Emerging Roles for Cancer Registries in Cancer Control

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Cancer registries are a vital part of the national cancer effort to cut United States cancer mortality rates in half by the year 2000. Registries provide the data to focus programs and monitor progress. Success in meeting the year 2000 goal will require aggressive attention to the opportunities for prevention, early detection, treatment, and applied cancer control research, all of which complement the current emphasis on basic research.

"The cancer registry is an essential part of any rational programme of cancer control benefitting both the individual and the society in which he lives."

—C.S. Muir
1984 [1]

The National Cancer Institute recently set a goal: to cut cancer mortality rates in half by the year 2000 [2]. How do we do this—how, using current knowledge, do we reduce the morbidity and mortality due to cancer? To achieve this goal requires the aggressive and widespread application of state-of-the-art methods for cancer prevention, early detection, and treatment. It requires the use of cancer registries to focus programs and monitor progress. And it requires that health scientists and health practitioners work as hard in applying current knowledge for our entire population—including research on applications—as they do on uncovering new knowledge and treating individual patients.

Thus, the National Cancer Institute (NCI) is currently expanding and accelerating the application of its research and the development of its resources. An essential component of the national cancer control effort is a comprehensive information base. This information base or, as we term it, cancer control surveillance system, incorporates data components within NCI and elsewhere within the federal government, as well as in state and local governments and the health care industry. As this system comes into full operation, it will be used to track and evaluate national cancer control efforts and to help give overall guidance to NCI’s cancer control program. The program is hierarchically structured, with activities being carried out at national, regional, and local levels; however, in order to achieve the year 2000 goal, efforts at all levels must be coordinated and implemented cooperatively. Providing the appropriate information is the goal of the cancer control surveillance system.

The most important element within the cancer control surveillance system is the network of cancer registries—hospital, local, regional, national—which has been
developed across the United States, in part supported by NCI. Population-based cancer registries, i.e., those which register information on every newly diagnosed cancer in a defined geographic area during a specified time period, have been responsible for tracking cancer incidence and mortality. All cancer registries—whether or not population-based—that follow patients from diagnosis through death are useful in establishing survival patterns and for helping to profile cancer screening and treatment practices. However, a challenge now before the experienced cancer registries is to analyze and transmit more effectively the information being collected. Such information should be disseminated to those who can make changes in the cancer control system: public health professionals and policy makers, health care professionals, and the general public. Another challenge is to assist emerging registries with methodology and technology to improve the quality of the information.

This paper addresses the emerging role of cancer registries in cancer control, describing only a small portion of their potential. Our particular focus is NCI’s nationwide cancer registry system, the Surveillance, Epidemiology and End Results (SEER) Program, its growth, its uses, and its relationship to the new cancer control surveillance system and to the year 2000 objectives.

THE HISTORY

The SEER Program is actually a product of two earlier NCI programs: a series of three National Cancer Surveys and the End Results Program. The National Cancer Surveys conducted in 1937–39, 1947–48, and 1969–71 gave the first profiles of cancer incidence in selected areas of the United States [3,4,5]. The End Results Program was conducted continuously from 1950 through 1973. At the conclusion of these programs it was decided by NCI staff, on the advice of experts from across the United States and Europe, to develop an ongoing cancer registry system that would provide a national profile of cancer incidence and survival.

Participants in the SEER Program have been selected on the basis of their ability to operate and maintain a population-based cancer reporting system and for the unique population subgroups that each of them offers. From eight participants in 1973, the program has grown to eleven today. Although SEER areas are not randomly selected, analysis of cancer mortality data from SEER shows a remarkable similarity to national data. The NCI believes that the cancer experience of the composite SEER population reflects that of the nation as a whole.

The traditional goals of the SEER Program have been to: (1) determine cancer incidence levels in the United States and selected geographic areas and monitor their trends; (2) determine the cancer survival experience of patients diagnosed in selected geographic areas and monitor their trends with respect to the form of cancer, extent of disease, therapy, and other parameters of prognostic importance (i.e., demographic and socioeconomic characteristics); (3) identify cancer etiologic factors by conducting special studies which disclose population groups at high or low cancer risks; (4) identify factors related to patient survival through special studies of referral patterns, diagnostic procedures, treatment methods, and other aspects of medical care; and (5) promote specialty training in epidemiology, biostatistics, and tumor registry methodology, operation, and management.

The network of SEER registries has helped to illuminate differences in the reporting of cancer experience of different population groups. For example, mainly from SEER data, we know that in the United States black males have a higher risk of developing
cancer than do white males, particularly cancers of the lung and prostate gland, while black females have a slightly lower risk than white females [6]. Furthermore, for almost every cancer site, black patients have a poorer survival experience than do white patients, even when considering stage of disease at the time of diagnosis [7]. In addition, the continuous monitoring of cancer by the SEER Program has enabled us to determine, early, that the incidence of lung cancer among males is beginning to be reversed, the age-adjusted incidence of lung cancer among white males having declined from 82.7 per 100,000 in 1982 to 79.3 in 1983 [8].

Incidence or death registration information often has been used to uncover etiologic leads. To take just one of many examples, leads about diet in the etiology of breast cancer have been suggested by international correlations [9], migrating population studies [10], and time trend analyses [11]. Extensions of these observational analyses to include field studies containing epidemiological, laboratory, and clinical measurement may add strength to the evidence. Such an extension would be particularly relevant in the above example, since the imprecision of dietary assessment methods [12] limits the usefulness of the usual case-control epidemiologic studies. Thus, in some instances, scientists using registries may have the opportunity to take advantage of the wider differences found in diet across populations than the more limited differences often found within populations.

These uses of SEER registry data have been important in cancer control, yet SEER and non-SEER cancer registries can do more to provide a planning and evaluation base for cancer control activities. This potential is one of the major reasons for NCI's efforts to develop a cancer control surveillance system. Furthermore, the attitude of the registry staff is important in utilizing the registry as a surveillance system: an attitude that a crucial part of their responsibility is research into public health applications of the data as well as the provision of leadership in the implementation of those applications. Particularly in respect to etiology and prevention, investigators in the past have been satisfied with bringing their work only to the point of publishing a manuscript on etiology. Now enough is known that there are some opportunities to go further, to follow through with applied research and prevention. It should be no more acceptable in prevention to drop the work after uncovering an etiologic lead than it is in treatment, after making the diagnosis, to walk away from the patient thinking that the problem has been taken care of.

THE CANCER CONTROL SURVEILLANCE SYSTEM

In addition to specific cancer registries, the United States has a wealth of information resources that can be used to help control cancer. In the past these resources were rarely used for cancer control purposes and, thus, they did not provide information to the cancer control system where it was needed. The new emphasis on cancer control and the setting of a national goal to reduce mortality by 50 percent by the year 2000 requires the full use of existing resources and the development of new resources. A key component of this initiative is the more complete use of data sources in a systematic way. These data resources in the aggregate are referred to as the National Cancer Control Surveillance System. Further planning for this system, including the use of available data in non-SEER areas, is under way.

NCI is currently in the process of integrating the various pieces of this system. As a first step, NCI has brought the SEER Program administratively closer to cancer control program planning and activities. Following a recent reorganization of the
cancer control effort at NCI, SEER was moved to the Division of Cancer Prevention and Control. While not lessening the important role for SEER in studies of etiology, this change has placed the program that provides the primary measures of cancer control progress as close as possible to the NCI staff who are primarily involved in cancer control. Thus, as with any registry, SEER is part of a program. We think that any registry—hospital, local, regional, or national—must devote at least as much resources, time, and talent to its use for research and control purposes as it does to data acquisition, computerization, and publication of annual reports. Otherwise, it is doubtful that the registry investment is being optimally used.

Plans are under way at NCI to make use of other tracking resources, including population-based cancer registries and hospital-based cancer registries outside SEER. Outside NCI a number of data systems exist that can be used to produce the indicators needed—for example, those of the National Center for Health Statistics (NCHS). NCHS currently has two data systems which can be used to monitor cancer mortality. Each year data tapes are available from NCHS on all deaths in the United States. These are used to monitor trends in mortality from specific cancers over time and thus form the core for monitoring progress toward achieving the year 2000 goal. In addition, NCHS has established the National Death Index (NDI), which allows researchers to determine through a centralized system of records whether a given person has died [13]. The NDI is particularly useful for following large groups of persons to determine their survival.

The role of the surveillance system is to track cancer and to evaluate the impact of cancer control activities (prevention, screening, and treatment). Clearly, the scope of the surveillance system depends on the "lens" used to view the system. At the NCI, we are charged with viewing the system with a "wide angle lens," necessarily taking a broad view of the cancer system. As geographic areas become smaller, the persons, groups, and agencies responsible for cancer control must necessarily use a lens with a narrower field of view. Thus, the surveillance system is, in fact, a nested set of systems ranging from the system used to monitor cancer at the hospital or clinic level to that at the regional and national level.

Local registries have an important role to play within the cancer control surveillance system. Their data can serve as the basis for local planning efforts. In addition, they can relate to SEER by sharing information and comparison of local data to the national picture. An example will show the importance of state or local cancer control programs to follow through on leads from cancer surveillance. Recently, the Saturday Evening Post conducted a survey on cancer prevention [14]. In spite of the strong evidence on efficacy of breast cancer screening by mammography plus physician examination, only 15 percent of women over 50 are receiving annual mammograms. Most surprising is that 65 percent said their physicians have never recommended the exams! This certainly suggests a physician education need and perhaps a need to reorder reimbursement incentives.

FUTURE PLANS

Despite limited financial resources, NCI is planning efforts to work with registries across the country to contrast and compare their information as well as their data-gathering procedures and quality control methods with those of the SEER Program. By fostering such comparisons in cooperative ventures, the quality of the information on cancer surveillance throughout the United States will be improved. A
method now being explored is to establish a professional association of cancer registries in the United States under whose mandate the above activities would take place. All population-based registries would be eligible to become a part of this association and to submit data on a periodic basis for inclusion in a monograph detailing cancer incidence in the United States.

Information is only useful if it is applied. Cancer registry information can be useful in cancer control planning. For example, the information in a cancer registry and allied information from other sources can be used to outline resources available in caring for cancer patients. Moreover, using the registry as a planning base, the future need for resources can also be estimated. Still another use of registry data related to cancer control planning is assessing the need for and the extent of screening programs. This might be done through the stage distribution of, for example, breast cancer, which could be compared with information reflecting a national perspective or from the clinical trials, reflecting the state of the art. If too many of the cases are found to be detected in the late stage of the disease, the fact would indicate that the screening programs are not functioning effectively. In addition, the information in the registry might be useful to tumor boards as they assess the quality of cancer care treatment.

In future data collection activities, registries need to be mindful of the changing health care system and will need to adapt their procedures accordingly where changes in delivery are anticipated. For example, the advent of Disease Related Groups will mean that certain types of cancer are not treated in hospitals, and it is possible that central pathology laboratories will not be involved in the diagnosis. This might be especially true for the diagnosis and treatment of melanomas. Recent data from the SEER Program indicate that the incidence of melanoma is decreasing [15]. This may in fact be due to the detection of fewer cases by the registry because of changes in the way in which the disease is diagnosed and treated.

Thus, one of the most important roles for the NCI in cancer surveillance is in the assurance of quality data in terms of both accuracy and completeness. Certainly, the information in the SEER Program must be of the highest quality, and the methods used to assure that quality should serve as a model for other registries. The NCI is now considering ways in which the surveillance methods, as practiced by NCI, can be made as widely available as possible to others.

In conclusion, we at NCI would be very pleased to receive suggestions as to the form and substance of cancer control surveillance and are committed to work toward making the nation's cancer control surveillance system as effective a tool as possible.

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REFERENCES

1. Muir CS: The cancer registry in cancer control—a review. Arch Geschwulstforsch 54:491–498, 1984
2. Greenwald PG, Sondik EJ (ed): Cancer Control Objectives for the Nation: 1985–2000. Nati Cancer Inst Monogr, in press
3. Dorn HF: Illness from cancer in the United States. Publ Health Rep 59:33–48, 65–77, 97–115, 1944
4. Dorn HF, Cutler SJ: Morbidity from cancer in the United States. U.S. Department of Health, Education, and Welfare, Publ Health Serv Monogr No. 56. Washington, DC: U.S. Government Printing Office, 1959
5. Cutler SJ, Young JL Jr (ed): Third National Cancer Survey: Incidence data. Natl Cancer Inst Monogr 41:1–454, 1975
6. Young JL Jr, Percy CL, Asire AJ (ed): Surveillance, Epidemiology and End Results Program, Incidence and Mortality Data, 1973–77. Department of Health and Human Services. Natl Cancer Inst Monogr 57:1–1082, 1981
7. Young JL Jr, Ries LG, Pollack ES: Cancer patient survival among ethnic groups in the United States, 1973–79. J Nat Cancer Inst 73:341–352, 1984
8. Horm JW, Kessler LG: Falling rates of lung cancer in men in the United States. Lancet i 425–426, 1986
9. Carroll KK, Khor HT: Dietary fat in relation to tumorigenesis. Prog Biochem Pharmacol 10:308–353, 1975
10. Staszewski J, Haenszel W: Cancer mortality among the Polish-born in the United States. J Nat Cancer Inst 35:291–297, 1965
11. Hirayama T: Epidemiology of breast cancer with special reference to the role of diet. Preventive Medicine 7:173–195, 1978
12. Block G: A review of validations of dietary assessment methods. Am J Epidemiol 115:492–505, 1982
13. Patterson BH, Bilgrad R: Use of the National Death Index in Cancer Studies. Submitted for publication
14. Maibach E, Gigliotti L, Block G: Report on the Post’s Cancer Prevention Survey. The Saturday Evening Post 258(2):66–67, 112, 1986
15. Sondik EJ, Young JL, Horm JW, Ries LA: 1985 Annual Cancer Statistics Review. U.S. Department of Health and Human Services, Publ Health Serv, Natl Inst Health, National Cancer Institute, NIH Publication No. 86-2789. Bethesda, MD, 1986