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Administrative & Marketing Data from Your Cancer Registry

by April G. Fritz, A.R.T., C. T. R.

Traditionally, the hospital cancer registry has been used by clinicians to evaluate patterns of care and outcomes (recurrence and survival). The registry is often viewed as a necessary cost center if the hospital intends to obtain and maintain cancer program approval from the American College of Surgeons' Commission on Cancer (ACSCOC) and if there are state cancer case reporting regulations to observe. However, with the advent of health care reform, the cost-benefit ratio of every hospital function is being questioned, and many nonrevenue generating services are being curtailed or eliminated.

One way to ensure that the cancer registry survives in this environment is to make it serve a wider variety of data users within the hospital, such as the oncology services administrator. In many instances, the oncology administrator recognizes the value of the registry as a clinician's aid, but does not realize the potential of registry data as an administrative and marketing tool.

The ACSCOC lists three levels of data collection: the core, the recommended, and the extended data sets (*Cancer Program Manual 1991*, pages 12-13). Every approved cancer program must collect the core data set, which includes basic demographic, staging, and treatment information about each cancer initially diagnosed or treated at the hospital. This is primarily clinical data of value to physicians and epidemiologists. The recommended and extended data sets add detail in the demographics and follow-up sections.

Data fields found in nearly every

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registry software program can be used by administrators to monitor a cancer program. The core data set includes class of case; date of diagnosis; diagnostic confirmation; TNM staging; race or ethnic background; and primary site. The extended data set includes hospital referred from and hospital referred to; zip code; city, county, state; and next follow-up method.

CLASS OF CASE

This single data field can be of great value to an administrator who understands its broader application (see Table 1). Originally intended to differentiate analytic from nonanalytic cases for the clinician, the codes for this data field were developed to define various categories of diagnosis and treatment status. The terms *analytic* and *nonanalytic* refer to analysis of cases for outcomes measurement. It is generally accepted that the initial course of therapy offers the best opportunity to cure a cancer. Therefore, a hospital monitors (analyzes) its success rates for patients who are diagnosed and/or receive first course of treatment at that facility. Cases that receive other than first course treatment at the facility are evaluated separately and referred to as nonanalytic cases.

When asking for data from a cancer registry, the oncology administrator should request that the caseload being studied include all cases that pass through the hospital cancer program, not just those newly diagnosed. In other words, the oncology administrator should request data on both analytic and nonanalytic cases.

When trended over five or more years (and combined with knowing whether the annual caseload is increasing, steady, or decreasing), changes in the proportions of these codes will help to provide a unique picture of the cancer patient

population within the hospital.

Consider the following scenarios:

Hospital A (Figure 1, page 19).

Hospital A has an increasing caseload. This cancer center is generally healthy and growing. The number of patients diagnosed and treated at this facility is growing, and the hospital is retaining for treatment the patients it diagnosed, even though the overall proportion of such patients is declining (code 1). Since the opening of the center, the hospital has experienced an increase in the number of patients diagnosed at other facilities who receive first course treatment at the new center (code 2). In addition, the cancer center has been attracting patients from other hospitals who have developed recurrence (code 3).

Hospital B (Figure 2, page 19).

Hospital B has a declining caseload. This cancer program faces potential trouble. There has been a drop of 11 percent in the number of cases seen at the facility over 10 years. The declining caseload could be due to a variety of reasons: decreased employment (factories closing), a shift in preferred provider cases to another facility, or the opening of a new and improved cancer center at a nearby hospital, a freestanding (physician-owned) cancer center, or a new clinic elsewhere. Code 0 shows that a rising proportion of patients are going elsewhere for treatment. In addition, after 1989 there is a decrease in the number of patients coming to the hospital for treatment of recurrence. Whatever the reason (older physicians or facilities, change in patient population, or any other factors), this facility with this type of trend in class of case should take a serious look at the health of its cancer program and decide whether it wants to remain competitive in the local oncology market.

Class of case should always be

evaluated in tandem with caseload because the changes in proportion are relative to the total number of cases. Even a cancer program with a steady caseload should look closely at its long range goals. With the graying of the population, all hospitals should have increasing caseloads simply because there are more people at risk. A steady caseload, as well as a low rate of recurrent cases, suggests that those patients are going somewhere else.

DATE OF DIAGNOSIS

For resource, staffing, services, facilities, and outreach planning, the date of diagnosis can prove useful in documenting whether cancer treatment (and diagnosis) fluctuates on a seasonal basis at a hospital. For example, is there an influx of snowbirds (patients with residences in the North in the summer and in the South in the winter) some time during the calendar year? A sort on month and year of diagnosis may help answer this question with more than just anecdotal information.

DIAGNOSTIC CONFIRMATION

This field, on the surface, applies almost entirely to clinical data. However, the oncology administrator can monitor the proportions of the categories in this field to assess completeness of casefinding. Ideally, the registry would like to have 100 percent of cases microscopically confirmed. However, there may be a number of patients with only clinical (unbiopsied) diagnoses who are treated in outpatient areas. These patients might not be identified by and included in the registry, but may serve as a barometer for future increases in outpatient services. In addition to histologic and cytologic diagnoses, the codes for this field include diagnosis by tumor marker, laboratory test, radiography and imaging, and endoscopic visualization.

TNM STAGING

The Tumor-Node-Metastasis staging system developed by the International Union Against Cancer is being adopted as the standard by

most oncology groups in the United States and overseas. Recording the T, N, and M elements and stage grouping has been required for cancer program approval since 1991 by the Commission on Cancer, and in 1995, the Commission will require that the staging be assigned by the physician. In addition, the Joint Commission on Accreditation of Healthcare Organizations has made TNM staging a part of its indicator monitoring system. An oncology program administrator should know the percentage of patients that are being staged by the TNM system, and whether the physicians are recording the stage in the medical record. If the percentages of either are low, educational sessions are needed.

As important as it is to the clinician, staging information is also valuable to the cancer program administrator, since it is indirect evidence of the success of public education programs. A high percentage of late stage cases for a particular primary site may indicate the need for screening programs or intensified public awareness programs. A trend toward earlier diagnosis (as exemplified by higher proportions of early stage cases) would signal the success of hospital outreach programs.

RACE OR ETHNIC BACKGROUND

This data field may provide information for facilities planning. For example, is there a large ethnic group in the community that would benefit from targeted educational programs or literature written in the language of the group? Are there language barriers within the facility, such as directional signs? Can protocols and consents to other forms of treatment be explained in language that the patient can understand?

PRIMARY SITE

As perhaps the most fundamental of all clinical items in a cancer registry, the primary site field is also useful to an administrator for planning equipment purchases and recruiting additional staff. Distributions and trends of distributions of cases by primary site can show whether special programs are needed (such as women's health or skin clinics). For nonspecialty facilities, it may be useful to compare hospital data to national data to determine if the distribution of cases at the hospital is similar to national norms. If it isn't, it may be worthwhile to investigate any

Table 1. Class of case codes and definitions

| Code | Registry Definition* | Administrator's Interpretation |
|------|---|---|
| 0 | First diagnosed at your hospital and all of first course of therapy elsewhere | Patients we lose due to lack of facilities better programs elsewhere |
| 1 | First diagnosed at your hospital and received all or part of first course of therapy at your hospital | Patients we keep for diagnosis and treatment |
| 2 | First diagnosed elsewhere and received all or part of first course of therapy at your hospital | Patients we attract because of our facilities and services |
| 3 | First diagnosed and all of first course of therapy elsewhere | Patients we attract for treatment of recurrence |
| 4 | First diagnosed or first course of therapy at your hospital prior to reference date | Patients we retain (patients treated at our facility prior to the organization of the cancer program who now have recurrence) |
| 5 | First diagnosed at autopsy | |
| 8 | Identified by death certificate only | (Infrequently used, but a signal of inadequate casefinding) |
| 9 | Unknown | (Infrequently used, but a signal that some quality control investigation is needed in the registry if proportion with "unknown" code exceeds 10 percent of all cases) |

*Cancer Program Manual 1991, American College of Surgeons

primary cancers that are underrepresented. Perhaps recruiting a specialist for that primary cancer will enhance the overall cancer program.

HOSPITAL REFERRED FROM AND HOSPITAL REFERRED TO

According to the definitions in the *Data Acquisition Manual*, these two data fields—hospital referred from and hospital referred to—identify where the patient received previous treatment and where the patient went for additional treatment following a stay at the reporting facility. Sorting on these fields can yield hard data that can be used to track the migration of patients from one facility to another. For example, if the sort shows a small rural hospital as the source of a large number of patients, it might be worth establishing some formal ties with the rural facility, such as an outreach program, visiting oncologists, or regular transportation to the larger cancer program. In addition, if a large number of patients are repeatedly referred to another facility, it may be worth investigating what services that facility provides that could be developed at your hospital.

ZIP CODE

This data field sometimes serves as a surrogate for household income level or socioeconomic status for the purpose of targeting campaigns for donations to the cancer center or advertising to attract patients to the hospital.

CITY, COUNTY, STATE

These three data fields are useful for monitoring service area penetration and the source of patients. For planning purposes, a large concentration of patients at a distance from the hospital might indicate the need for mobile diagnostic services or an outreach clinic or laboratory. Patients coming across a state border may be affected by different third party payers or different rules for financial aid.

NEXT FOLLOW-UP METHOD

Like "hospital referred from and hospital referred to," this data field helps track the migration of patients, not just to other hospitals, but to physicians, patients, and other contacts. If the patients are not returning to the hospital for annual check-ups, who are they seeing? If they are not seeing anyone, should the hospital contact them

Figure 1. Class of case trends: Hospital A

Increasing caseload; cancer center opened 1991

Sample data, Autopsy only and unknown class of case not shown.

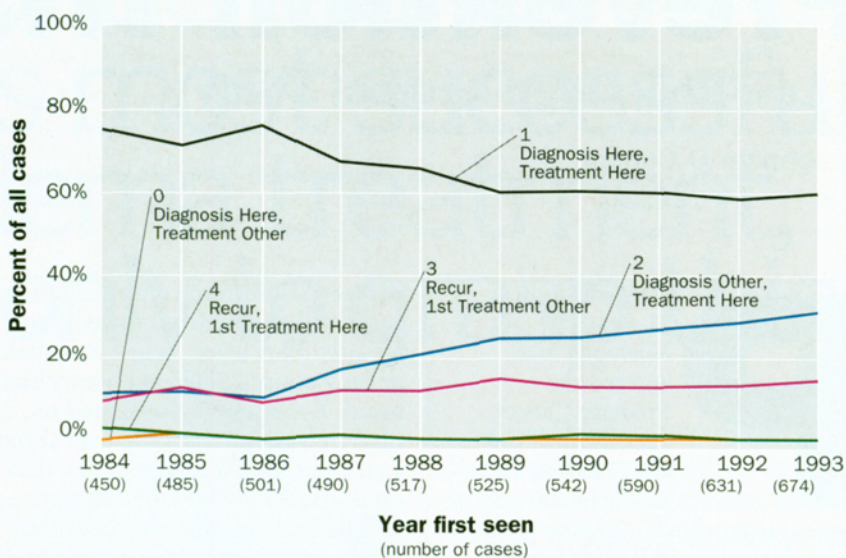
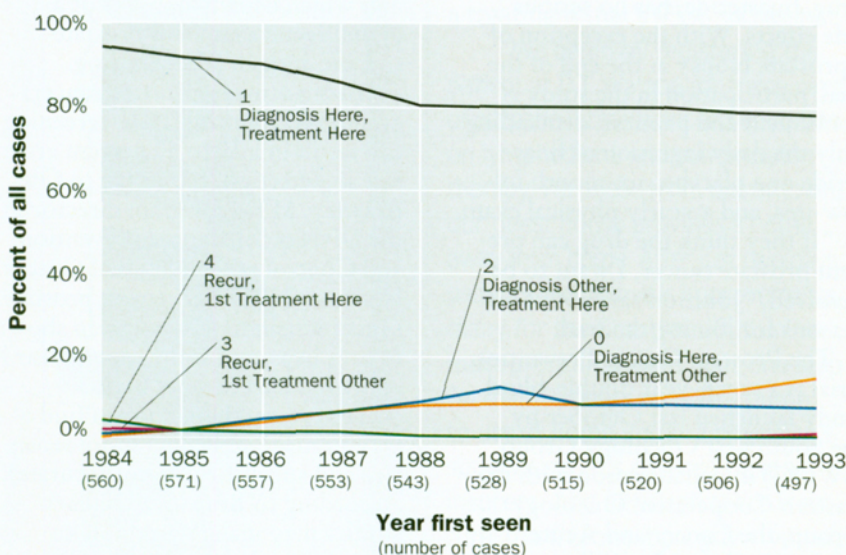


Figure 2. Class of case trends: Hospital B

Decreasing caseload; cancer center open throughout interval

Sample data, Autopsy only and unknown class of case not shown.



and make appointments to bring them in? Remember, it is the obligation of a registry in an approved cancer program to follow patients on a yearly basis.

FINAL THOUGHTS

These are examples of administrative uses for only a few items routinely collected by cancer registries. Most registry software systems also allow for the creation of user-defined fields in which administrators can collect very specific items of interest, such as 1) referrals to medical or radiation oncology, pro-

tol-eligible patients, 2) referrals to hospital services, such as social services, nutrition, and rehabilitation, 3) source of the patient (screening program, advertising campaign), or 4) the individual who staged the case (the attending physician or the registrar).

The cancer registrar in each facility will be able to further explain these and other data fields that have administrative uses. As knowledgeable data users, cancer program administrators can make the registry a powerful tool in oncology management. ■