Cancer Registries: Opportunities and Responsibilities

For many years, cancer registries have been recognized instruments for the promotion of continuous care of patients, the evaluation of diagnostic and treatment practices, the assessment of end results, and the description of the nature and magnitude of the cancer problem in defined population groups. Since 1956, cancer registries have been an integral part of the American College of Surgeons' effort to improve the quality of care of patients with cancer through hospital-based cancer programs. Connecticut has maintained a statewide cancer registry since 1941 and collected data on cases diagnosed since 1935. Since 1956, the National Cancer Institute has sponsored a collaborative program that brings together data from cancer registries in various parts of the United States. Currently, the program, which is known by the acronym SEER, includes 11 population-based registries with a combined total of 23 million people.

The centralized registries have provided a description of important changes in the cancer picture in the United States during the past 3 decades. The incidence of cancers of the stomach and invasive cancers of the uterine cervix has decreased sharply. The incidence of cancers of the lung, colon, breast, prostate, urinary bladder, and pancreas has increased (1, 2). For several organ sites [breast, uterus (both cervix and corpus), prostate, and bladder], available data (3) point to an increase in the proportion of cancers classified as localized when diagnosed and first treated. With the introduction of antibiotics and development of more effective supportive techniques, the proportion of cancer patients treated by surgical resection increased markedly during the late 1940's and 1950's, particularly in the treatment of cancers of the buccal cavity, digestive tract, larynx, and urinary system (4). The 1960's were marked by increased use of chemotherapy in the treatment of cancers of the lung, breast, uterus corpus, ovary, prostate, and thyroid, and melanoma of the skin, as well as in the treatment of the leukemias and lymphomas (4).

The changes mentioned above were accompanied by encouraging improvement in patient survival rates. Marked increases in survival rates among patients with almost all forms of cancer occurred between the 1940's and 1950's. During the 1960's, improvement in patient survival was less dramatic, but survival rates did increase for forms of cancer that account for more than 40 percent of all malignant neoplasms. Early returns on patients treated during 1970 and 1971 indicate continuing improvement in survival rates for half of all cancers (5).

Much of the information made available through continuing, centralized cancer registry programs can be and has been obtained via surveys (6, 7). Continuing reporting systems, however, have several advantages: 1) They provide a mechanism for monitoring patient follow-up and collection of information on therapeutic end results, 2) they facilitate investigation of questions and issues uncovered by routinely collected data through the availability of an experienced technical staff with established working relationships in the community, 3) they provide an information system for continuing review of the impact of cancer control programs and the medical care provided to cancer patients, and 4) they make available current information for use in professional and public education programs.

For individual patients, the information collected by hospital registries and centralized registry systems is fundamentally the same. Although specific reporting mechanisms vary, centralized registries essentially are coordinated networks of individual hospital registries. However, when the data pertaining to an individual hospital are interpreted, the following should be considered: 1) Except for a few large specialty centers, the number of patients with a particular form of cancer seen during 1 year, or even 5 years, is small, and observed figures are subject to considerable chance variation; 2) the patients seen in an individual hospital may be drawn largely from a particular segment of the population, and factors not directly related to the disease and the care received in the hospital may influence therapeutic end results; 3) the routinely available data are generally more useful for the formulation of questions to be investigated than for the provision of clean-cut information. This third point is equally applicable to data routinely collected by centralized registry systems.

Medical procedures, both diagnostic and therapeutic, have become more sophisticated and complex during the past 2 or 3 decades. Cancer registries have both an opportunity and an obligation to gear up to provide information relevant to current medical practice. For example, the percentage of cases with microscopically confirmed diagnoses is no longer a useful index of the

**ABBREVIATION USED:** SEER=Surveillance, Epidemiology, and End Results.

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**Editor's note:** Periodically, the Journal publishes solicited guest editorials as a means of transmitting to investigators in cancer research the essence of current work in a special field of study. The Board of Editors welcomes suggestions for future editorials that succinctly summarize current work toward a clearly defined hypothesis regarding the causes or cure of cancer.
quality of diagnostic practice, inasmuch as 90% of cancers are now microscopically confirmed (6). Similarly, information on the percentage of surgically resected breast cancers is of limited interest when 90% of all breast cancers are so treated, the extent of the resection is becoming increasingly varied, and the use of adjuvant therapy is becoming more frequent (8).

Since January 1976, the criteria for approval of a hospital cancer program promulgated by the American College of Surgeons include “a system for quality-of-care evaluation with documentation of its operation.” The NCI-sponsored SEER program provides a model for the collection of descriptive information that is sufficiently detailed for assessment of the quality of medical practice in the care of cancer patients. For example, a site-specific code has been developed for recording pretreatment diagnostic procedures and pretreatment assessment of the extent of disease spread. Thus treatment practice can be assessed in the light of information available before treatment is initiated. Meaningful case review requires examination of the full patient record, but a properly organized cancer registry can be an important instrument in selecting cases for review.

Cancer registries have raised the level of awareness of the medical profession regarding the importance of evaluating the care given to cancer patients. The data produced in past years by both individual hospital and centralized registries have been useful, but have tended to be “crude” (i.e., lacking in detail). Registries can more fully contribute to the continuing improvement of the quality of care given to cancer patients by collecting information in sufficient detail to facilitate review of diagnostic and treatment practice while they continue to promote patient follow-up and provide information on end results.

REFERENCES