Chapter 13. The hospital-based cancer registry

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Introduction

The purposes of a hospital-based cancer registry are by definition different from those of a population-based registry. The uses of the latter in research and planning have been described in Chapter 3. The purpose of the hospital-based registry is to serve the needs of the hospital administration, the hospital's cancer programme, and above all, the individual patient. The establishment of individual hospital cancer registries is historically rooted in the belief that individual patients are better served through the presence of a registry, since the registry will serve to ensure that patients return for follow-up examinations on a regular basis. In fact, in some hospital registries throughout the world it is the responsibility of the tumour registrar to schedule follow-up appointments.

As stated above, the orientation of a hospital registry is towards administrative and patient purposes. Thus, some of the data items collected by hospital registries will be different from those collected by a population-based registry. Conversely, because many hospital registries also submit their data to a central population-based registry, the hospital registry often has to include data items which are needed by the central registry, but have no utility for the hospital registry. Each of these situations will be discussed in detail below.

Within the hospital, a registry is often considered to be an integral part of the hospital's cancer programme or cancer care/health delivery system. In the United States of America, for example, the American College of Surgeons has an active accreditation process whereby it approves the cancer programmes of individual acute care hospitals. Over 1200 hospitals within the USA have obtained such approval. The College requires that any approved programme should have four major components: a hospital cancer committee; regularly scheduled cancer conferences; patient care evaluation studies; and a cancer registry.

Within this framework, the cancer registry serves the other three programmes through active participation in their various functions and is directly responsible to the cancer committee. This committee must be a standing committee within the hospital and multidisciplinary in composition, and must have clearly delineated duties and responsibilities. Thus, the hospital registry is organized to assist the cancer committee in carrying out its duties and responsibilities, which range from organizing, producing, conducting and evaluating regular educational conferences, to

patient care evaluation studies, determining the need for cancer prevention programmes, and providing consultative services directly to patients.

One of the functions of a hospital registry is to produce an annual report to the hospital administration on the cancer activities that have taken place during the year and to document things such as the cancer burden borne by the hospital. The American College requires its approved programmes to compare the data from their individual hospitals with national data, so that the college can obtain an idea of how the experience of any hospital compares to that of the general population. One consideration in preparing such a report is exactly which cases should be included. Should it include all patients with a diagnosis of cancer seen at any time during the year? Should patients seen for consultation only be included? Should patients who have been previously diagnosed and/or treated in another hospital be included? This consideration has given rise to the concept of 'class of case' which is one of those data items which is of great importance to a hospital registry, but has no meaning for a population-based registry unless it undertakes population-based follow-up of all patients, in which case the 'class of case' can be used to indicate those patients an individual hospital is responsible for following. The generally accepted definitions of the six classes of case are:

(1) Diagnosed at this hospital since the reference (starting) date of the hospital registry and all of the first course of therapy given elsewhere

(2) Diagnosed and treated at this hospital (Note: if the patient is considered to be not treatable, he or she is still included in this category)

(3) Diagnosed elsewhere but received all or part of the first course of therapy at this hospital

(4) Diagnosed and all of the first course of therapy received elsewhere (this would include patients admitted for only supportive care)

(5) Diagnosed and treated at this hospital before the reference (starting) date of the hospital registry

(6) Diagnosed only at autopsy

Cases included in categories 1, 2 and 3 are generally referred to as analytical cases and all such cases are included in the hospital's annual report in tabulations that attempt to assess how well the hospital is doing in terms of caring for cancer patients. Cases included in categories 4–6 are considered to be non-analytical cases and are specifically excluded from most tabulations, especially patient survival calculations, but may be included in tabulations which attempt to assess the cancer burden of the hospital, how many patients were served during the year etc.

It should be noted that categories 1–6 are not exhaustive, implying that some cancer patients are not included in the registry at all. Among these are patients seen only in consultation to confirm a diagnosis or a treatment plan, patients who receive transient care to avoid interrupting a course of therapy initiated elsewhere, for example while on vacation or because of equipment failure at the original hospital, and patients with a past history of cancer who currently have no evidence of the disease.

Some hospitals may also wish to include neoplasms of uncertain behaviour,

benign lesions, especially benign brain tumours, and/or precancerous conditions. It is recommended that all lesions with a behaviour code of /2 or /3 in the International Classification of Diseases for Oncology (WHO, 1976b) (ICD-O) be included in a hospital registry. The exception to this rule would be the registering of basal-cell and squamous-cell carcinomas of the skin and *in situ* carcinomas of the uterine cervix. Many hospitals have found that the registering of these cases is prohibitively time-consuming and expensive, and have opted to exclude them from the registration process. The recommendation of the American College of Surgeons (ACSCC, 1986) is that localized basal-cell and squamous-cell skin tumours be excluded, but that those with regional spread at the time of diagnosis be included. It is further recommended that cases of *in situ* carcinoma of the uterine cervix be entered into a patient index file, but that such cases need not be fully abstracted into the data-base.

Traditionally, most hospital-based registries have been manual operations with completed case abstracts being filed in a certain year–site sequence following completion. However, more and more individual hospital registries are now being computerized which requires that data not only be abstracted but that they be coded and that key data are also entered. Most of the operations of manual and computerized registries are described in Chapter 8, and the discussion below concentrates on those aspects more important to hospital-based registries.

Case-finding

Within the confines of a hospital there are many places where a cancer diagnosis may be made and documented. It is necessary, therefore, to identify each of those sources and to arrange access to the appropriate records. This is complicated in many countries by the question of the ownership of the various record systems and who may or may not have access to them. Clearly, however, it is the responsibility of each hospital registrar to identify all such systems within the institution and to arrange access to them. Careful consideration should be given to such issues as:

- Are haematology and cytology records kept in separate departments or are all such records kept in the pathology records?
- Where are autopsy reports kept?
- Are outpatient records to be screened for cases never admitted on an inpatient basis?

In most hospitals, the two main sources for case identification will be pathology logs and the medical records department disease index. In many instances, the disease index will be coded and computerized so that listing of cases with cancer codes can be utilized. For cases not microscopically confirmed, a decision must be made as to which clinically diagnosed cases will be included when non-specific terms such as 'probable,' 'possible,' 'consistent with' etc. are a part of the final diagnosis. The following is a list of such terms which conventionally are used to determine whether a case is included or excluded in a registry:

- the ambiguous terms 'probable,' 'suspect,' 'suspicious,' 'compatible with,' or 'consistent with' are interpreted as involvement by tumour;

– the ambiguous terms 'questionable, 'possible,' 'suggests,' 'equivocal,' 'approaching,' or 'very close to' are not interpreted as involvement by tumour.

The registration process

The actual processes of registration in a hospital registry differ little from the principles described in Chapter 8. If physical files are maintained, they will comprise the accession register, patient index file and tumour record file. When the registry is computerized, access to the data-base can, of course, be by registration number, patient name, tumour site etc.

Once a case of a registrable tumour has been identified, information about the patient and his or her tumour is abstracted from the medical record, either via a predesigned form, or directly into a computer without the intermediate step of a paper abstract. Considerations of coding and medium conversion, as described in Chapter 8, are relevant here. Since most hospital registries will be recording information on relatively few cases (compared with population-based registries), it is recommended that text as well as codes be entered into the computer so that there will be some documentation of the encoded information. Since most desk-top computers do not have adequate storage space to maintain large blocks of text, the text, once entered, can be printed as a paper document/abstract and maintained in a manual file and the text portion of the computerized record erased thereafter. The text documentation of items such as primary site, histology, and extent of disease is essential for quality control purposes and for the maintenance of more detailed information for future studies. As an example of the latter, a patient may be maintained on the computerized data-base with an ICD-O site code of T-173.6, skin of the arm and shoulder, but the textual back-up will denote whether the lesion is located on the hand, palm, wrist, forearm, elbow etc.

Another reason for maintaining a textual abstract of the medical record is that the hospital medical record is often not available when special studies utilizing cancer patient records are done. It may be in use elsewhere if the patient has been readmitted for some reason, or in dead storage if the patient has died, or have been destroyed if the patient has been dead for a certain length of time. Thus, an abstract of the pertinent information maintained within the hospital registry is essential.

Items included in the abstract will be determined by the hospital and its cancer committee. However, at a minimum there should be space provided to record pertinent details for the physical examination and history, diagnostic tests and laboratory procedures, pathology report and operative report. Details of treatment should be recorded at the level specified by the hospital, but, at a minimum, should allow the determination of whether the patient had surgery, radiotherapy, chemo/hormonotherapy, immunotherapy, or any other approved form of therapy. With regard to chemotherapy, specific drugs should be recorded for quality control purposes, since sometimes drugs are given only to relieve symptoms (e.g., prednisone is given as an anti-inflammatory agent rather than for curative reasons).

Once the abstract has been completed and verified, it is filed for future use. Of course, registries which are computerized will enter the abstract before filing. As mentioned above, the registry may elect to maintain all records electronically,

although computer storage limitations may make such a plan impossible. The American College of Surgeons (ACSCC, 1986) recommends that abstracts be filed by site and year of diagnosis, alphabetically by patient name. This makes abstracts readily available for statistical review by site. In hospitals with large case-loads, abstracts of deceased patients are often filed separately or are maintained on microfilm or microfiche.

In many large hospitals, the medical record may not be available for abstracting for some time following the discharge of the patient from the hospital. It is recommended that all abstracts should be completed within six months of the discharge of the patient from the hospital whenever possible. It is also recommended that abstracting should not take place too soon after discharge, since some of the necessary information may not yet have been included in the patient's record. Often, laboratory reports, operative reports and pathology reports will not be available immediately upon discharge.

Since accuracy and consistency are of prime importance, a regular quality control programme should be in place which includes re-abstracting and, if computerized, recoding a sample of records. Continued training and retraining of hospital registrars is an essential part of the quality control programme.

Data items

As previously mentioned, because the hospital registry serves both an administrative and a patient function, it will include items that will be of no interest to a population-based registry, whose prime function is often to measure the incidence of cancer in a given population. Items of interest to population-based registries have been discussed in Chapter 6 and will not be repeated in detail here.

The following data items which are of importance to hospital registries were either not discussed earlier or their importance to the population-based registry is rather slight:

- Name of spouse, friend, guardian
- Telephone number
- Department of hospital
- Hospital record number
- Date of admission
- Date of discharge
- Hospital referred from
- Hospital referred to
- Primary physician
- Other physicians
- Class of case (definitions given above)
- Diagnostic procedures
- Extent of disease (TNM classification; size of tumour; number of nodes examined; number of nodes positive; summary stage)
- Date of first course of treatment

- First course of treatment:
  Surgery, including type and extent
  Radiation, radiation sequence
  Chemotherapy
  Hormonotherapy
  Immunotherapy
  Other therapy
- Residual tumour, distant site(s)
- Date, type and site of first recurrence
- Date and type of subsequent course(s) of therapy
- Condition at discharge
- Patient status (1) before (2) after first treatment and at anniversaries (quality of life)
- Contact name and address
- Following physician.

For administrative purposes hospital registries may be interested in measuring utilization of facilities. Thus, in addition to measuring hospital bed days (date of admission versus date of discharge), a registry may consider tracking usage of computerized tomography (CT) scanners, biological marker assays, phenotyping, electron microscopy, oestrogen receptivity etc., in order to assist the hospital administration in justifying equipment usage, replacement, upgrading or deletion. Also, by examining patterns of referral (hospital referred from, hospital referred to), the catchment/service area of a given hospital can be more clearly defined. This is useful to hospital administrators in establishing satellite relationships with other hospitals, planning training and continuing education programmes for multiple facilities, and equipment and resource sharing.

Patient follow-up

Since the major focus of the hospital registry is on the continued well-being and care of the patient, additional items of relevance for serving the patient must be included to denote: which physician will be responsible for the patient upon discharge (surgeon, oncologist, or general practitioner); whether the patient has been referred to another hospital, and if so, which; the functional status of the patient at discharge (quality of life) and how that status changes over time, and when the cancer recurred.

Since it will be the responsibility of the hospital registrar to follow the patient, two or three points of contact should be established. The primary point of contact should be through the physician responsible for the patient's care. However, it is not always clear which physician is primarily responsible, and in addition, patients may lose contact with the physician, or the physician may move, retire or die. Therefore, the hospital registrar should attempt to know how to contact the patient directly (current address, telephone) or through the spouse, guardian (in the case of minor children), relative or friend. Depending on the particular tumour type, patients should be contacted at some defined frequency—every six months, annually, etc. However, because of the nature of the disease, and the time and expense involved, it is not recommended that patients with *in situ* carcinoma of the uterine cervix be followed.

At the time of follow-up an attempt should be made to document the patients' disease and functional status, whether any further therapy has been given, and if so, where, and when the patient was last seen by a physician, and which physician. These items are then used to monitor the progression of the patient's disease and to trace the patient at the time of next follow-up.

Various standards have been utilized to measure how successful a registry has been in following cases. The most common method is to include all patients ever registered in calculating a success rate. Thus, to measure the success rate for 1987, for example, all living patients with a date of last contact in 1987 or later would be counted together with all cases known to be dead, and the total would be divided by the number of patients ever registered. This percentage would then represent the successful follow-up rate for that registry. While this method of calculation is a good indication of how good follow-up has been over time, and how accurate survival calculations based on such follow-up might be, for registries with large case-loads and long histories, such a measure may be misleading, since follow-up in the most recent years might be much poorer than in previous years.

This point is best illustrated by an example. A hospital registered 1000 cases per year for 10 years 1978–87, so that a total of 10 000 cases were known to the registry. At the close of 1987, 7000 cases were known to have already died, and 2200 were contacted at some time during 1987. (It should be noted that all 1987 cases by definition were contacted at some time during 1987.) The success rate for this registry would then be 7000 (deaths) + 2200 (1987 contacts)/10 000 cases registered, which is 92%. However, if 6400 of the 7000 deaths had occurred before 1 January 1987, so that of the 9000 cases registered between 1 January 1978 and 31 December 1986, 2600 were thought to still be alive as of 1 January 1987, then the follow-up load for that hospital would then be 2600 previously diagnosed cases to be contacted during 1987. Continuing with the example, of the 2200 cases contacted in 1987, if 1600 were cases diagnosed before 1987 and 600 diagnosed in 1987 and if, of the 600 deaths occurring in 1987, 200 were among persons diagnosed before 1987 and 400 among patients diagnosed in 1987, then the successful follow-up rate of the 2600 cases which the tumour registrar needed to follow during 1987 would actually be 1600 (alive cases contacted in 1987) + 200 (deaths)/2600 to be followed, which is 69.2%. This success rate evaluates how well the registrar's follow-up function was completed during the previous twelve months and is a more accurate assessment of how well and how currently patients are being followed in a given hospital. It is recommended that the follow-up rate be calculated by this second method and that the goal of a hospital registry should be to achieve a success rate of at least 90%.

Reporting of data

It is recommended that every hospital-based cancer registry should report its data annually to the hospital administration and to the hospital's cancer committee. The report should be written and the American College of Surgeons suggest that at least the following should be included:

– a narrative summary of the goals, achievements and activities of the hospital's cancer programme;

- a report of registry activity;
- a statistical summary of registry data for the calendar year, which should include the distribution of primary sites, tables or graphs highlighting the most frequent sites, and data on follow-up activity, and should be accompanied by a brief narrative statement that ties the data to the management of cancer in the hospital;
- a detailed statistical analysis of one or more major sites of cancer, which must include survival data calculated by the life-table or actuarial method, other descriptive statistics presented in appropriate graphic, tabular, or narrative form, and an overall critique of the data by a physician member of the cancer committee.

In addition to the annual report, data from the registry should be utilized at all tumour boards and conferences. In addition, the hospital cancer committee should encourage use of the data by all hospital staff as appropriate. Also, hospital registrars are encouraged to initiate studies independently, pointing out unusual changes from one year to the next and raising questions to the cancer committee about what these changes might mean.

Utilization of data at the hospital level is the only justification for the expense of such an activity. In summary, it is the responsibility of the registrar working in conjunction with the cancer committee to ensure that the procedures of the registry are adequately and accurately documented, that they are followed, that cases are identified and registered in a timely manner, and that information from the medical record is correctly and completely abstracted for registry use, so that data of the highest quality are available for utilization.