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Letters to the Editor

Unique obstacles to establishing thyroid cancer registries

The establishment of population-based cancer registries requires the use of rigorous methodology in order to ensure complete and timely data ascertainment [1,2]. Developing a thyroid cancer registry poses unique obstacles that are related to the nature of the disease. Because of the relatively indolent nature of most differentiated thyroid cancers, there is typically a long interval between initial diagnosis and disease recurrence, which, in turn, means that lengthy follow-up is necessary in order to ascertain outcomes. Since differentiated thyroid cancer confers a low risk of death, registries need to be targeted instead toward the identification of prognostic factors for tumor persistence and recurrence, as has been previously comprehensively described by Mehra and colleagues regarding their proposal of a Thyroid Cancer Care Collaborative in the U.S. [3]. The number of known risk factors for tumor persistence and recurrence is expanding rapidly, and much of the data currently required for disease prognosis are not readily extractable from medical records. For example, the number and size of all cervical lymph nodes present is not a required part of the College of American Pathologists' standard pathology report [4].

We recently developed a comprehensive thyroid cancer registry with the intent to capture both retrospective and prospective individual patient data at Harvard Vanguard Medical Associates, Boston, MA. During the timeframe of this study, this integrated health system was comprised of 23 sites across the greater Boston area (now even larger), connected by a robust electronic health record (EHR) that has been in operation for nearly 40 years. Our registry houses over 400 discrete variables related to patients' demographics, thyroid cancer diagnosis, tumor characteristics, and the multiple aspects of long-term thyroid cancer management, most of which is not extractable without dedicated individual patient-level review. As such, this type of systematic, comprehensive, and complex data capture requires a research assistant to be trained in the specific thyroid cancer terminology documented in the medical records for entry into the registry tool. We look forward to taking advantage of marketplace progress toward EHR and registry interoperability that are envisioned under the Centers for Medicare and Medicaid Services Meaningful Use incentive program. Our hope is to better integrate data collection into the patient care workflow for basic data, allowing research assistants to focus their data collection on specialized data elements, such as family history, pathological staging, and genetic markers. In comparison with the many other types of thyroid cancer registries that have been described [3], our database captures patients within an integrated multi-site institution who reside in a discrete geographic area, collects longitudinal data recorded in a single EHR spanning nearly 4 decades, and incorporates elements advocated in the most recent thyroid nodule and cancer guidelines.

Data collection continues to be ongoing, and we share our experience to illustrate the complexities of designing and executing longitudinal thyroid cancer registries, which should be developed in a collaborative fashion. Such thyroid cancer registries need to prospectively include all of the prognostic criteria advocated in the most current thyroid nodule and cancer guidelines [5], and will need to be plastic enough to adapt as guidelines and known risk factors evolve. Genetic characteristics of both tumors and hosts are increasingly important to clinical decision making, and may over time change the definitions and staging of many cancers. Such registries should also include diverse patient populations in order to produce rich, generalizable data.

Finally, the development and ongoing maintenance of such registries is an expensive endeavor. Joint partnerships with stakeholders in academia, industry, and government ideally will be required to fund future comprehensive thyroid tumor registries. Despite their complexity and expense, we strongly believe that such registries are needed, as they are able to provide a wealth of data which is not readily available from other sources.

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Disclosures

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References

[1] Bray F, Parkin DM. Evaluation of data quality in the cancer registry: principles and methods. Part I: comparability, validity and timeliness. Eur J Cancer 2009;45:747–55.

[2] Parkin DM, Bray F. Evaluation of data quality in the cancer registry: principles and methods Part II. Completeness. Eur J Cancer 2009;45:756–64.

[3] Mehra S, Tuttle RM, Orloff L. Database and registry research in thyroid cancer: striving for a new and improved national thyroid cancer database. Thyroid 2015;25:157–68.

[4] Seethala RR, Asa SL, Carty SE, Hodak SP, McHugh JB, Richardson MS, et al. College of American pathologists protocol for the examination of specimens from patients with carcinomas of the thyroid gland. <http://www.cap.org/apps/docs/committees/cancer/cancer_protocols/2014/Thyroid_14Protocol_3100.pdf>; 2014 [accessed 24.10.15].

[5] Haugen BR, Alexander EK, Bible KC, Doherty G, Mandel SJ, Nikiforov YE, et al. American thyroid association management guidelines for adult patients with thyroid nodules and differentiated thyroid cancer. Thyroid 2016;26: 1–133.