

The Cancer Registry Profession: A Unique Role in Cancer Care and Control

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One of the unsung, and often unknown, heroes in cancer care delivery and cancer control is the cancer registrar.

Cancer registrars are trained health care professionals with the technical expertise necessary to identify reportable cancers and then abstract, code, and enter relevant demographic, diagnostic, staging, treatment, and follow-up information into a computerized database. The collected data provide cancer incidence, treatment, outcome, and trend data for public health and facility planning, development of cancer programs, quality improvement, and research activities. This commentary describes the history of the profession, its unique role in both hospitals and the North Carolina Central Cancer Registry (CCR), and its challenges for the future.

History and Evolution of a Profession

The first modern case registries for the study of cancer emerged in the early 1900s as individual physician or institutional projects. In the 1930s, surgeons in the United States began to use “Surgical Follow-Up Registries” to learn more about their surgical patients’ outcomes.¹ These early registries evolved into tumor registries which, in the early days, collected rudimentary data on cancer sites, types of surgery, and short-term and long-term outcomes and required little specialized training to follow the patients and record dates in a card file. By 1953, the American College of Surgeons’ cancer

program guidelines required all approved hospitals to have a tumor (cancer) registry.²

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The Certified Tumor Registrar (CTR) credential was established in 1983 by the National Cancer Registrars Association (NCRA).³ Currently approximately 5000 registrars have earned the credential. The credentialing process assures that certified individuals have met a level of competence required to provide accurate information for cancer surveillance and research activities. The CTR credential marks achievement, fosters professional pride, and is nationally recognized in recruitment and retention of registry personnel.⁴

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Successful candidates demonstrate a standard of knowledge and field experience in the cancer registry through on-the-job training or clinical practice rotation from a formal education program. For approved cancer programs accredited by the American College of Surgeons, standards require that a CTR perform or supervise abstracting, coding, and staging activities. In order to maintain the credential, registrars are required to accrue 20 hours of continuing education credits in a 2-year cycle. This requirement promotes professional growth to keep abreast of the changes in oncology treatment including new surgical techniques, drug regimens, and radiation modalities.

The Role of a Hospital Cancer Registrar in a CoC-Approved Cancer Program

Cancer registrars are employed by hospitals with cancer programs to coordinate a variety of activities to ensure the program meets the American College of Surgeons' Commission on Cancer (CoC) approval standards and state cancer reporting requirements. The standards set by the CoC are the foundation of the cancer program. Within this framework lie the day-to-day registry operations that include abstraction of cancer information, patient follow-up, quality assurance, submission of data to state and national organizations, cancer program administration, and internal and external support for those invested in the field of cancer.

The cancer registrar creates an accurate account of the health care experience of the cancer patient. All malignant diagnoses and benign tumors of the central nervous system are included. Any patient diagnosed and/or treated with a reportable neoplasm is abstracted into the registry database and then followed for the remainder of his or her lifetime. Patients who enter the facility for recurrent disease or disease management but who were diagnosed at another facility are also entered but are not followed for their lifetime. Cancer registrars collect information about each patient and each incidence of cancer including demographics, cancer identification, diagnosis, stage of disease, and treatment. Because lifetime follow-up information is maintained in the database, hospital cancer registries have the ability to provide survival data in addition to incidence data.

The cancer registrar supports all areas of an institution's cancer program through the management of certain hospital activities and through the use of its data. Cancer registrars fulfill data requests from physicians, residents, research staff, administration, students, and members of the community to support hospital initiatives including the purchase of new equipment, data to support a Certificate of Need application, implementation of new programs and support groups, and validation of the need for educational programs and staff. Registrars also perform case finding for research (prospective and retrospective epidemiologic studies) and provide data to assist in planning clinical trials and for specialized departmental research databases. In addition to facility-specific requests, the cancer registrar may provide rapid reporting to the CCR (within 1 month of diagnosis) for population-based research and may also participate in studies requested by the CoC. The cancer

registrar is instrumental in the publication of the Cancer Program Annual Report that provides hospital administration, medical staff, and the community with a summary of cases during the last year, a compilation of activities of the cancer program, and an in-depth analysis of one cancer site with a comparative survival analysis.

Hospital registrars electronically submit the data to the CCR on a monthly or quarterly basis. They also submit data to the CoC's National Cancer Data Base annually. The CoC uses the data to study patterns of care among its approved programs, and results are benchmarked with national data.

The Role of a Cancer Registrar in the Central Cancer Registry

In North Carolina, more than 200 cancer registrars and data collectors representing 120 different reporting sources report approximately 60 000 records to the Central Cancer Registry each year. Through extensive processing of these records, the CCR reports approximately 43 000 unique cases of cancer each year.⁵ Cancer registrars at the CCR consolidate multiple reports from facilities across the state, perform quality reviews, conduct audits and train staff at reporting facilities, abstract data for small facilities with no registry staff, and consult on data use and research. The CCR uses these data for population-based cancer incidence rates, research, and to plan and evaluate cancer control programs.

The CCR utilizes many resources to ensure all cases are identified and reported. Cancer registrars in CoC-approved cancer programs provide approximately 80% of all cases to the CCR. The remaining 20% must be obtained from facilities that do not have a CoC-approved cancer program including hospitals, hematology/medical oncology clinics, radiation therapy facilities, and physician practices. As the medical arena advances in technology and treatment practices, there has been an increase in cancer patients who are diagnosed and treated without entering the hospital setting. This is particularly common with melanoma and prostate cancer. Cancer registrars at the CCR are responsible for training staff at these non-registry facilities in cancer reporting. The challenges are many. In addition to high turnover, staff are usually inexperienced in cancer data collection. The CCR works closely with these facilities to provide individual training based on their level of knowledge and to provide yearly regional workshops to address changes in reporting requirements and data quality issues.

Pathology laboratories also serve as a reporting source and are required by state legislation to report to the CCR. In addition, the CCR regularly links its database with information from the state's Breast and Cervical Cancer Control Program, records from studies that use Rapid Case Ascertainment, and North Carolina Vital Records (deaths). These reports are used to identify cases that were not previously reported by other sources and to follow back to the ordering physician or facility to obtain all the information necessary to abstract the case.

A major effort of the cancer registrar at the CCR is record consolidation. This process ensures that cases of cancer are

counted only once by compiling data obtained from multiple reporting sources on the same tumor. Highly trained CTRs review each case, identify discrepancies, and consolidate the data into one record that contains the most accurate and complete information. Records describing separate, independent tumors for the same patient also need to be identified so that they can be linked to the patient but remain stored as separate cases. The task of consolidation and linkage cannot be easily automated as it involves a comparison of essentially every data item required to be collected. The final coding decision is dependent on the manual intervention and expertise of the CTR.⁶

Quality Control: Ensuring Meaningful Information

There are certain quality control activities that must take place in both hospital registries and at the CCR in order to ensure that meaningful information is available. Reconciliation of data edits is a requirement for all cancer registries. Data edits follow logical rules, typically embodied in a computer algorithm, that are applied to all records to check for item validity and consistency. An example of a failed edit would be a conflict between the primary site and histology. Re-abstracting audits are also used to retrospectively assess the level of agreement with the source document and reproducibility of registry data.

For CoC-approved cancer programs, a physician must review 10% of the cancer registry cases to assess the quality of diagnosis, stage, and treatment data. The Cancer Committee in each hospital also sets guidelines to measure data quality which are included in the review.⁷ Hospital facilities, as well as the CCR, establish an intricate array of quality measurement requirements such as a visual review of abstracted cases or generating reports designed to identify specific conflicts or common errors in the data.

Quality control involves more than correcting errors in the data. It is essential that feedback be given to abstractors on a regular basis so that recurring errors are eliminated. Elements that contributed to the errors must be analyzed and training programs targeted around these areas.

Training: An Ongoing Challenge

A standardized dataset is a valuable product of cancer registries. The primary value of these data lies in their uniformity and the ability to compare data from multiple databases. Because cancer registry data are coded in such detail, instructions are continually being evaluated and revised. Over a longer term, instructions are modified to reflect changes in medical technology, computer technology, and in the use of registry data itself. Adding to the complexity of this task are the varying requirements mandated by the standard setting organizations. The accumulation of these factors makes training new cancer registrars and keeping existing cancer registrars informed of the latest changes especially challenging.

North Carolina cancer registrars have taken a role as leaders in training and education with the development of two

“Diagnosed August 1, 2003; radiation & chemo, temporary ileostomy, liver (2) & lung resections, RFA, and still in treatment today. Colon Cancer Alliance volunteer, also active in NCCCP, 4CNC, other awareness programs. Continues to work, play golf, and practice healthy lifestyle through nutrition and exercise. THERE IS HOPE!!”

*— Gordon
Colorectal Cancer*

nationally-recognized training programs. The Association of North Carolina Cancer Registrars (ANCCR), in collaboration with the CCR, offers an intensive training program for new cancer registrars. ANCCR is the only state association to offer a training program of this magnitude. In 2006, Davidson County Community College in Lexington, North Carolina, began offering an Associate in Applied Science degree in Cancer Information Management. This program is 1 of only 4 NCRA-approved formal education programs that offer an Associate's degree in cancer registry management. Both programs were developed by and are currently taught by North Carolina cancer registrars.

Depending on the experience and education a person brings to the position, training can span many months before the person is considered to have the expected proficiency in cancer data management. The opportunity to attend a training program or a formal education program such as those offered in North Carolina not only builds cancer registrars with a stronger understanding of their responsibilities but also reduces the labor-intensive process required with on-the-job training. North Carolina cancer registrars are very active in the profession, serving in various capacities of leadership at the state and national levels, and several North Carolina cancer registrars have received state and national recognition for their contributions to the cancer registry profession.

A Profession at Risk: Recruitment and Retention of Cancer Registrars

Recruitment and retention of Certified Tumor Registrars is a unique challenge to the profession. Recruitment is challenging because the degree of specialization is great, the workforce is small, and there are few training programs available. Because of this quandary, most registrars receive the specialized training on the job. In recognition of these challenges, the education requirement for certification has been increased to include an allied health background along with 1 year of cancer registry experience. Successful retention tactics can include an emphasis on flexible hours, the ability to work from a remote environment, and most importantly, emphasis on the fact that this is not just a

job but a career with an impact on cancer surveillance and control. In addition to adequate salary compensation, opportunities for professional growth such as attendance at forums, symposiums, Webinars, and state and national meetings can improve retention. Opportunities to support health fairs, screening programs, and fundraisers allow the cancer registrar to play a more visible role and to connect with the larger community.

A hospital cancer registry does not generate revenue for the hospital, which makes it difficult to provide competitive salaries for its staff. At the CCR, the personnel classification of these positions makes it difficult to hire highly experienced CTRs at competitive rates. Recognition and respect for the CTR as part of the health care team at the hospital and the state cancer control program is essential. All the facilities, administrators, physicians, public health programs, and nonprofit agencies that benefit from the cancer registrars' efforts are encouraged to recognize their important role in the fight against cancer and to support the profession through monetary and training

resources. It is also important that data users acknowledge the registry as the source of data in presentations, publications, and other data products. This acknowledgement and support is essential to the recruitment and retention of high quality cancer registrars.

To meet the needs of the 21st century, cancer registry data has become much more complex. Cancer registrars face many challenges as they keep abreast of rapid changes in the practice of oncology and maintain the skills needed for high-quality data collection. While it is not certain exactly what the cancer registrar's job will be like in 5, 10, or 15 years, technology will play an important role. The cancer registrar must have the technological and analytical skills to ensure accurate data, efficient electronic data systems, and appropriate data use and dissemination. To meet the challenges of today, a cancer registrar uses self-training, formal education, and certification in order to serve within a field that is considered the backbone of national and local cancer surveillance efforts.³ **NCMJ**

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