



Pitfalls & opportunities using cancer registry data for thyroid cancer research

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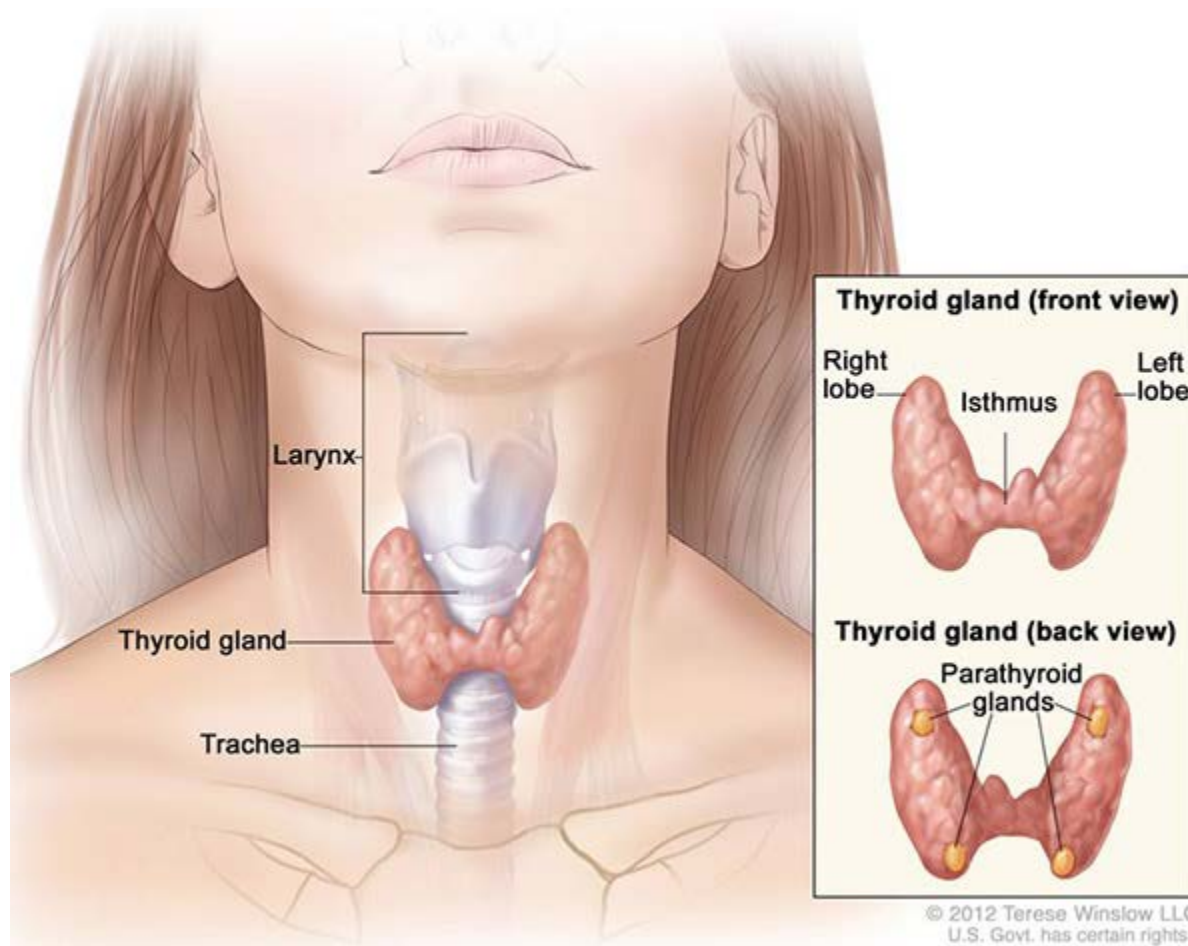


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Goals of Study

- This study evaluated the quality of thyroid cancer data in one statewide central cancer registry.
- Specifically, thyroid cancer lobectomy cases (2004-11) were evaluated to determine the accuracy of coding RXSummSurgPSite and RadRegModal.
- Comparison to National Comprehensive Cancer Network treatment guidelines was performed.
- Specifically, the number and percent of patients who received thyroid lobectomy surgical intervention and also received radioiodine.

Thyroid Gland



Thyroid Cancer Subtypes

- **Over 90% of all thyroid cancers diagnosed in the US are “differentiated thyroid cancers”.**
- **Differentiated thyroid cancers include the following subtypes:**
 - a) **Papillary: diagnosed in about 80% of all cases**
 - b) **Follicular: diagnosed in about 10% of all cases**
 - c) **Hürthle Cell: diagnosed in about 3% of all cases**
- **Medullary thyroid cancer: about 4% of all cases**
- **Anaplastic (undifferentiated) thyroid cancer: about 2% of all cases**
- **Thyroid lymphoma, sarcoma or other rare cancer: about 4% of all cases**

NCCN Guidelines

- Since most patients are diagnosed at localized stage, the large majority of patients receive surgery.
- Patients subsetting into high-risk and low-risk patients.
- High-risk subjects—e.g. age < 15 or > 45 years of age, known distant metastases, tumor > 4 cm in diameter—recommend total thyroidectomy
- Low-risk subjects less agreement of NCCN panel members. Majority of panel members recommended total thyroidectomy in those diagnosed pre-operatively or during surgery.
- Radioiodine is not recommended for patients with unifocal or multifocal disease <1 cm, confined to the thyroid, clinically NOMO.

Previous Research

- A study using data from the NCDB evaluated radioiodine use in differentiated thyroid cancer patients receiving thyroid lobectomy. Twenty-four percent of differentiated thyroid cancer patients who received lobectomy also received radioiodine.
- In another study using NCDB reporting on the management trends of anaplastic thyroid cancer patients, 49% of patients underwent surgical resection, and of these patients, 26% underwent thyroid lobectomy as the definitive procedure.
- The findings of these two studies and others bolstered the concern that the reporting of the variable “surgery of the primary site” in thyroid cancer registries may sometimes be inaccurate. Thus, TN Cancer Registry data was used to evaluate the extent of radioiodine use in thyroid lobectomy patients, as well as the accuracy of thyroid lobectomy coding.

Distribution of Cases

- A total of 926 thyroid cancer cases (N=6938) were coded as having received thyroid lobectomy (TL; code '20'-'23') during the period 2004-11.
- A total of 143 patients were coded as '20', TL NOS.
- A total of 490 patients were coded as '21', lobectomy only.
- A total of 7 patients were coded as '22', isthmectomy only.
- A total of 286 patients were coded as '23', lobectomy with isthmus.
- A total of 186 patients out of 926 (20.1%) TL cases also received radioiodine therapy.

(86 cases out of the original 6938 cases were coded '25'-'27')

Results Cont.

- There were 369 incorrectly coded TL cases (39.8%) of the 926 original TL cases, 308 (84.2%) from CoC facilities. For 10 observations of the 926 original TL cases had no information on CoC status, 3 total incorrectly coded cases.
- For cases originally coded as '20' (143 total), 131 (91.6%) were incorrectly coded, 109 (83.2%) from CoC facilities.



Results Cont.

- Of the 131 TL cases errantly coded '20' (out of the 143 originally coded '20'), 35 (26.7% of the 131 errant cases) were changed to a code of '50'.
- A total of 93 (71.0% of the 131 errant cases) cases were changed to another TL code, '21'-'23'. (The large majority were changed to '23', none were changed to '22'.)
- A total of 3 (2.3% of the 131 errant cases) cases were changed to another surgery code.
- Hence, in essence, of the 143 cases originally coded as '20', 105 (73.4%) of these cases were "correctly" coded by basic procedure type, i.e. TL still performed.

Results Cont.

- For cases originally coded '21' (490 total), 135 (27.6%) were incorrectly coded, 108 (80.6%) from CoC facilities, 1 unknown CoC status.
- Of the 135 TL cases errantly coded '21' (out of the 490 originally coded '21'), 119 (88.1% of the 135 errant cases) were changed to a code of '50'. **(Note the larger percentage changed to '50' Compared to code '20' cases!)**
- A total of 10 (7.4% of the 135 errant cases) cases were changed to another TL code, '20' or 22'-'23'. (The large majority were changed to '23', one was changed to '22' and one was changed to '20'.)
- A total of 6 (4.4% of the 135 errant cases) cases were changed to another surgery code.
- Hence, in essence, of the 490 cases originally coded as '21', 365 (74.5%) of these cases were "correctly" coded by basic procedure type, i.e. TL still performed.

Results Cont.

- For cases originally coded '23' (286 total), 130 (45.5%) were incorrectly coded, 88 (68.8%) from CoC facilities, 2 unknown CoC status.
- Of the 130 TL cases errantly coded '23' (out of the 286 originally coded '23'), 86 (66.2% of the 130 errant cases) were changed to a code of '50'.
- A total of 12 (9.2% of the 130 errant cases) cases were changed to another TL code, '20'-'22'. (The large majority were changed to '21', four were changed to '22'.)
- A total of 2 (1.5% of the 130 errant cases) cases were changed to another surgery code.
- Hence, in essence, of the 286 cases originally coded as '23', 198 (69.2%) of these cases were "correctly" coded by basic procedure type, i.e. TL still performed.

Results Cont.

- Overall, out of the 926 total TL cases, 673 (72.7%) of all cases were “correctly” coded based on basic surgical procedure type.
- Once the analysis was complete, “correctly” coded TL cases based on basic surgical procedure type who also received radioiodine amounted to only 71 (10.5%) cases out of the 673 “correctly” coded cases.
- Recall at the beginning, we had 186 cases out of 926 total TL cases, or 20.1%, of all originally coded TL cases who received radioiodine.
- These differences are statistically significant, chi-square test, at $p < 0.0001$

Conclusions

- Overall, this study demonstrates that surgical data on thyroid cancer contained in central cancer registries likely needs to be validated before research use.
- A simple text-to-code re-abstraction audit methodology can easily accomplish this.
- CoC facilities overall are as likely to make mistakes coding surgery primary site as non-CoC facilities, with the exception of code '23'.
- Reported national rates of radioiodine therapy following thyroid lobectomy, non-standard care, appear to be excessive.

Questions?

