More Than Just Case Counts
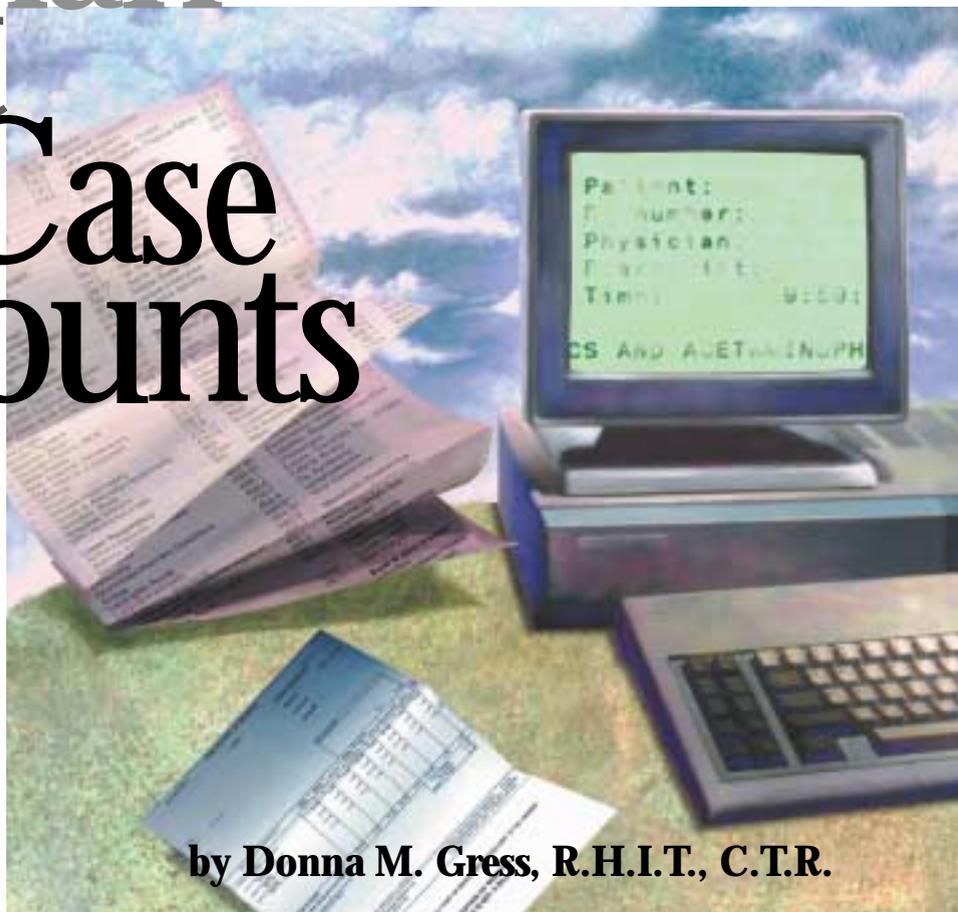
by Donna M. Gress, R.H.I.T., C.T.R.

A hospital's cancer registry is an important public health tool that can be used to verify suspected cancer clusters, provide useful information for researchers, and help physicians determine the results of different cancer treatments. Although the registry's primary goal is usually the improvement of in-house patient care by monitoring all aspects of care and treatment outcomes, the hospital cancer registry also can be an important source of data for facility utilization assessments and the allocation of resources by hospital administrators as they plan for future needs.

Establishing a registry is the first step to approval of the hospital's cancer program by the Commission on Cancer (COC), a part of the American College of Surgeons (ACoS). To satisfy COC requirements, cancer registries must capture information on all aspects of the patient's diagnostic work-up and treatment. To do so, they must "abstract" or take information from many different sources and create a database file for each cancer patient within six months of admission to the facility as either an inpatient or outpatient. The COC also requires that each registry compare its data on at least one malignancy to national data every year to help local hospitals gain insight into how their treatment and survival statistics compare with those from other areas of the country. This comparison is included in the annual activity report the COC requires the registry to produce, which is due by November of the following year.

COC-approved cancer registries may also send the commission reports relevant to two Patient Care Evaluation (PCE) studies that the COC conducts annually. In 2001 the COC requested information on gastric carcinoma and non-small cell lung cancer. These special studies allow the COC to observe diagnosis and treatment trends in different parts of the country.

The COC conducts evaluations of an institution's

entire cancer program every three years based on 10 standards. The registry is a major focus of these visits. If its records do not comply with COC standards, the entire cancer program can lose its accreditation. The registry also assists with the activities and documentation of the majority of other COC standards.

If your program is COC compliant, your registrar must be able to perform all the registrar-related functions listed in "Standards of the Commission on Cancer Volume I: Cancer Program Standards" as well as those functions in "Standards of the Commission on Cancer Volume II: Registry Operations and Data Standards (ROADS)."

ABSTRACTING AND CASEFINDING

Typically, cancer registrars spend about 25 percent of their time abstracting. Data must be submitted annually to the National Cancer Database (NCDB), which provides feedback on quality. This information is sent directly from the database through selection of the appropriate data items, but does not include patient identifiers. In addition to submitting data to NCDB, new case abstracts must be submitted to the state for the National Program of Cancer Registries in accordance with the state's requirements. Here, patient identifiers are included to help eliminate duplicate records for those patients who may have been seen at more than one facility.

COC registry abstracting requires collecting *all* pertinent information on the patient. To find out exactly how the patient was diagnosed, physician offices may be called. Documentation of any diagnostic work-up referred to must be obtained because it influences staging. Complete treatment records from private physicians or other facilities are also necessary.

Registrars monitor the mandatory physician staging in the medical record. Staging may be dictated in consults or in the discharge summary or written in progress notes or on staging forms. If forms are used (they are not mandatory), registrars ensure that correct staging forms are placed in the medical record and are marked as a deficiency for the physician to complete. Health Information within the hospital actually marks deficiencies in a chart; the registry just brings such deficiencies to its attention. Registrars also monitor the compliance with this process. All staging information must be complete and accurate or the data will be useless for studies.

Only patients whose cancer was either diagnosed or treated at the institution are included in the hospital's registry of cancer patients. The registry includes patients who are diagnosed with metastases or progression of their disease, even if their original diagnosis took place elsewhere. Patients are included only if the hospital is actively involved in some form of diagnosis or treat-

ment. Patients who come to the hospital for a second opinion or who receive only palliative care are *not* included. Often, many more cases are reviewed than are actually abstracted.

To identify eligible cases ("casefinding") for abstracting, the registrar must review pathology reports, radiation and medical oncology logs and reports, and medical record indices. By logging charts already reviewed by discharge dates, the registrar can help minimize the need to look up every name in the indices.

Keeping track of all the aspects of a patient's treatment and all COC requests requires an extremely alert registrar and sophisticated software that is flexible and can accommodate multiple users.

Beginning with a reference date and meeting the histology requirements of the reportable list mandated by the COC, registrars place all identified cases into a computer system using the appropriate data set and codes. The COC data-set change in 1998 brought the total items to 170. There were additions in 2000, and another revision is expected in 2003.

Registrars must complete the case within the designated timeframe of either the state or the COC; both cannot exceed six months. Some registrars collect the data (abstract) while the patient is still in the facility, or within days after discharge (concurrent method). Most others wait until the patient is discharged and the record

Typically, cancer registrars spend about 25 percent of their time abstracting.

is complete, which can be any time between weeks after discharge to no later than six months after discharge. The closer to discharge the case is abstracted, the quicker the data will be available for analysis. However, as one gets closer or concurrent, procedures must be in place to document or code in the computer the database information that is still needed. Doing so ensures that subsequent work-up or treatment—whether it takes place at the facility or elsewhere—is added to the abstract.

Registrars who find medical-record coding errors when they do casefinding or abstract should work with the hospital's Health Information Department to assure accuracy, since coding errors affect reimbursement. Most states perform random audits of casefinding using medical-record indices, and inaccurate coding will affect audit results.

Follow-up information is obtained at least yearly,

although records are updated whenever new information becomes available. Follow-up information is obtained from patient-readmission records, outpatient-services records, hospices, and state listings. Hospitals are required to maintain a 90 percent successful follow-up rate on all patients and an 80 percent rate on living patients to receive COC accreditation.

QUALITY CONTROL

Although the hospital's Cancer Committee monitors registry quality by reviewing abstracts with the help of a physician advisor, the registrar is responsible for ensuring that abstracts are complete, accurate, and recorded correctly. Typically, registrars keep a "suspense system" that keeps track of cases that have been identified but have not yet been abstracted. The suspense system is a compilation of all casefinding sources and eliminates duplicates. This system is used to project the caseload and provide timely information.

Registrars are also responsible for keeping an accession register (a yearly listing of all new cases entered into the registry, which may be run from the computer or entered by hand), a data request/usage log, and a reportable list, which is a listing of diagnoses that must be included in the registry by regulation or by agreement. Some registries enter cases onto log sheets to be used for quality control, audits, or as a check-off list for other activities. Maintaining the data request/usage log facilitates the use of data for special studies, cancer conferences, and administrative reports. Administration should encourage hospital departments to use registry data.

A necessary component of a well-functioning cancer registry is the procedure manual, which documents all phases of registry operation and procedures as well as any other duties (for example, budget preparation and support for community outreach programs of the cancer program) not related to data collection, follow-up, or studies. The manual should be presented to the Cancer Committee for its approval. The procedure manual must be updated at least annually, but is most accurate when updates are made as changes are instituted.

DATA COLLECTION AND ANALYSIS

Although registries do not produce revenue, they provide the hospital with a valuable knowledge base that can be used, for example, to plan revenue-producing activities. Registrars compile and report data to their hospital administrators to help them assess diagnosis, treatment, survival, and resources for specific patient services. Data such as patient trends, referral patterns, utilization of hospital service areas, and allocation of resources are used by hospital administration to plan for

In My View

Stephanie Levy, C.T.R.
Cancer Registrar
Suburban Hospital
Bethesda, Md.

The cancer registry gets its statistics from you, the physicians and clinicians who treat patients. These statistics can be used to identify superior treatment regimens, describe the natural history of a malignancy, and provide the building blocks for creating best practices within the field.

Although cancer registries offer the hospital and the community a wide variety of resources, these resources tend to be ignored and underutilized. For example, suppose an institution is constantly referring bone marrow transplants to other institutions. Registry data will show the number of bone marrow transplant patients the hospital sees each year. If there are enough patients at the hospital who need this service, the board might consider starting a bone marrow transplant unit in-house.

The cancer registry also can be useful in clinical trials management. If a clinical trial for a specific type of malignancy is suggested and the registrar finds that the hospital sees only five patients a year with that disorder, the facility most likely will refuse to participate.

The registry can provide information to justify grant requests and may be able to help identify areas of need within the community. For example, if a specific ethnic group has a disproportionate number of late-stage diagnoses for a particular malignancy, perhaps the hospital might start a screening education program for this patient population.

Doctors don't realize the importance of filling out and returning follow-up requests from the registry. Although the time involved is annoying, the potential rewards are great.

Maria-Teresa Ramirez, C.T.R.
Cancer Registry Supervisor
Anne Arundel Medical Center
Annapolis, Md.

Your registry won't be underutilized if you, as the registrar, market your department. Talk to administrators and offer the registry's services to committees that can use your data. Become involved in tumor boards, and distribute interesting statistics you have found during the month.

Make sure that everyone you can think of knows what you are doing and what information you can provide. Become involved with your whole institution. To help this along, at Anne Arundel Medical Center we are starting a cancer registry newsletter that will be distributed to the medical staff.

We have aggressively marketed the registry at Anne Arundel, and the results have been rewarding. Administration often comes to us for planning and utilization statistics, and we receive numerous calls from physicians doing their own research projects asking for data.

If you don't like the way administration and the doctors at your hospital view the registry, get out and change their minds. ◘

Hiring Registry Staff

While most institutions require credentialing as a certified tumor registrar (C.T.R.), many prefer their registrar to have a registered health information technician (R.H.I.T.) certificate or some other allied health field degree that ensures a formal college education and management skills. At a minimum, the registrar should have college-level courses in anatomy and physiology, medical terminology, and disease pathology (to understand what is cancer related), and be acquainted with the ICD-O-3 and ICD-9-CM coding systems. Registrars must also know Windows-based computer systems and their own special cancer database software.

Registrars must think analytically, be curious, pay attention to detail, and enjoy continuous learning. Other vital skills include having the ability to do calculations, manipulate and interpret numbers, develop forms, and organize well. Registrars must also be able to see trends, analyze, and problem-solve, and have good people skills so they can work as part of a team and interact with other members of the cancer center staff. Success requires skill at multitasking, organization, discretion, and communication—all crucial to higher levels of responsibility.

The number of staff members your registry needs will depend on the volume of cases and the number of responsibilities. Each registry must define its own needs and make its own staffing decisions. Staffing surveys and manuals cannot determine exactly how many and what kind of personnel are needed for a particular registry, but the National Cancer Registrars Association's textbook *Cancer Registry Management: Principles and Practice* is a good source of information.

Registrar positions vary widely, and administration must recognize that each position may require different skills, although all may be categorized as CTRs. The registrar holding the title of supervisor/coordinator handles staff problems, formulates procedures, conducts in-service education in both general and problem areas, and evaluates job performance. An abstractor documents new cases and follows the case by documenting the patient's subsequent hospital history. Clerical staff may be used for follow-up functions and to process nonmedical information. ❧

---

the future. What's more, this data can be used in the annual report and to market screening and prevention programs, public education, and cancer center activities that promote community awareness.

An important registry responsibility is data collection and analysis for the two COC-initiated PCE studies. Registrars can contribute to the national data collection for the PCE studies, or they may design their own studies by processing, maintaining, compiling, and reporting data to assess diagnosis, treatment, survival, and the need for specific patient services.

The COC requires two improvement projects per year. The registrar ensures that goals and specific performance improvement projects are chosen according to a written plan that is submitted to the COC. In addition, registrars perform data retrieval and analysis, prepare graphic presentations, assist with physician review, and document the improvement results annually, as well as help with follow-up studies to ensure improvement is maintained.

Throughout the year, registries take requests for data from various departments.

Clearly, unless data are used, data collection is a wasted effort.

HELPING THE HOSPITAL AND THE CANCER PROGRAM

Registrars help coordinate the hospital's Cancer Committee by ensuring the implementation of COC standards, tracking compliance, preparing the reports and statistical information the committee needs, and doing projects per committee request.

The registrar assists Quality Management on Joint Commission on Accreditation of Healthcare Organizations (JCAHO) improvement projects dealing with cancer, and provides the hospital's Quality Council with the data

for reports on the latest efforts to improve cancer services.

Registrars also help coordinate cancer conferences (tumor boards) by handling requests for case presentations; preparing meeting agendas; notifying pathology, radiology, and appropriate physicians; compiling pertinent registry data for presentation; and documenting the conferences themselves. The multidisciplinary cancer conferences are prospective. A prospective cancer conference enables decision making about the planned course of treatment for a patient, especially when more than one mode of treatment is an option or when more than one mode of treatment would be the best approach. Retrospective conferences, a discourse on what has already happened, are discouraged by COC standards as they do not affect treatment decisions, and should only be used as a teaching tool in unusual cases.

Finally, the registry provides data to hospital administrators to help them assess needs for and market screening/prevention programs. The registry assists in the development of the data collection and report forms and, most importantly, provides a comparison of data before and after screening/prevention programs to aid in project evaluation.

Most registrars and their staff are very committed to their jobs and take great pride in their registries. They are essential members of the cancer care team and often are unsung heroes. Understanding what registrars do and the data the cancer registry can provide will help you fully utilize the resources of this valuable part of your organization. ❧

Donna M. Gress, R.H.I.T., C.T.R., is coordinator of the cancer registry at South Coast Medical Center in Laguna Beach, Calif. She has been a cancer registrar for more than 20 years.