Assessment of the Accuracy of Disease Coding Among Patients Diagnosed With Sarcoma

The rarity of sarcoma makes performing appropriately powered studies challenging and increases the significance of accurate data collection. Tumor registries and population-based databases are increasingly used to determine sarcoma incidence, treatment patterns, and outcomes. The utility of these databases is contingent on meticulous data collection. Although the validity of large databases has been questioned, little is documented about the initial coding process. This study characterizes inaccuracies in coding practices that result in incorrect sarcoma surgical diagnostic codes and tumor registry data at a high-volume health care center. Identification of coding practice errors has implications for the validity of larger oncology databases.

Methods | The Brigham and Women's Hospital Institutional Review Board approved the study and waived the need for patient consent. Patients who underwent resection of primary or recurrent sarcoma between January 1, 2012, and December 31, 2016, by 5 sarcoma surgeons (including C.P.R.) were identified using prospectively collected data from Brigham and Women's Hospital and Dana-Farber Cancer Institute. Demographic data were not collected.

Diagnoses were confirmed by comparing Brigham and Women's Hospital operative diagnosis codes (International Classification of Diseases, Ninth Revision [ICD-9], and International Classification of Diseases and Related Health Problems, Tenth Revision [ICD-10]) with pathology reports. Each patient was labeled as true positive, false negative, or true negative. Using the true positive data set, each patient’s Dana-Farber Cancer Institute diagnosis code (International Classification of Diseases for Oncology, Third Revision [ICD-O-3]) was collected to determine the accuracy of the tumor registry. The ICD-O-3 codes are an extension of International Classification of Diseases codes and specify the site and histologic characteristics of neoplasms. Statistical analyses were conducted in May 2017 using Stata, version 13.0 (StataCorp).

Results | During the study period, 2715 patients with soft-tissue and bone oncologic cases were treated by 3 surgical oncologists (1856 cases) and 2 orthopedic oncologists (859 cases). Of these, 1237 patients (855 treated by surgical oncologists, 382 treated by orthopedic oncologists) had a sarcoma diagnosis confirmed by pathologic findings.

On the basis of ICD-9 and ICD-10 codes, 764 of 1237 patients (61.8%) had cases that were accurately coded as sarcoma, 208 of 1237 patients (16.8%) had a nononcologic diagnosis, and 265 of 1237 patients (21.4%) had an organ site-based malignancy code; 487 of 855 patients (57.0%) treated by surgical oncologists and 277 of 382 patients (72.5%) treated by orthopedic oncologists had cases that were accurately coded. Organ-confined sarcoma was commonly coded with a nonsarcoma, organ-site ICD-9 or ICD-10 code (Table). For instance, 49 of 156 (31.4%) gastric gastrointestinal stromal tumor cases and 24 of 46 (52.2%) breast angiosarcoma cases were coded as gastric and breast cancer, respectively (Figure).

Based on ICD-O-3 codes from the Dana-Farber Cancer Institute tumor registry during an overlapping 4-year period, 631 of 1055 patients (59.8%) had cases that were accurately coded,

Table. ICD-9, ICD-10, and ICD-O-3 Codification of Sarcomas by Specialty

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>No. (%) of Cases</th>
<th>ICD-9 and ICD-10</th>
<th>ICD-O-3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Surgical Oncology</td>
<td>Orthopedic Oncology</td>
<td>Total (N = 1237)</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>487 (57.0)</td>
<td>277 (72.5)</td>
<td>764 (61.8)</td>
</tr>
<tr>
<td>Nononcologic diagnosis or not listed</td>
<td>109 (12.7)</td>
<td>99 (25.9)</td>
<td>208 (16.8)</td>
</tr>
<tr>
<td>Oncologic diagnosis</td>
<td>259 (30.3)</td>
<td>6 (1.6)</td>
<td>265 (21.4)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>110 (12.9)</td>
<td>1 (0.3)</td>
<td>111 (41.9)</td>
</tr>
<tr>
<td>Breast</td>
<td>32 (3.7)</td>
<td>0</td>
<td>32 (12.1)</td>
</tr>
<tr>
<td>Cutaneous</td>
<td>29 (3.4)</td>
<td>0</td>
<td>29 (10.9)</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>17 (2.0)</td>
<td>1 (0.3)</td>
<td>18 (6.8)</td>
</tr>
<tr>
<td>Gynecologic</td>
<td>13 (1.5)</td>
<td>0</td>
<td>13 (4.9)</td>
</tr>
<tr>
<td>Hematologic</td>
<td>9 (1.1)</td>
<td>1 (0.3)</td>
<td>10 (3.8)</td>
</tr>
<tr>
<td>Neurologic</td>
<td>8 (0.9)</td>
<td>1 (0.3)</td>
<td>9 (3.4)</td>
</tr>
<tr>
<td>Thoracic</td>
<td>0 (0.0)</td>
<td>1 (0.3)</td>
<td>1 (0.4)</td>
</tr>
<tr>
<td>Other</td>
<td>41 (4.8)</td>
<td>1 (0.3)</td>
<td>42 (15.8)</td>
</tr>
</tbody>
</table>

26 of 1055 patients (2.5%) had cases that were coded with an other cancer diagnosis, and 398 of 1055 patients (37.7%) had cases that were not listed in the registry.

Discussion | This study emphasizes that the vague nature of definitions for diseases can lead to coding inaccuracies that can be propagated through data sets, which is an issue that possibly extends beyond any single institution. Our study has several limitations. First, the coding inaccuracies as identified in this study may be specific to our institution. Our findings may not be generalizable to all sarcoma centers, and confirmation from other institutions is needed. However, tumor registrars are trained uniformly by American Joint Committee on Cancer guidelines, which raises concern that this issue could be widespread. Consequently, national data sets may not be as comprehensive or useful as expected for studying population-based outcomes for sarcoma. Nevertheless, properly framed questions may still be valid within the limitations of such data sets. Potential reasons for our findings include the heterogeneity, number of histologic subtypes, and variable nomenclature of sarcoma, which renders accurate characterization of cases challenging.\textsuperscript{5,6} Sarcoma may be inaccurately classified on the basis of the organ site rather than on the basis of the pathologic findings.

National databases—including the National Inpatient Sample; the American College of Surgeons' and American Cancer Society's National Cancer Database; the Centers for Disease Control and Prevention National Program of Cancer Registrars; and the Surveillance, Epidemiology, and End Results Program—that rely on \textit{International Classification of Diseases} codes are vulnerable to limitations attributable to inaccurate coding. Gross underestimation in coding data representing sarcoma resections may also contribute to skewed market forecasts. Our findings, if validated by others, suggest that the number of sarcoma cases may be higher than that reported by studies that use these data sets. At present, the net effect of coding errors is unknown. Discussions among surgeons, pathologists, coders, and tumor registrars about how to specify sarcomas are encouraged.

Heather G. Lyu, MD
Leah A. Stein, MPH
Lily V. Saadat, MD
Sheila N. Phicil, MPH
Adil Haider, MD
Chandrajit P. Raut, MD, MSc;
for the Dana-Farber/Brigham and Women's Cancer Center Sarcoma Surgery Group

Author Affiliations: Department of Surgery, Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts (Lyu, Saadat, Haider, Raut); Dana-Farber/Brigham and Women's Cancer Center, Boston, Massachusetts (Stein, Phicil); Center for Sarcoma and Bone Oncology, Dana-Farber Cancer Institute, Harvard Medical School, Boston, Massachusetts (Raut).

Accepted for Publication: May 14, 2018.

Corresponding Author: Chandrajit P. Raut, MD, MSc, Department of Surgery, Brigham and Women's Hospital, Harvard Medical School, 75 Francis St, Boston, MA 02115 (craut@bwh.harvard.edu).

Published Online: August 9, 2018. doi:10.1001/jamaoncology.2018.2979

Author Contributions: Dr Lyu and Raut had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: Lyu, Phicil, Haider, Raut.

Acquisition, analysis, or interpretation of data: All authors.

Drafting of the manuscript: Lyu, Haider, Raut.

Critical revision of the manuscript for important intellectual content: All authors.

Statistical analysis: Lyu, Stein, Phicil.

Obtained funding: Raut.

Administrative, technical, or material support: Stein, Saadat, Phicil, Haider, Raut.

Supervision: Phicil, Haider, Raut.

Conflict of Interest Disclosures: None reported.

Funding/Support: Research reported in this article was supported by the National Library of Medicine Institutional training grant for research training in biomedical informatics and data science (T15) under award number T15LM07092.

Role of the Funder/Sponsor: The funder had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

Group Information: Additional members of the Dana-Farber/Brigham and Women's Cancer Center Sarcoma Surgery Group include Jiping Wang, MD, PhD, Dana-Farber Cancer Institute, Harvard Medical School, Boston, Massachusetts and Marco L. Ferrone, MD; and John E. Ready, MD (Center for Sarcoma and Bone Oncology, Dana-Farber Cancer Institute, and Department of Orthopedic Surgery, Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts).

Meeting Presentation: This paper was presented at the 22nd Connective Tissue Oncology Society Meeting; November 8, 2017; Maui, Hawaii.

In Reply We appreciate the interest and comments by Li and colleagues regarding our article, which compared the incidence of endocrine adverse events following treatment with immune checkpoint regimens in a systematic review and meta-analysis of published trial reports. Our work included a total of 38 clinical trials retrieved from the PubMed database evaluating the use of checkpoint inhibitors for the treatment of advanced solid tumors, resulting in a total of 7551 patients who were eligible for this meta-analysis. Thus, it is unlikely that the data regarding the incidence of thyroid toxic effects or hypophysitis would differ significantly if further studies were added. We recognize that after the date of the database search (July 18, 2016), new articles have been published, and an update of our work with new studies and additional information sources would be welcome. By including newly reported clinical trials, such efforts may help to establish the incidence and risks of less frequent endocrinopathies, such as primary adrenal insufficiency and type 1 diabetes. Moreover, in our meta-analysis we did not include other types of immunotherapy combination regimens, such as programmed cell death/programmed cell death ligand 1 inhibitors plus chemotherapy or combinations with antiangiogenic drugs. A work including these regimens would be of interest now that some combinations have been approved, and many are under review for approval, for the treatment of different advanced solid tumors.

As stated in our article, one of the limitations of our work is that we conducted a meta-analysis at the study level, and we could not establish additional potential risk factors possibly associated with the development of endocrine adverse events. In our analyses, dosage was not a modifier of drug effects and exploratory analyses of other patient characteristics, including age, sex, and smoking status, failed to identify...