence of all primary brain and CNS tumors in the United States.17 CBTRUS’s database is compiled from data gathered from state central cancer registries, and include data starting from 1992 on both malignant and nonmalignant (benign and uncertain) brain tumors. CBTRUS works closely with the NAACCR, the membership of which includes central registries in US states and Canadian provinces.

While North American cancer registries, including CBTRUS, limit themselves to collecting data on all primary brain tumors, the field of neuro-oncology has a significant interest in the treatment of metastatic brain tumors that arise from primary cancers from many organs.18 It is important to note that The Brain Tumour Charity is recommending the collection of data on both primary and secondary brain tumors (otherwise known as metastases) in the United Kingdom.19

Current Status of Brain Tumor Surveillance in Canada

The Canadian Cancer Registry (CCR) is an administrative database that is compiled via collaboration between Statistics Canada’s Health Statistics Division and the 13 P/T registries in Canada.10 The CCR includes data on all Canadian residents, both alive and dead, who have received a cancer diagnosis from 1992 onwards.10 This database details the type and incidence of primary cancers for each case and follows each case until their death.10 The CCR is also linked to mortality data, which allows both the identification of primary cancers that are not already registered10 and the estimation of survival rates. While the CCR is operated by Statistics Canada, the originating registries hold responsibility for ensuring data quality and completeness.10 NAACCR awards certification to cancer registries, based on data quality.20 Gold Certification is awarded to registries achieving a minimum of 95% case ascertainment, whereas Silver Certification is awarded to registries achieving a minimum of 90% case ascertainment.20 In 2012, 3 provinces (Alberta, Manitoba, Saskatchewan) and 1 territory (Northwest Territories) achieved Gold Certification, while 2 of the remaining provinces and territories (Newfoundland and Labrador, Nova Scotia) achieved Silver Certification.20 Since NAACCR uses the same criteria to evaluate all registries, this tool is useful to assess data quality across the registries.

Since 1987, a national report on cancer, the Canadian Cancer Statistics Report, is produced annually by the Canadian Cancer Society’s Advisory Committee on Cancer Statistics, a joint effort by the Canadian Cancer Society, Statistics Canada, the Public Health Agency of Canada, and the P/T cancer registries.21 The report includes separate incidence rates and mortality rates for overall brain cancers. Recent reports have expanded to include relative survival rates and prevalence rates. Table 1 contains data on the prevalence, incidence and mortality rates of brain cancer for the last 5 years of these reports. The table indicates that prevalence, incidence, and mortality rates have been stable over the last 5 years. Nonmalignant tumors of the CNS may be reported to the CCR10 but as of yet, they are not included in national reports.

<p>| Table 1. Brain Cancer Surveillance Information Extracted from the Canadian Cancer Statistics Reports: 2010–2014 |
|-----------------|-----------------|-----------------|</p>
<table>
<thead>
<tr>
<th>Year</th>
<th>No. of Cases</th>
<th>Incidence Rate (per 100,000)</th>
<th>Mortality Rate (per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>2,900</td>
<td>6.9</td>
<td>4.2</td>
</tr>
<tr>
<td>2013</td>
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<td>6.9</td>
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<tr>
<td>2012</td>
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<td>4.0</td>
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<tr>
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<td>2,700</td>
<td>7.0</td>
<td>4.0</td>
</tr>
<tr>
<td>2010</td>
<td>2,600</td>
<td>7.0</td>
<td>4.0</td>
</tr>
</tbody>
</table>

Data are estimated rates using data from previous years

Table 2 shows the annual percent change in age-standardized incidence and mortality rates of brain/CNS cancers in Canada, reported in overlapping date ranges. Incidence rates among males and females have increased from the period of 1996–2005 to the period of 2001–2010, but within each time period a modest declining percent change associated with incidence rates is present. In contrast, the decreasing trend in mortality rates in the 1996–2005 period has shifted to an increasing trend for mortality rates among males in the 2000–2009 period, while mortality rates have continued to decline among females.

While survival data for brain/CNS cancers are limited, information from 2006–2008 are available.21,22 These data indicate a 5-year relative survival ratio of 25% (95% CI, 24%–27%) for both sexes combined.21,22 Conditional survival rates indicate that, among those who have lived with brain/CNS cancer for 2 years, there was a 65% (95% CI, 62%–68%) chance of surviving to 5 years.21,22 Prevalence estimates are also available for brain/CNS malignancies: among individuals diagnosed since 1999, an estimated 7,385 of these people were living with disease in 2009.21,22

The Public Health Agency of Canada (PHAC) recently extracted data from the CCR on all primary tumors diagnosed between 2005 and 2009 to assess the number and
rates of malignant and nonmalignant CNS tumors captured in Canada.\textsuperscript{4} National coverage of malignant tumors was similar to that expected while coverage of the nonmalignant tumors represented about one-third of the expected rate. These findings suggest that Canadian registries do a good job of reporting malignant brain tumors and while they are transitioning towards compiling nonmalignant brain tumors, the current underreporting of nonmalignant tumors is substantial. The capture of nonmalignant CNS tumors also varied by province, suggesting that case ascertainment may need to be addressed at the P/T level.\textsuperscript{5}

Current Status of Non-malignant Brain Tumor Registration at the P/T Level

Most provinces began collecting nonmalignant brain tumor data in the early 1990s, with the exception of Prince Edward Island (PEI) and Alberta, which began collecting these data about 2 decades earlier. Quebec began collecting benign brain tumor data starting in 2008 from hospitalized cases only. Ontario has recently put a registration system in place which is now accruing all primary brain tumors retrospectively from 2010. The survey revealed that P/T registries may deal with interprovincial migration of cases differently, that the majority of P/T registries do follow CCR guidelines for reporting data and some also follow Surveillance, Epidemiology, and End Results (SEER) guidelines. There is currently no provincial legislation to collect benign brain tumor data in Manitoba, New Brunswick, and PEI. Although there is no legislation in Manitoba to collect benign brain tumor data, data are included in the cancer registry by practice.

All P/T registries indicated that mechanisms were in place making the sharing of brain tumor surveillance data for a pan-Canadian report feasible. Outside of the CCR system, the sharing of aggregate and individual data is also feasible; although sharing data without identifiers is generally a simpler and shorter process than the sharing of individual data with identifiers because of the requirement for ethics board approval.

Discussion

These discussions with registries and supporting documentation lead us to conclude that data reporting is likely of high quality for malignant BTs, but as registrars are less familiar with the nonmalignant BTs, the completeness and quality of this data may need to be assessed. There appears to be no barriers to reporting information on the nonmalignant BTs within the CCR system once the tumors have been recorded and forwarded, but a system for doing this is currently undefined.

Without a population-based brain tumor registry, health care services cannot adequately plan for and fund healthcare for brain tumor patients, as we would not have an accurate estimate of the burden of disease. Health care services would also be unable to measure whether they are meeting their targets. Health care services will therefore be able to allocate their limited funds more efficiently with the existence of a brain tumor registry. Moreover, we need to gain a better understanding of whether or not the number of Canadians affected by brain tumors is changing. Since the causes of brain tumors are largely unknown, having an accurate estimate on brain tumor incidence may support the conduct of collaborative research needed to improve our understanding of underlying risk factors. An infrastructure which supports case identification may stimulate a more comprehensive approach to studies of etiology and may increase the potential for collaboration with international studies of brain tumors. A brain tumor registry will also allow us to compare how Canada fares against other countries on brain tumor survival and other outcome measures. The current BTFC goal of making “every brain tumor count” could be initially achieved with an initial focus on primary tumors.

The data available in the Canadian Cancer Statistics Reports, show that incidence rates of brain/CNS cancers may be stable or slightly increasing and that mortality rates are modestly rising among males. These forces, combined with population aging and growth provide estimates of prevalence—over 7,300 individuals living with brain cancer in 2009— which may change over time. If nonmalignant tumors were included in this estimate of prevalence, and the proportions in Canada are similar to those reported in the US (20% of prevalent cases are malignant\textsuperscript{23}) an estimated 36,875 individuals living with BTs (malignant and nonmalignant) were likely in 2009 in Canada. The discrepancy between this crude prevalence estimate and that reported by BTFC point to the need for clarifying the actual numbers and estimates of all primary brain cancers in Canada.

Survival rates reported for 2006–2008 (25% 5-year relative survival) are quite similar to those reported several decades earlier (1967–1986) in Saskatchewan (22.5% 5-year relative survival\textsuperscript{3})). Although these estimates are not

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Annual Percent Change: Incidence Rate</th>
<th>Annual Percent Change: Mortality Rate</th>
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<tr>
<td></td>
<td>Males</td>
<td>Females</td>
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<tr>
<td>2001–2010 (from 2013 and 2014 reports)</td>
<td>–0.1</td>
<td>–0.3</td>
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<tr>
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<tr>
<td>1996–2005 (from 2010 report)</td>
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<tr>
<td>1996–2005 (from 2009 report)</td>
<td>–0.8**</td>
<td>–0.9</td>
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</table>

* Significant, $P < .01$.  
** Significant, $P < .001$.  

Table 2. Annual Percent Change (APC) in Age-Standardized Incidence and Mortality Rates for Brain/Central Nervous System Cancers in Canada (Extracted from Canadian Cancer Statistics Reports: 2009, 2010, 2013, 2014)
comparable by regions and may have some definitional differences, they do suggest that limited progress has been made in brain cancer outcomes. These survival estimates are also lower than those reported by CBTRUS (33.8% for all malignant brain and other CNS 5-year relative survival\(^{24}\)) but differences in topography codes included between the Canadian and CBTRUS estimates limit their comparability. More importantly, the lack of histologic or age-specific information in these reports limits the usefulness of the malignant data currently being reported at the national level.

Based on our review of the literature and assessment of the survey results, we believe the quality of brain cancer data that are currently collected in cancer registries in Canada is likely to be high. Underreporting of nonmalignant brain tumors is present (the reasons for which vary across provinces and are not well understood) and they are not routinely included in surveillance reports. There is concern that cases may be missed through radiological diagnosis at freestanding radiology centers that may not routinely be included in cancer registry case finding. Quality control issues may also be present and multifaceted involving issues of case ascertainment, accuracy of reporting the diagnosis of cases, and tumor-specific knowledge. Registries may benefit from access to a team of experts (eg, clinicians and pathologists) from whom they can draw knowledge and expertise from in providing guidelines for the reporting of data on brain tumors at the provincial level. The feasibility of a pan-Canadian brain tumor registry relies on not only identifying strategies to eliminate barriers to comprehensive reporting, but also addressing them in an effective manner. Since P/T registries operate under legislation specific to their jurisdiction, interprovincial/territorial collaboration requires agreements with each province/territory. The rationale for doing this is well accepted within the provincial registries and work is progressing towards having data on all primary brain tumors available across the country. Transition costs towards implementing new data mandates, including reconfiguring data systems and training staff, are unknown and they are currently being borne individually by provincial registries. The uneven availability of human and financial resources in the regions is reflected in uneven progress across regions. Most importantly, the mechanism for generating a pan-Canadian surveillance report which is meaningful to decision makers at the regional and national levels is not currently in place and the agency or agencies accountable for creating such a reporting structure have not been defined.

It is ironic that recent Canadian efforts to contribute to the understanding of the etiology of brain tumor have been primarily through collaboration with international studies.\(^{25,26}\) While these efforts are welcome contributions to the field, the scarcity of independent hypothesis driven studies conducted across provinces suggests that barriers to interprovincial collaboration exist. If so, the innovative/creative hypothesis testing which tends to emerge when collaborations between the neuro-oncology, cancer registry, and epidemiology communities exist and which are highly valued by the Canadian Institutes of Health Research and other funding agencies may be stymied and opportunities to maximize the potential from collecting these data are not being realized.

**Conclusion**

A population registry that limits reporting of brain tumors to malignant cases will miss approximately half of the brain tumors diagnosed. This gap has been recognized in Canada and unfunded efforts are ongoing to implement Bill 235. This involves improving case ascertainment procedures at the provincial level and conducting quality control studies to ensure that data are of high quality. Once data become available, the mechanism by which they will be used to generate tumor-specific surveillance reports to accurately reflect the burden of primary brain tumors needs to be defined. The ability to describe patterns of brain tumors and to identify subpopulations or regions of this country at high or low risk for brain tumors has not been feasible in the past, but it may be that soon, clinicians will be able to plan and evaluate clinical programs and population researchers can consider developing cross-provincial tumor specific collaborations.

Current data available on brain cancers suggest a modest unexpected increase in mortality rates in males and suggests that little progress has been made in improving survival rates in the last three decades. With an aging and growing population we can expect the number of individuals living with a brain tumor to be upwards of 36,000 currently and health care providers and patient support systems need clearly defined estimates in order to plan accordingly. Efforts to facilitate such collaborations across P/T registries, Statistics Canada, the neuro-oncology provider and research communities will serve to enhance this process.

**Acknowledgements**

This work was conducted with the support of the Brain Tumor Foundation of Canada. We would like to thank Carol Russell for her assistance in developing the survey, the Provincial Cancer registry staff who participated in this survey, and the participants at the Brain Tumor data workshop in October 2014 in London, Ontario for their thoughtful comments and discussion.

**References**


APPENDIX

Survey on Benign Brain Tumor Data Collection
Please answer the following questions regarding your provincial cancer registry.

Data Collection

1. What are your eligibility criteria (ICD0 codes and behavior) for recording brain tumor incident cases?
   1a. Do you collect benign tumors? If so, when did you begin collection? In what year do you consider the data quality good?
   1b. What are your methods to collect benign tumors? (Please check all that apply)

2. Do you follow SEER guidelines or CCR guidelines for brain tumor data collection?
3. Does legislation to collect benign brain tumors exist in your province?
4. What are some obstacles you face in collecting benign brain tumors?

Table 1. Identification Methods for Benign Brain and CNS Tumours by PTCR in Canada

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<th>Report Item</th>
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<th>NB</th>
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<th>ON</th>
<th>MB</th>
<th>SK</th>
<th>AB</th>
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</table>

Adapted from Jiang Y. Benign brain tumor surveillance project [unpublished]. Public Health Agency of Canada, Chronic Disease Surveillance Division. 2009.
## Data Reporting

<table>
<thead>
<tr>
<th>Question</th>
<th>Malignant Brain Tumors</th>
<th>Benign Brain Tumors</th>
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</thead>
<tbody>
<tr>
<td>5. Do you have data quality processes specific to brain tumours in place? If so, please describe them.</td>
<td></td>
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<tr>
<td>6. What is the current lag time between cancer diagnosis and final reporting in the cancer registry?</td>
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<tr>
<td>7. How do you record brain tumour patients who migrate into the province for care?</td>
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<tr>
<td>8. Are provincial cases who are diagnosed out of province reported back? If so, how?</td>
<td></td>
<td></td>
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<tr>
<td>9. What geographic sub-regions are available in your province for reporting?</td>
<td></td>
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<tr>
<td>10. What counts and rates specific to brain tumours do you standardly report? How are they available to the public?</td>
<td></td>
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<tr>
<td>11. What categories do you report (morphology, typography)?</td>
<td></td>
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<tr>
<td>12. Do you have explicit criteria to distinguish between a brain metastasis and a second primary brain tumour?</td>
<td></td>
<td></td>
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<tr>
<td>13. Is there any brain tumour-specific training of staff in the registry system?</td>
<td></td>
<td></td>
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</tbody>
</table>

## Data Sharing

14. Would it be feasible to share brain tumour surveillance information for the purpose of a pan-Canadian report on brain tumours?
   a. Would this be feasible as individual data with identifiers?
   b. Would this be feasible as individual data without identifiers?
   c. Would this be feasible as aggregate data?

15. What is the data request process for obtaining data as indicated above?

16. Once approved, how long on average, does a cancer registry data request process typically take to complete?

## Informal Questions

17. What makes a request more likely to be approved?
18. Ideally, what organization (ie, academic, nonprofit, provincial cancer registry) should such a request come from in order to increase its potential of being approved?
19. Do you have a data request form for aggregate data and a contact person to submit this to?
Analysis of the National Cancer Data Base to Describe Treatment Trends in Stage IV Oral Cavity and Pharyngeal Cancers in the United States, 1998–2012

Shai White-Gilbertson, PhD, MSCR, Dipl Ac, CTR; Sybil Nelson, MS; Kevin Zhan, MD; Christopher Xiao, BA; Linda Cope, CTR; Terry Day, MD

Abstract: Treatment recommendations for head and neck cancers have evolved over the last several decades, with a particularly clear shift in 2004 toward use of chemotherapy in late-stage patients. This study examines the national trends in treatment combinations for patients with stage IV oral cavity and pharyngeal cancer between 1998 and 2012 using the National Cancer Data Base (NCDB). Our analysis demonstrates that chemotherapy was widely integrated into the treatment plans for this population following 2004, confirming that recommendations were successfully translated into practice. Stage IV patients treated after this shift in treatment experienced higher 5-year survival rates compared to patients treated prior to the adoption of increased chemotherapy usage. We also examined the patient population for other changes over time and found that smaller primary tumors became more common and that 2 primary sites (base of tongue and tonsil) came to represent a larger percentage of the patient population; these changes may also contribute to a rising survival rate. Patients receiving the recommended trimodal therapy of surgery, radiation, and chemotherapy were found to be more geographically widespread over time, suggesting a penetrance of the recommendations into the medical system across the country.

Key words: head and neck cancer, National Cancer Database, treatment trends

Introduction

Survival rates for cancer patients with stage IV disease of the oral cavity and pharynx have been rising in the United States over the last 15 years. Some have attributed this to the widespread adoption of adjuvant chemoradiation therapy. The use of adjuvant chemoradiation for improved locoregional control in this patient population was recommended in 2 landmark studies from 2004, now adopted as the standard of care for high-risk patients. A correlation between use of adjuvant chemoradiation and improved outcomes across the nation for these patients has been studied indirectly, most recently in a particularly cogent review by Lin et al. However, previous retrospective reviews lacked detailed treatment information and do not comment on specific treatment strategies and survival rates.

Stage IV cancer in the head and neck sites is subdivided into 3 categories: stage IVA, stage IVB, and stage IV C, and distant metastasis is only a requirement of stage IV C, meaning that some stage IV head and neck cancers can be resected. Indeed, surgery is an important modality in the aggregate stage IV group, and surgery is the foundation of the aforementioned 2004 recommendations.

Using the National Cancer Data Base (NCDB) participant user file (PUF), we aimed to elucidate the relationship between treatment strategies and increasing survival. We examined the distribution of treatment modalities across the entire stage IV patient group on a year-by-year basis and report on a clear trend within patients treated with surgery, such that trimodal therapy became more common. Five-year survival for patients diagnosed before and after the recommendations was evaluated, with stratification by treatment strategy. We also compared the patients who received trimodal therapy in the 1998–2004 time frame and those who were treated with this approach between 2004 and 2012, allowing us to evaluate the penetrance of the new recommendations across the country.

Methods

National Cancer Data Base Participant User File

The NCDB database contains approximately 30 million records, representing the cases seen at all facilities which are Commission on Cancer accredited and making it the largest such repository of information on cancers arising in the United States that is available for query. The PUF is a flat file containing demographic, disease, treatment, and outcome data for a single disease site. The PUF patient information is deidentified, compliant with the Health Insurance Portability and Accountability Act (HIPAA), and

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The data used in the study are derived from a deidentified National Cancer Data Base file. The American College of Surgeons and the Commission on Cancer have not verified and are not responsible for the analytic or statistical methodology employed, or the conclusions drawn from these data by the investigator.

The National Cancer Data Base is a joint project of the Commission on Cancer of the American College of Surgeons and the American Cancer Society.
can only be accessed by members of facilities accredited by the Commission on Cancer. A periodic call for PUF applications allows members to submit a study proposal for a disease site of interest. These applications are reviewed by the Commission on Cancer and the files made available for download to the primary investigator if deemed appropriate. We requested sites designated C00.0–C14.8 in the International Classification of Diseases for Oncology (ICD-O), which are the collective head and neck sites in the NCDB, which categorizes the larynx as a thoracic site. Therefore, this study does not address a variety of subsites which are sometimes included in the definition of “head and neck.” In addition to the larynx, the nasal cavity, middle ear, accessory sinuses, and skin/bone/nerve/connective tissues of the head and neck are excluded. We were awarded a PUF file including diagnoses from 1998–2012. The Medical University of South Carolina institutional review board has categorized use of this data set as nonhuman research.

Inclusion and Exclusion Criteria

Patients in the 1998–2012 NCDB head and neck cancer PUF coded as “4” in the Analytic_Stage_Group variable were included in this study (N = 149,940). This criteria captures cancers which initially presented as stage IVA, IVB, and IVC. To create the subset of these patients with confirmed adjuvant use of chemoradiation, only the patients meeting both of the following criteria were included: 1) extensive surgery coded as “30-80” for variable RX_SUMM_SURG_PRIM_SITE, and 2) both chemotherapy and radiation were coded, both with start dates after the date of definitive surgery. The sequence of treatments was determined for each patient using the PUF variables which describe days from diagnosis to the start of each modality. If the variable DX_DEFSURG_STARTED_DAYS was smaller than both DX_RAD_STARTED_DAYS, fewer days passed between diagnosis and surgery compared to days between diagnosis and administration of chemoradiation, qualifying the patient for inclusion in the defined subgroup of patients treated with adjuvant trimodal therapy. A total of 14,187 patients met the criteria for the confirmed adjuvant set (58.4% of the full trimodal group). Patients were included in survival analysis based on year of diagnosis as indicated in the Results section.

Statistical Methods

All analysis was performed in Excel, SAS, or SPSS with survival rates and significance calculated using the SPSS Life Tables function, using the calculated Standard Error as indicated. Student’s t test was used to analyze the difference of means for age and the χ² was used to compare distributions within categorical variables over time. For analysis of survival rates, the time period immediately prior to the trimodal therapy recommendations was defined as 2001–2004 and patients diagnosed during this block of time were compared to those diagnosed 2005–2008, which allowed a 5-year follow up because dates of last contact in in the NCDB PUF extended through 2013. Statistical significance was set at P < .01 in view of the large size of the data set.

Results

Treatment of Stage IV Oral Cavity and Pharyngeal Patients has Moved toward Trimodal Therapy Nationally

The set of head and neck patients with stage IV disease was defined as described in Methods. Each patient in this set was assigned a new variable which described whether the patient received surgery, chemotherapy, radiation, or any combination of these for a total of 8 possible combinations. For each year, the distribution of patients across each of the 8 possible modalities was calculated and these distributions graphed over time in Figure 1, with modality combinations denoted with acronyms based on S = surgery, C = chemotherapy, and R = radiation. The most specific recommendation made in 2004 was to add adjuvant chemotherapy to a typical course of surgery and radiation, and we used this as an organizing principle for analyzing results. Each possible modality or modality combination is shown without (white bars) or with (black bars) the inclusion of chemotherapy (Figure 1 A–D). We found a clear year-by-year increase in the use of chemotherapy after 2004 in the stage IV population (Figure 1 A–D). In particular, trimodal therapy became a more common approach (8.0% in 1998 rising to 20.5% in 2012) while rates of surgery/radiation without chemotherapy fell (28.9% in 1998, 10.4% in 2012).

Survival for Multiple Treatment Groups Increased over Time for Stage IV Patients

We analyzed 2 time periods for 5-year survival rates as described in Methods. Five-year survival analysis of the total stage IV group showed a statistically significant rise after trimodal recommendations were made (39% to 42%), and this rise was largely accounted for by improvements in 3 of the studied treatment groups (Figure 2A–B). Patients
The goal of this study was to elucidate the relationship between national trends in treatment strategies and outcomes in stage IV oral cavity and pharyngeal cancers. Using a national hospital data base, we were able to demonstrate a consistently rising rate of chemotherapy use over time, which is likely due to the increasing use of chemotherapy as a part of the trimodal therapy approach. The trimodal therapy group (surgery/radiation/chemotherapy) showed a significant increase in usage, particularly after 2004. This trend was seen across all age groups, with the most notable increase in the 60-70 age group. However, there was no significant change in the use of surgery alone, indicating that the adoption of chemotherapy has been most pronounced in the trimodal therapy group.

When the subgroup of patients treated with trimodal therapy was considered, a rise in pT1 cancers (21.7% to 26.7%) and a decline in pT4 (36.3% to 31.2%) was seen, reflecting the trend in the larger population. These changes were seen in the national trend, with a consistent rise in pT1 and a decline in pT4 stages. This trend was particularly pronounced in the younger age groups, where the increase in pT1 was more pronounced.

The analysis of the trimodal therapy group also showed a significant increase in the use of chemotherapy over time, with a rise in pT1 cancers (21.7% to 26.7%) and a decline in pT4 (36.3% to 31.2%). These changes were seen in the national trend, with a consistent rise in pT1 and a decline in pT4 stages. This trend was particularly pronounced in the younger age groups, where the increase in pT1 was more pronounced.

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### Table 1. Total Stage IV

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</thead>
<tbody>
<tr>
<td>Total</td>
<td>58,184 (100)</td>
<td>91,756 (100)</td>
<td>0.3 (+)</td>
<td>0.011, NS</td>
</tr>
<tr>
<td>Age (mean +/- sd)</td>
<td>60.63 +/- 12.8</td>
<td>60.80 +/- 12.1</td>
<td></td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Gender</td>
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<tr>
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<td>43,031 (74.0)</td>
<td>69,938 (76.2)</td>
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<tr>
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<td>3,479 (6.0)</td>
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<td>Mid-Atlantic</td>
<td>8,193 (14.1)</td>
<td>12,893 (14.0)</td>
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<tr>
<td>South Atlantic</td>
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<tr>
<td>EN Central</td>
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<tr>
<td>WN Central</td>
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<td>6,689 (11.5)</td>
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<td></td>
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<td>4,005 (4.3)</td>
<td>0.1 (-)</td>
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<tr>
<td>Insurance</td>
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<td></td>
<td></td>
<td>&lt; .001</td>
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<tr>
<td>Medicare</td>
<td>20,228 (34.8)</td>
<td>31,762 (34.6)</td>
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<tr>
<td>Other government</td>
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<td>2,016 (2.2)</td>
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<td>pT, excluding unknown</td>
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<td></td>
<td>&lt; .001</td>
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<td>8,483 (23.6)</td>
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<td></td>
</tr>
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<td>4,071 (11.4)</td>
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<td>4</td>
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<td>15,746 (43.9)</td>
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<td>Subsite</td>
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<td>&lt; .001</td>
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<td>Base of tongue/tonsil</td>
<td>22,563 (38.8)</td>
<td>43,540 (47.4)</td>
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<td>Other</td>
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<td>48,216 (52.6)</td>
<td>8.6 (-)</td>
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<td>-----------------------</td>
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</tr>
<tr>
<td>Total</td>
<td>6,131 (100)</td>
<td>18,182 (100)</td>
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<td>Age (mean ± SD)</td>
<td>55.6 ± 11.2</td>
<td>57.4 ± 10.7</td>
<td>1.8 (+)</td>
<td>&lt; .001</td>
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<td></td>
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<td>4,831 (78.8)</td>
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<tr>
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<td>1,300 (21.2)</td>
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<td>0.7 (+)</td>
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<td>Facility Location</td>
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<td>&lt; .001</td>
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<td>913 (5.0)</td>
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<td>Mid-Atlantic</td>
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<td>1,339 (21.8)</td>
<td>3,810 (21.0)</td>
<td>0.8 (-)</td>
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<td>1,276 (7.0)</td>
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<td>0.7 (+)</td>
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<tr>
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<td>253 (4.1)</td>
<td>924 (5.1)</td>
<td>1.0 (+)</td>
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<tr>
<td>Pacific</td>
<td>571 (9.3)</td>
<td>1,929 (10.6)</td>
<td>1.3 (-)</td>
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<td>&lt; .001</td>
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<tr>
<td>White</td>
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<td>16,048 (88.3)</td>
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<td>202 (3.3)</td>
<td>704 (3.9)</td>
<td>0.6 (+)</td>
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<td>Insurance</td>
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<td>&lt; .001</td>
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<tr>
<td>None</td>
<td>281 (4.6)</td>
<td>927 (5.1)</td>
<td>0.5 (+)</td>
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<tr>
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<td>3,565 (58.2)</td>
<td>10,098 (55.5)</td>
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<td>554 (9.0)</td>
<td>1,781 (9.8)</td>
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<td>Medicare</td>
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<td>304 (5.0)</td>
<td>514 (2.8)</td>
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<td>935 (21.7)</td>
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<td>1,697 (11.6)</td>
<td>2.3(-)</td>
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<tr>
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<td>1,561 (36.3)</td>
<td>4,544 (31.2)</td>
<td>5.1(-)</td>
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<td>pN, excluding unknown</td>
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<td></td>
<td>&lt;0.001</td>
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<td>1</td>
<td>413 (9.6)</td>
<td>1,245 (8.9)</td>
<td>0.7(-)</td>
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<tr>
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<td>319 (7.4)</td>
<td>802 (5.8)</td>
<td>1.6(-)</td>
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<td>3,252 (75.8)</td>
<td>11,280 (80.8)</td>
<td>5.0(+)</td>
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<td>4</td>
<td>308 (7.2)</td>
<td>627 (4.5)</td>
<td>2.7(-)</td>
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<td>5,957 (97.2)</td>
<td>17,034 (97.8)</td>
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<td>174 (2.8)</td>
<td>375 (2.2)</td>
<td>0.6(-)</td>
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</tr>
<tr>
<td>Subsite</td>
<td></td>
<td></td>
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<td>0.358</td>
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<td>BOT/tonsil</td>
<td>3,124 (51.0)</td>
<td>9,391 (51.7)</td>
<td>0.7(+)</td>
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<tr>
<td>other</td>
<td>3,005 (49.0)</td>
<td>8,791 (48.4)</td>
<td>0.7(-)</td>
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</tr>
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</table>
release and implementation of these recommendations and those diagnosed afterward revealed a significant increase in survival time at the national level in the later time frame. The redistribution of the greater stage IV oropharyngeal cancer patient population amongst the possible treatment regimens may be a contributing factor in increased survival rates nationwide. Interestingly, after the use of trimodal therapy became more widespread, the survival rates of those patients receiving only surgery and radiation also increased, presumably because their cohort no longer contained patients needing the more aggressive therapy. Other factors which may contribute to the increased overall stage IV survival are a trend toward smaller cancers, with pT1 becoming more common at presentation, and an increase in BOT/tonsillar cancers, which tend to have a favorable prognosis.

Over time, the trimodal therapy cohort revealed one important trend which was specific to that patient group. After 2004, this therapy was more likely to be administered across the country, suggesting a movement toward more widespread application of the treatment. An important consideration when interpreting these results is that the NCDB is comprised of hospital data and is not intended as a proxy for population-based databases. The very high number of captured cases in NCDB must be considered in light of the fact that only patients within the accredited Commission on Cancer network are represented. This may over or under select subpopulations based on access to accredited facilities. Nonetheless, the geographic shift in treatment patterns seen in the trimodal group was not a reflection of a larger change in the underlying stage IV population and this suggests a treatment-specific difference.

An advantage of using the NCDB is its robust collection of treatment information, allowing the tracking of treatment trends and outcomes. However, other variables are known to be changing in the head and neck cancer populations. Of most clinical interest is the recent epidemic of oropharyngeal human papillomavirus (HPV)+ cancers. The NCDB began collecting information about HPV status in head and neck cancers in 2010 and future work will undoubtedly rely more on this data field. Historical overview studies such as this one cannot probe for that key information. The epidemic may be indirectly observed in the sharp increase of tumors arising in affected sites. Cancers caused by HPV are typically found at the base of tongue or tonsil and we observed that these subsites came to represent a larger proportion of new cancers over time in the overall stage IV population but not in the group receiving trimodal therapy.

The population-based database SEER (Surveillance, Epidemiology, and End Results Program) can assist in putting trends into perspective. A comprehensive study on the rise of HPV positive oropharyngeal cancers indicates that this disease has been rising in incidence since the mid-1990s, and has a markedly better prognosis than HPV-negative cancers of the same sites. Such a rise in incidence rate requires a clear understanding of the role of the population database and how it relates to the growing US population to make a rigorous interpretation. The present study, based on hospital data, is limited to reporting on the raw numbers entered into the database, which rise en masse with the growth of the country’s population and addition of Commission on Cancer–accredited facilities, as well as in response to incidence trends. Further work on the interplay of HPV and head and neck cancers is likely to be a fertile research area in the coming years, and will certainly make use of multiple data sources. The combined goal of all such work is to help refine treatment planning for patients’ survival and improving quality of life after therapy.

**Conclusion**

Evidence-based recommendations for adjusting treatment approaches for late-stage head and neck cancers made in 2004 highlighted the importance of adding chemotherapy to surgery and radiation. Since this time, rates of chemotherapy usage in the most advanced patients have risen appreciably, as have survival rates. The new distribution of treatment approaches amongst patients presenting with stage IV disease may have significant value, contributing to concurrent improvement in survival for these patients.

**References**


How I Do It

Remote Abstracting: A Home Guide

Danillie Clark, RMA, AAS, CTR\textsuperscript{a}; Danette Clark, BS, RMA, AAS, CTR\textsuperscript{a}

Introduction

As the demand for registrars’ increases, the opportunity for remote abstracting or telecommuting has almost become a necessity. There are a few things you should consider before signing on for telecommuting. Here are a few guidelines that will help you get started.

So, you think you want to be a remote abstractor (telecommuter)? You can start with a self-evaluation. Are you suited for working on your own, at home with little to no supervision and still make your goals? If you are a self-motivated person who requires minimal supervision, remote abstracting may be a good fit for you. If not, it could be a disaster. If you are a “social butterfly” and need daily interaction with coworkers, then remote abstracting may not be for you. Be honest with yourself.

Workstation

You will need an area that is appropriate to set up a workstation, and the area should not be acceptable. A workstation should be private, secure, and allow for little-to-no distractions. Working remotely is not a substitute for child care, elder care, or doggie daycare. You must be able to separate your home from your remote workstation. You relax at home, and you work at your remote workstation. Don’t confuse the two. Just like in the office, you will be responsible for being productive, but on your own. Ask for a trial period. If you decide you really want to be in the office you can switch back. You may prefer to split your time between both places—you get the best of both worlds.

The following costs need to be considered: Will your facility provide you with the necessary equipment or do you need to provide it at your own cost? Some facilities require that you use their equipment, which may not be the easiest to work with. Also, find out if you can use dual screens because some facilities do not allow this. If you are accustomed to using dual monitors, your productivity may decrease in the beginning. Ask how much information technology (IT) support you will get. Will there be an issue with IT accessing your computer remotely, and if so, what is the procedure? If no equipment is supplied, are you able to invest in the necessary equipment? Take into consideration your Internet: the speed and reliability of your carrier can greatly impact your workflow. If you live in an area that has limited service, make sure you have a backup plan. You will be logging in through a virtual private network (VPN), and you will need to work with IT to make sure your computer system is compatible with the network requirement. When you set up, you don’t want to find out the new computer system you just bought is not compatible with your employer’s system, so check before you make any purchases. Find out if you will be logging into a computer onsite or using a VPN. If you are logging into a computer onsite, make sure it is labeled “in use by remote abstractor” (or your name), so that someone on site won’t bump you off. Whom do you contact when your onsite computer needs to be restarted in the office? Find out beforehand; otherwise, you will not be able to work. This can be an issue if there is a power outage (or your computer locks up) at the office. Who will reboot your computer? Find your favorite IT people and ask what computers they recommend; check with other registrars to see what they are using. Make sure you know which browser and operating systems are compatible with your facility.

Your desk is your preference, so make sure it is comfortable, and don’t forget your chair. I suggest that you go to the local office supply store and find a desk similar to yours and sit in different chairs until you find the best fit for your body type. As registrars, we sit a lot, and a good chair makes a big difference. Check with your facility on the requirements for keeping/storing/transporting medical documents. Also, a good shredder is a good investment. A locked file cabinet (they come in different sizes) may be required, so make sure you have the space for it.

Remote Computer Etiquette (Webinars/Virtual Meetings/Conference Calls)

Once you are set up by IT, remember that your employer now has access to your computer. When you’re working on the VPN, your employer can track your every move. Be careful what websites you visit while logged into the VPN. Most facilities block certain websites that are not allowed to be used. Required video conferences and virtual Web meetings should be kept professional, so invest in a good headset. Remember to mute yourself when you are not talking. If it is a video conference, be aware of your surroundings and keep your work area tidy. Remember to keep yourself looking professional (at least your top half needs to look good); don’t be caught in your pajamas.

Work Ethic

Document accurately on your timesheet and be honest with your hours and productivity. If you work on a VPN, everything you do while logged in is recorded and is tracked. Don’t email yourself a list of patients with names, birth dates, and Social Security numbers unless it is approved by your facility. This can trigger an email security

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alert if not approved and is a serious violation of the Health Insurance Portability and Accountability Act (HIPAA). If you are going to split time between the office and home, have your employer clarify how you document these hours. Will you be paid for traveling back and forth or will you need to clock out? Know your policies and procedures and your goals. Keep the same rules that apply in the office at your workstation. If you’re not allowed to browse the Web in the office, don’t do it on the VPN at home because someone is always watching.

A Manager’s Perspective

Your facility should have a policy and procedure set up specifically for remote abstracting or telecommuting. Make sure you read it very carefully, understand it, and agree with it. Some policies include specific productivity goals. Make sure the goals are achievable. Just because you are working remotely does not mean your production will triple. If you are the first remote abstractor at your facility, you might have to convince administration that you are trustworthy – don’t take it personally. Be flexible and work with your manager. It is very important that everyone is comfortable and that trust is established early. Working remotely is a fairly new concept and not everyone is on board. Production and quality of work are easy to track.

Tracking time does not need to be complicated (see Figure 1). You should have a set schedule. You might have to experiment with a few different shift times. If you are a morning person, work in the morning; if you like sleeping in, select a later time. Your manager or administration may choose for you, but make sure it works for you. A simple Excel document with formulas is easy to set up (Figure 1). Lock the columns that you don’t want the certified tumor registrar (CTR) to change. The CTR will enter the date, in and out times, total time worked (gray column), no lunch option, abstracts, and treatment column. Some facilities track time to the exact minute, and others use a whole, half or quarter hour segments. Check with the human resource or payroll department. The notes section allows the CTR to document specific cases and to add notes if they worked on other projects.

Tracking computer use is easily done with the assistance from the information systems (IS) department. I simply call the IS department and they will provide me a detailed account of computer activity. This gives administration peace of mind. Don’t be afraid to take a sick day. Just because you are remote doesn’t mean you won’t get sick. Working while sick will impact your productivity and quality. Staff meetings are essential when you are remote. This helps you stay informed and it keeps you part of the team. Some CTRs start to feel isolated after a while, so open communication is essential. Email or phone calls are a great way to stay connected and you’ll feel less isolated. Working remotely takes the right person. Making sure you are a good fit is extremely important. Asking for a trial run or starting out a few days at home is a good way to determine if it is right for you.

Conclusion

Telecommuting is something that contracting agencies have been doing for a long time and it has been proven to be very effective, especially in places where there are few local CTRs. Set up your workstation in compliance with your facility’s policies and procedures, and become a telecommuter. On the National Cancer Registrars Association website Center for Cancer Registry Education page, there is a tool kit on the under the resource tab that is very informative with sample documents and a self-evaluation (http://www.ncraeducationfoundation.org/links.html).

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NCRA’s Job Bank also includes sites where students can complete their clinical hours and search for mentors.
Update from the American Joint Committee on Cancer TNM Edits Task Force

North American Association of Central Cancer Registries (NAACCR) Edits Workgroup

With the arrival of 2016, the transition from Collaborative Stage (CS) to directly assigned Summary Stage and American Joint Committee on Cancer (AJCC) TNM Stage is complete. Accompanying this are changes to existing data edits, primarily edits related to AJCC TNM stage. In an effort to assure that good, strong edits are available, the North American Association of Central Cancer Registries (NAACCR) Edits Workgroup created a smaller task force in January 2015 to review and update previous AJCC TNM edits, to review CS edits to determine if they should or could be converted to AJCC TNM edits, and to identify areas where new edits may be needed.

The group has completed their review of existing AJCC TNM edits and updated those as necessary. Several were made available for use with the release of the NAACCR v15 edits metafile in February 2015. Review and revision of CS edits is ongoing, several of which have also been made available. Recent attention has focused on finalizing standards setters’ requirements and adjusting edits to match those requirements. In some instances, the requirements are different which requires separate edits. Requirements for using existing site-specific factors (SSFs) is an example; the Commission on Cancer and the Surveillance, Epidemiology, and End Results (SEER) Program have no changes to their required SSFs, while the National Program of Cancer Registries requires SSFs that impact AJCC TNM stage group assignment (e.g., prostate-specific antigen [PSA] for prostate) or that are prognostic factors of interest.

Edits currently under review are also focusing on enforcing data relationships such as age, tumor size, histology, grade, SSFs, and positive regional nodes. In many instances, the T value is assigned based on the tumor size, so edits are being written to assure that the correct T category is assigned based on the recorded tumor size. Likewise, the number of positive regional lymph nodes may be needed to determine the correct N category and appropriate edits are being written for those instances.

These edits are expected to be included in the NAACCR v16 edits metafile to be released in late February or early March. Watch for announcements of the availability of the metafile. The Edits column in the spring issue of the Journal of Registry Management will highlight the major changes in the v16 metafile.
Continuing Education Quiz—WINTER 2015

ANALYSIS OF THE NATIONAL CANCER DATA BASE TO DESCRIBE TREATMENT TRENDS IN STAGE IV ORAL CAVITY AND PHARYNGEAL CANCERS IN THE UNITED STATES, 1998–2012

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

After reading this article and taking the quiz, the participants will be able to:
• Discuss how treatment recommendations for head and neck cancers have evolved over the last several decades
• Describe how increased chemotherapy usage impacted 5-year survival rates
• Identify changes over time in the most common primary sites and tumor size for head and neck cancers

1. Recommendations from 2 landmark studies of stage IV oral cavity and pharynx cancer patients resulted in:
   a) increased use of adjuvant chemotherapy
   b) decreased use of adjuvant chemotherapy
   c) increased locoregional recurrence rates
   d) decreased survival rates

2. Stage IVA and IVB cancers of the head and neck sites are:
   a) associated with distant metastasis
   b) limited to locoregional disease
   c) potentially resectable
   d) unresectable

3. The National Cancer Data Base Participant User File (NCDB PUF):
   a) contains demographic, disease, treatment, and outcome data
   b) contains de-identified and HIPAA-compliant patient information
   c) requires patient consent
   d) can be accessed by any facility

4. The collective head and neck sites in the NCDB include:
   a) larynx
   b) pharynx
   c) nasal cavity
   d) middle ear

5. The subset of patients from the 1998–2012 NCDB head and neck cancer PUF included those who met the following criteria:
   a) codes indicating minor surgery
   b) codes indicating extensive surgery
   c) chemoradiation start dates before surgery
   d) chemoradiation start dates after surgery

6. According to Figure 1, National Oral Cavity and Pharyngeal Stage IV Treatment Trends, after 2004, there was an increase in:
   a) surgery/radiation without chemotherapy
   b) radiation without chemotherapy
   c) surgery with chemoradiation
   d) surgery with radiation

7. According to Table 1, Demographic and Cancer Characteristics in the Stage IV Oral Cavity and Pharyngeal Cancer Population, 1998–2004 and 2005–2012, and the authors, which variables showed an increase requiring further investigation?

8. Advantages of using the NCDB include:
   a) robust collection of treatment information
   b) serves as a proxy for population-based databases
   c) equal representation of subpopulations
   d) ability to track treatment trends and outcomes

9. Oropharyngeal cancers associated with HPV-positive status:
   a) have decreased in incidence since the mid-90s
   b) typically occur in the BOT and tonsil
   c) have a worse prognosis than their HPV-negative counterparts
   d) typically receive trimodal therapy in the Stage IV population

10. Evidence-based treatment recommendations for late-stage head and neck cancers have resulted in an increased usage of:
   a) chemotherapy
   b) radiation
   c) surgery
   d) immunotherapy

The JRM Quiz and answers are now available through NCRA’s Center for Cancer Registry Education (CCRE). For your convenience, the JRM article and quiz can be accessed online at www.CancerRegistryEducation.org/jrm-quizzes. Download the article, complete the quiz and claim CE credit all online.
Instructions: Mark your answers clearly by filling in the correct answer, like this ■ not like this □. Passing score of 70% entitles one (1) CE clock hour per quiz.
Please use black ballpoint pen.

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

March 31, 2018

Quiz Identification Number:

4204.01

JRM Quiz Article:

ANALYSIS OF THE NATIONAL CANCER DATA BASE TO DESCRIBE TREATMENT TRENDS IN STAGE IV ORAL CAVITY AND PHARYNGEAL CANCERS IN THE UNITED STATES, 1998–2012

☐ Processing Fee: Member $25 Nonmember $35

☐ Payment is due with submission of answer sheet. Make check or money order payable to NCRA. US currency only. Do not send cash. No refund under any circumstances. Please allow 4–6 weeks following the submission deadline for processing.

Please check one:

☐ Enclosed is check #__________________ (payable to NCRA)

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Please print clearly in black ballpoint pen.

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City

State/Province

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NCRA Membership Number (MUST complete if member fee submitted)

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Reviewer acknowledgement: JRM gratefully acknowledges the individuals who have served as manuscript reviewers or have otherwise assisted in the review process during the past year. Their wise counsel and contributions to the Journal have been most valued.

Multiple Author Index—Vol. 42 (2015)

A

Abedin, Zainul

Adagarla, Bhargav

Adamo, Margaret (Peggy)

Amstein, Brad

Anjohrin, Suzanne B.

Buchanich, Jeanine M.

Burns, Jeffrey M.

Butts, Elizabeth

Chen, Vivien W.
Weiss NS, Cooper SP, Socías C, Weiss RA, Chen VW. Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences. Fall;42(3):103-110.

Clark, Danette

Butts, Elizabeth

Cope, Linda
Corley, Brittany

Correia, Jane A.


Coyne, Karen
Coyne K. The Good, the Bad, the Ugly… and the Even Better of Rapid Abstracting. Summer;42(2):73-74.

Cronin, Kathleen

Cyr, Jean

Davis, Faith

Day, Terry

Foote, Mary

Graves, Rasino S.

Gress, Donna

Groves, Carmela

Guat, Lee Bee

Hablas, Ahmed

Hannah, Liane M.

Harrison, Denise

Roberson DC, Harrison D. Summer 2015 Continuing Education Quiz. Summer;42(2):78-79.

Roberson DC, Harrison D. Fall 2015 Continuing Education Quiz. Fall;42(3):122-123.


Hawhee, Vicki

Hernandez, Loretta L.
Hsiang, Lim Gek

Hunt, Suzanne L.

Irvin-Barnwell, Elizabeth A.

Kirby, Russell S.


Kosary, Carol

Kraemer, Dale F.

Liu, Benmei

Lin, Jie

M

Mahnken, Jonathan D.

Megyesi, Joseph

Mulla, Zuber D.

Mertz, Kristen J.

North American Association of Central Cancer Registries (NAACCR) Edits Workgroup

Nagamuthu, Chenthila

Negoita, Serban

Nelson, Sybil

Noone, Anne-Michelle
Penberthy, Lynne

Plavsic, Sanja Kupesic

Price, Cathy

Ramadan, Mohamed

Richardson, Terri

Roberson, Deborah C.
Roberson DC, Harrison D. Summer 2015 Continuing Education Quiz. Summer;42(2):78-79.
Roberson DC, Harrison D. Fall 2015 Continuing Education Quiz. Fall;42(3):122-123.

Rockswold, Paul D.

Ross, Jordan

Rutkowski, Rachel E.


Salemi, Jason L.

Sandar, Moe

Shah, Nipa R.

Schussler, Nicola

Seifeldein, Ibrahim A.

Shah, Nipa R.

Shriver, Craig D.

Smith, Britteny L.
Smith, Roy E.

Smotherman, Carmen R.

Socías, Christina
Weiss NS, Cooper SP, Socías C, Weiss RA, Chen VW. Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences. Fall;42(3):103-110.

Soliman, Amr S.

Sun, Leon

Swerdlow, Russell H.

T

Tanner, Jean Paul


V

Vidoni, Eric D.
Williams, Vonetta L.

Wilson, Bailey

Wilson, Reda J.

Woytowitz, Donald V.

X

Xiao, Christopher

Y

Yew, Chow Khuan

Z

Zhan, Kevin

Zhu, Kangmin

Key Word Index—Vol. 42 (2015)

A

Acute Myocardial Infarction

AJCC TNM

Alzheimer’s Disease

B

Benign

Birth Defects


Brain Tumour

C

Canada

Cancer Registrar Education
Cancer Registry


Weiss NS, Cooper SP, Socias C, Weiss RA, Chen VW. Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences. Fall;42(3):103-110.


Cancer Staging

Case Ascertainment

Chronic Myelogenous Leukemia

Colorectal Cancer

Commendation

Completeness

Data Quality

Weiss NS, Cooper SP, Socias C, Weiss RA, Chen VW. Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences. Fall;42(3):103-110.


Database Management System

Death Certificates

Diabetes

Diabetes Registry

Disease Notification

Egypt

Emergency Department
Environmental

Epidemiology

Exposure

Head and Neck Cancer

Industry and Occupation
Weiss NS, Cooper SP, Socías C, Weiss RA, Chen VW. Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences. Fall;42(3):103-110.

International Classification of Diseases Codes

Low- and Middle-Income Countries

National Cancer Database

NIOCCS Coding Software
Weiss NS, Cooper SP, Socías C, Weiss RA, Chen VW. Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences. Fall;42(3):103-110.

Occupational Cancer
Weiss NS, Cooper SP, Socías C, Weiss RA, Chen VW. Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences. Fall;42(3):103-110.

Patient-Centered

Pregnancy

Quality

Regional Meeting

Registry

Renal Cell Carcinoma

Risk Factors
Singapore Cancer Registry

Statewide Hospital Inpatient Discharge Database

Surveillance

Survival


Training


Treatment Trends

Unknown Ethnicity
Title Index—Vol. 42 (2015)

A

Acute Myocardial Infarction in Pregnancy: A Statewide Analysis

Arizona Cancer Registry: Identifying Barriers and Developing Strategies to Improve Melanoma Reporting by Physicians in Arizona

Analysis of the National Cancer Data Base to Describe Treatment Trends in Stage IV Oral Cavity and Pharyngeal Cancers in the United States, 1998–2012

Availability of TNM Staging Data Elements in the Medical Record and Training Needs Assessment: Results from the 2014 SEER Training Needs Assessment for TNM Study

C

Cancer Data Registry of Idaho: Using Area-Based Measures to Target Disparities and Guide Policy Initiatives

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

Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences
Weiss NS, Cooper SP, Socias C, Weiss RA, Chen VW. Coding of Central Cancer Registry Industry and Occupation Information: The Texas and Louisiana Experiences. Fall;42(3):103-110.

Current Status of Brain Tumour Surveillance in Canada and Why it Matters.

D

Diabetes Registries in Patient-Centered Medical Homes

Edits Updates

Evaluating Difficult Decisions in Public Health Surveillance: Striking the Right Balance between Timeliness and Completeness

E

Fall 2015 Continuing Education Quiz
Roberson DC, Harrison D. Fall 2015 Continuing Education Quiz. Fall;42(3):122-123.

H

How the Wisconsin Cancer Reporting System’s Data Quality Task Force Started a Cancer Information Management Education Program to Improve Certified Tumor Registrar Recruitment in Wisconsin
Foote M. How the Wisconsin Cancer Reporting System’s Data Quality Task Force Started a Cancer Information Management Education Program to Improve Certified Tumor Registrar Recruitment in Wisconsin. Summer;42(2):70-72.

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

I

Improving the Completeness of Ascertainment in Florida’s Birth Defects Surveillance Program: The Impact of Adding Infant Death and Emergency Department Data
Measuring the Effect of Improved Medical Facilities and Focused Training on Data Quality and Completeness: An Example from the Gharbiah Population-Based Cancer Registry, Egypt


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


New Jersey State Cancer Registry: Implementing CDC’s Registry Plus™ Web Plus for Ambulatory Centers and Physicians’ Offices


Open-source, Rapid Reporting of Dementia Evaluations


Raising the Bar: How to Get People to Step Up

Webb M. Raising the Bar: How to Get People to Step Up. Fall;42(3):115.

Raising the Bar: Never High-Five a Porcupine


Raising the Bar: Setting Expectations

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Registrars in Action: How Cancer Registry Data Are Used to Improve Public Health


Remote Abstracting: A Home Guide


Renal Cancer Patients with Unknown Ethnicity in Cancer Registry Data: Comparisons to Patients with Known Ethnicity


Spring 2015 Continuing Education Quiz


Summer 2015 Continuing Education Quiz

Roberson DC, Harrison D. Summer 2015 Continuing Education Quiz. Summer;42(2):78-79.

The Good, the Bad, the Ugly…and the Even Better of Rapid Abstracting

Coyne K. The Good, the Bad, the Ugly…and the Even Better of Rapid Abstracting. Summer;42(2):73-74.

Update from the American Joint Committee on Cancer TNM Edits Task Force


Use of Population-Based Cancer Registry Data to Determine the Effect of Timely Treatment on the Survival of Colorectal Patients.


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


Winter 2015 Continuing Education Quiz

TRAUMA REGISTRIES
CALL FOR PAPERS

*Journal of Registry Management*, the official journal of the National Cancer Registrars Association, announces a call for original manuscripts for a Fall 2016 Special Focus on **TRAUMA REGISTRIES**. Invited papers should cover a broad range of topics related to trauma registry management, including the collection, quality review, reporting, and use of trauma registry data. We encourage authors to report on the special challenges associated with the collection and management of data, and the development and operation of trauma registries, as well as the benefits to patients, care institutions, and research that accrue through the operation of hospital-based trauma registries. We invite practitioners, researchers, registrars, and interested others to submit manuscripts on these topics and on results of original research studies using registry data.

Manuscripts for this issue will be accepted through **June 1, 2016**, and should be submitted to Guest Editor Michelle Pumphrey, MLT, RN, CSTR, President, Pumphrey Consulting, 2683 Springhill Road, Staunton, VA 24401. Telephone: (540) 448.2770. Please email articles to Michelle.Pumphrey@PumphreyConsulting.com and cc: JRMEditor@NCRA-USF.org with the subject line: JRM Trauma Registry Article.

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). All papers will be subject to peer review procedures.
INFORMATION FOR AUTHORS

Journal of Registry Management (JRM), the official journal of the National Cancer Registrars Association, invites submission of original manuscripts on topics related to management of disease registries and the collection, management, and use of cancer, trauma, AIDS, and other disease registry data. Reprinting of previously published material will be considered for publication only when it is of special and immediate interest to the readership. JRM encourages authorship by Certified Tumor Registrars (CTRs); special value is placed on manuscripts with CTR collaboration and publication of manuscripts on articles or texts related to the registry profession. CTR continuing education (CE) credits are awarded; a published chapter or full textbook article equals 5 CE hours. Other published articles or documents equal CE hours. All correspondence and manuscripts should be addressed to the Vonetta L. Williams, PhD, MPH, CTR, Editor-in-Chief at JRMEditor@ncra-usa.org or (813) 745-1783.

Manuscripts may be submitted for publication in the following categories: Articles addressing topics of broad interest and appeal to the readership, including Methodology papers about registry organization and operation; Research papers reporting findings of original, reviewed, data-based research; Primers providing tutorials on relevant subjects; and “How I Do It” papers are also solicited. Opinion papers/editorials including position papers, commentaries, and essays that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management; Letters to the Editor; and specifically-targeted Bibliographies of significant interest are invited.

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

Submission Requirements

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

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

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

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

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

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

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

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

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


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