

SOME USES OF THE CANCER REGISTRY IN CANCER CONTROL

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During the past 30 years institutions called cancer registries have been established in many countries in various parts of the world, and the concept is encountered with increasing frequency in the literature dealing with cancer or health statistics (see Bibliography). The institutions covered by this designation actually differ widely in functions and methodology.

LOCAL HOSPITAL REGISTRY.—At one end of the scale is the local registry serving just one hospital. This type, which is found in an increasing number of cancer hospitals all over the world, has as its essential element a file of all cancer patients seen, and its main functions are to ensure that case records contain sufficiently detailed information on site, type, stage of the disease, and treatment, that cases are correctly classified for statistical purposes, that follow-up is complete, and finally, to prepare from time to time detailed survival statistics covering all cases seen within a specified time. A hospital unit with these functions is not always called a cancer registry but may be described as a Statistics Department, Follow-up Department, or Records Department.

The value of this kind of record-keeping in guiding the activities of the hospital is becoming widely recognized.

The local hospital registry does not, as a rule, contribute much to our knowledge of the epidemiology of cancer. Except in very special circumstances, it is not possible from the registry data to arrive at incidence rates for the various forms of cancer in the surrounding population, nor is it possible from the proportional frequency of the various forms of cancer in the hospital registry to draw any inference regarding the proportional frequency in the population. Changes in the frequency of cancer apparent from the statistics of such a registry may be entirely independent of the trends in cancer incidence in the

surrounding population. For example, it is well known that adding a new department of urology to a hospital previously without such a department will probably lead to an increase in the number of urinary tract cancers seen in the hospital and, likewise, adding a famous thoracic surgeon to the staff will probably attract lung cancer cases that would earlier have gone elsewhere for treatment. The resulting changes in the statistics of the hospital registry are of considerable interest to the hospital administration but are not nearly as interesting to the cancer epidemiologist.

CENTRAL REGISTRY.—A further development in cancer registration is the central registry serving a number of selected hospitals within a region (city, state). It usually has the same functions as the local hospital registry, the main objective being to organize follow-up and produce survival statistics. From the epidemiological point of view this type of central registry suffers from the same deficiencies as the local hospital registry, because the co-operating group of hospitals does not completely cover any definable population. Examples of this development in cancer registration are found in the U.S.A. (California) and in Europe (England and Wales).

In recent years we have seen the beginning of a co-operation between central registries, particularly within the U.S.A., but also between centres in the U.S.A. and in several European countries. Again, the sole purpose has been to study survival in cancer, using a highly standardized statistical procedure. Two main concepts seem to influence this co-operation:

(1) By pooling data from several registries a very large number of cases can be quickly collected, permitting a detailed breakdown into subgroups for analysis.

(2) Material derived from several centres covering a wide area is likely to provide more variety and greater contrasts for study than material from one central registry alone, and it will more often be possible to compare end-results in centres using widely differing methods of treatment. For example, it may be possible to compare end-results in cervical cancer in some centres where radiological treatment is the rule, with results obtained in other centres where treatment is predominantly surgical.

In co-operative studies of this type serious problems of comparability always arise. Lack of comparability may create apparent differences where real differences do not exist and may mask or conceal the differences of real significance.

It should be clearly understood, therefore, that differences found in comparisons of this kind will not make it possible to reach a decision regarding the relative merits of different methods of treatment. The most that can be hoped for is that such an exploratory comparison may serve to emphasize the need for a properly designed study of the problem.

POPULATION-BASED REGISTRY.—By contrast with the other types, all of which deal exclusively with hospital material, the population-based registry attempts to collect as detailed information as possible about all new cases of cancer diagnosed in a population of known size and composition. The classic example is the registry that has been in operation for 25 years in Connecticut, U.S.A., but similar registries covering entire states have since been established, for example, in Finland, Iceland, and in all the Scandinavian countries. European registries covering varying fractions of the national populations have been established in Belgium, England and Wales, France, Germany (Federal Republic), the Netherlands, Yugoslavia, and the U.S.S.R. The essential feature is that they all represent a serious attempt to provide complete cover for a defined population, and to account for every recognized case of cancer in that population, whether in hospital or not, and whether radically treated or not.

This brief description will serve to emphasize that different types of cancer registries differ with regard to the services and information provided. The most important difference lies in their ability to furnish data of epidemiological value. The cost of running the various types of registries also differs considerably. The extra returns obtained from the more complex population-based registry undoubtedly have to be paid for quite heavily in personnel and equipment.

FUNCTIONS OF THE POPULATION-BASED REGISTRY

This kind of registry, if efficiently operated, will furnish a wealth of information on many aspects of the cancer problem in the population. It will show, for example:

- (1) The proportion of patients admitted to hospital.
- (2) The proportion in whom the diagnosis is confirmed by histological examination.
- (3) How many are treated radically.
- (4) What treatment is given.

It will show this not only for the total population but for any important sub-group. Delay in diagnosis and treatment, due either to the patient or to the doctor, and the stage of the disease at which treatment is instituted are among other data that become routinely available.

Information of this kind is indispensable in teaching students and post-graduates, in popular health education, and in the overall planning of cancer services. It is the kind of information that every teaching institution, every health administrator, and every cancer association is happy to get. It also constitutes some of the basic information needed to evaluate any measures taken for improved cancer control.

The most interesting and most difficult task of the population-based registry is the study of the epidemiology of cancer. Registries in the Scandinavian countries were established primarily for this purpose. Such a registry spends much of its total effort in ensuring that every recognized case of cancer in the population is duly registered. The resulting material undoubtedly gives more complete and more precise information on the incidence of the various forms of cancer in the different groups of the population than is otherwise available. One of its main purposes is to discover groups that differ significantly in cancer incidence. Their recognition may suggest hypotheses regarding their cause and regarding the aetiology of the specific forms of cancer involved, and may thus assist the discovery of preventive measures.

A criticism that usually arises is that, although the cancer registry may provide the best information, similar results could perhaps be obtained more quickly and cheaply from other sources such as the official mortality statistics produced by an increasing number of countries. Some of the deficiencies of cancer mortality statistics are well known, however, and need not be detailed here. In areas where both

official mortality data and morbidity data from a cancer registry are available, they generally agree in many respects, and show similar trends, *e.g.* a similar increase in the incidence of lung cancer, and similar urban/rural and sex differences for many forms of cancer. This being so, is the extra precision of the registry data worth the cost and effort? The answer seems to be that, in the absence of cancer registry data, it is difficult to know when and to what extent the official mortality statistics can be relied upon—where both are available it is often observed that the mortality statistics can be misleading, sometimes because they are incorrect and sometimes because they are incomplete.

The difference in precision and detail between current cancer registry data and official mortality statistics is well illustrated by the following examples from Norway—a country in which national mortality statistics have been produced annually for more than 100 years and where the quality of the official statistics is supposed to be relatively high:

(1) Before the introduction of cancer registration in Norway in 1952, the national mortality statistics showed that the mortality from cancer of the *larynx* was approximately twice as high among males as among females. The actual number of deaths from this form of cancer was small, however, so that little attention was paid to the sex differential. When the registry data became available, it became clear that the incidence of this disease among males was not twice but *ten* times as high as among females. Investigation revealed that the deaths ascribed to cancer of the larynx included many cases of cancer of the hypopharynx. Since cancer of the hypopharynx is relatively frequent among females in Norway, the striking sex differential in laryngeal cancer had been masked in the mortality statistics.

(2) According to the Norwegian mortality statistics for the last few years before cancer registration was started, an almost identical number of males and females died from what was stated to be cancer of the liver. With the exception of age distribution no further details about this site could be obtained from the mortality statistics, simply because the death certificates did not contain adequate specific information on the site and type of the tumours. Thus the mortality figures for this site failed to attract attention. The registry data, however, brought out the distribution shown in Table I, which shows an excess number of female cases due to a

strikingly higher frequency of carcinomata of the gall bladder among females. Hepatomata, on the other hand, are clearly more frequent among males than among females. The sex differentials would have been essentially the same had age-adjusted incidence rates been given instead of the actual numbers. The majority of those classified as “Other and Unspecified” intra-hepatic tumours in Table I were reported as cholangiocarcinomata.

TABLE I

NUMBER OF NEW CASES OF PRIMARY MALIGNANT TUMOURS OF THE LIVER IN NORWAY, 1953–58, BY SEX

Site		Sex	
		Male	Female
Extrahepatic	Gall bladder	15	151
	Gall ducts, including the ampulla of Vater ..	66	70
Intrahepatic	Hepatoma	66	36
	Other and unspecified ..	22	17
Total		169	274

(3) Cancer of the thyroid is a rare disease in Norway and very little information about it could be found in the official mortality statistics, as in most tabulations it was grouped with other rare forms of cancer. No single source of hospital data could show its distribution in the population. However, routine analysis of the registry data showed that, among both males and females in the urban and rural populations, the age-adjusted incidence rate was two to three times higher in Northern Norway than in Southern Norway (Table II).

TABLE II

INCIDENCE OF THYROID CANCER PER 100,000 PER YEAR IN SOUTHERN AND NORTHERN NORWAY, 1952–57 AGE-ADJUSTED RATES, BY SEX

Region	Sex			
	Male		Female	
	Urban	Rural	Urban	Rural
Southern Norway	1.1	0.8	2.2	2.6
Northern Norway	3.2	1.6	6.6	5.4
Total	1.2	1.0	2.4	3.1

In both regions the incidence was higher among females. A closer study revealed a consistent increase in incidence towards the north of the country, the peak being found on the Arctic coast (Table III, overleaf).

TABLE III

INCIDENCE OF THYROID CANCER PER 100,000 PER YEAR
IN SOUTHERN AND NORTHERN NORWAY, 1952-57

Counties of Northern Norway shown in geographical order, Finnmark being the northernmost. Rates adjusted for age and urban/rural residence, by sex

Region (County Number)	Sex	
	Male	Female
Southern Norway (1-16)	0.9	2.4
Nord-Trøndelag (17)	1.2	2.9
Nordland (18)	1.7	3.5
Troms (19)	2.0	8.3
Finnmark (20)	3.3	14.6

These examples cited above have been selected because they demonstrate clearly the type of difference in detail and accuracy that is likely to arise between official mortality statistics and those from a population-based cancer registry.

In studies of the epidemiology of cancer it is often difficult or impossible to know whether observed variations in incidence rates are real or whether they are due to differences in diagnosis. Cancer registration does not eliminate this problem, but it enables the investigator to compare the bases of the diagnosis.

SOME USES OF THE CANCER REGISTRY IN EVALUATING CANCER DETECTION PROGRAMMES.—The picture which the cancer registry gives of cancer detection in various sub-groups of the population often indicates that measures should be taken in order to improve it. This is a routine function of the cancer registry and needs no further comment. A much more important and too often neglected problem relates to special cancer detection surveys. Many such surveys of cancer at various sites have recently been carried out. Their value is still a matter for discussion, and many have been based on conjecture and faith together with a strong desire to "do something". Some of the best have been true "pilot" studies, a name indicating that the motive is the desire to find out whether such a project is acceptable and effective, whether it leads to improved control of the disease, and whether it should be introduced on a larger scale—or dropped. There is a real need for the evaluation of such programmes. Apart from financial considerations, the questions one would like to be able to answer after a cancer detection survey include the following:

- (1) How many new cases of cancer were detected as a result of the survey?
- (2) Does that figure indicate that the survey was effective in detecting cases?

- (3) Has the survey been successful in detecting cases earlier than would otherwise have been possible?
- (4) What influence, if any, has the survey had on prognosis (*i.e.* on the total duration and final outcome of the disease in the cases so detected)?

These questions may seem simple, but the cancer detection surveys so far carried out have hardly ever answered them satisfactorily. The following examples will illustrate that, in suitable conditions, a cancer registry can furnish the standards needed for partial evaluation of such surveys:

(a) *Mass Examination*

In 1956 the Norwegian Cancer Society started a mass examination of women for breast cancer. The purpose was partly to study the applicability and effectiveness of mass examinations in this form of cancer, and partly to obtain, by interview, material for a prospective epidemiological study of cancer of the breast and genital organs. Four counties with 130,000 women in the age group 20-69 years were selected, and every effort was made to examine as many women as possible. To begin with, 75 per cent. of all local women were examined in the most co-operative county, and this figure was increased later to nearly 90 per cent. Participation in the other counties ranged from 60 to 70 per cent. Nearly 3 per cent. of all those examined were referred to a specialist and slightly less than 1 per cent. had a biopsy. A detailed personal history was obtained from all attending, and samples of those attending and those not attending were also interviewed in their homes by social workers.

Because the Cancer Registry had been in operation for some time, it was possible, on the basis of the material collected from the four counties during the last 5 years before the survey, to tell how many new cases of breast cancer would "normally" be diagnosed in that population during the survey period. It was found that after the survey had started the number of diagnosed cases far exceeded the expected value (Figure, opposite).

This indicates that the survey was to some extent effective in finding cases, and it is axiomatic that some of these cases must have been detected earlier than would otherwise have been the case. This is supported by a comparison of duration of symptoms, stage of disease, and size of tumours in the cases diagnosed during the survey with the corresponding "expected" values, the latter being the values observed in all the cases from that same area during the

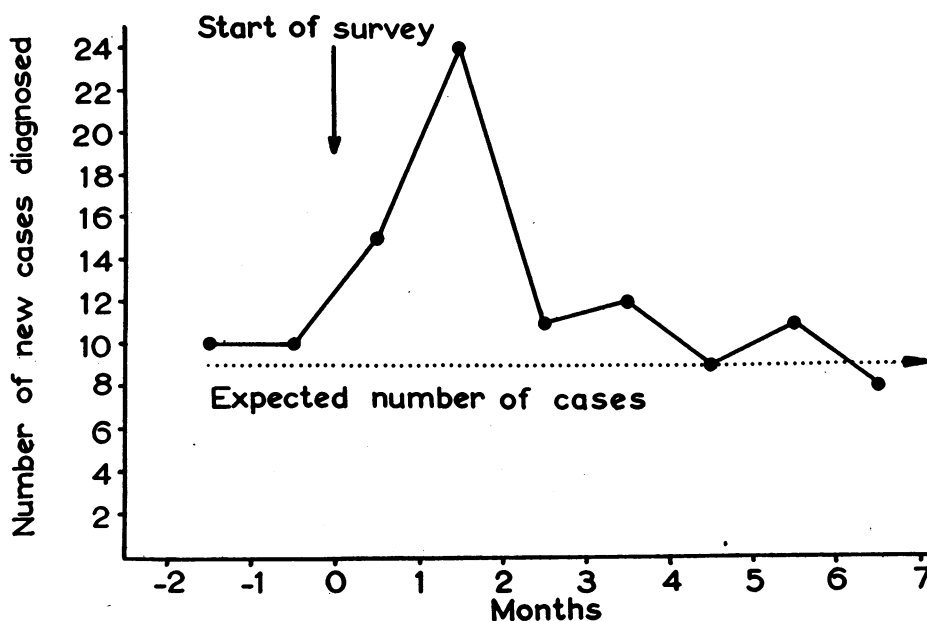


FIGURE.—Breast cancer detection in four counties of Norway, 1956-57, showing number of new cases diagnosed per month, and expected number derived from cancer registration during 5 preceding years.

5 preceding years. As an example, the stage of disease distribution of the two series is shown in Table IV. It is noted that the difference between the distributions is not statistically significant.

TABLE IV

BREAST CANCER DETECTION IN FOUR COUNTIES OF NORWAY, 1956-57. CLINICAL STAGE OF CASES DIAGNOSED BEFORE AND DURING FIRST SURVEY. PATIENTS OVER 70 YEARS OF AGE EXCLUDED

Stage	Before Survey		During Year of Survey	
	Number of Cases	Per cent.*	Number of Cases	Per cent.
I	170	45.2	53	54.6
II	164	43.6	38	37.2
III-IV ..	42	11.2	8	8.2
Unknown ..	15	—	—	—
Total ..	391	100.0	99	100.0

* Cases with stage unknown excluded.

There are obvious fallacies in such a comparison of tumour size and stage of disease in series of patients from different time periods. The improvement in distribution by stage and the observed reduction in tumour size might not be attributable to the survey but might result from a general tendency in recent years for cases to be diagnosed earlier. However, the Cancer Registry data makes it

easy to undertake similar comparisons of tumour size and stage of disease among breast cancer patients from corresponding time periods in other parts of the country, where no breast cancer survey had been conducted. Such a comparison offers some protection against the misinterpretation of the difference between the observed and "expected" values in the survey area.

It is also possible to see what happens after the survey has been finished. In Norway it was found that the stage of disease in the cases diagnosed in the four counties after the termination of the survey was exactly the same as in the cases diagnosed in the same areas during the 5-year period preceding the survey.

The facilities of the Cancer Registry make it relatively easy to follow up the total screened population, so that the data needed for a prospective epidemiological study and for the assessment of end-results will ultimately become available. By the end of 1961 more than 600 cases of cancer of the breast and genital organs had been recorded in the study population.

The Cancer Registry is now assisting, as already described, in the evaluation of an extensive cytology screening programme which was started in Norway in 1959.

(b) Mass Radiography

As part of the national tuberculosis control programme Norway has a National Mass Radiography Service which attempts to examine all persons above the age of 15 years at varying intervals of time. Examination is compulsory and attendance has generally been high. It was natural to ask how helpful this service had been in detecting cases of lung cancer, and it was obvious that the Cancer Registry data offered the most satisfactory starting point for such an investigation (Høst, 1960).

The registry data included all cases of primary lung cancer diagnosed in Norway between January 1, 1952, and July 1, 1956, 972 cases altogether. For every case the previous history, with reference to mass radiography examinations, was traced as far back in time as possible, and films were located and subjected to double re-reading. This was done to study, as far as possible, the duration of lesions, the possible association between lung cancer and preceding, non-malignant lesions, and the frequency of mis-diagnosed cases.

Among the 972 cases, 813 (84 per cent.) were diagnosed by the usual procedures after symptoms had impelled the patient to consult a doctor, 99 (10 per cent.) were apparently diagnosed incidentally as a result of routine mass radiography, and in sixty cases (6 per cent.) the diagnosis was made only at autopsy.

It is apparent from this that mass radiography, as carried out in Norway and with the present lung cancer situation, contributed very little to the detection of cases.

However, a higher percentage of cases was resectable among those detected by mass radiography (45 per cent.) than among those diagnosed on the basis of clinical symptoms (24 per cent.). Survival after treatment also was found to be slightly more favourable for those detected by the mass survey, and this was true both for those who underwent resection and for those who received palliative treatment only—in the majority of cases roentgen or Betatron treatment. But the difference was very small indeed. Moreover, as survival is conventionally measured from the start of primary treatment, the difference, even if statistically significant, would not justify the conclusion that the incidental—and presumably earlier—detection of cases had led to improved control of the disease; longer survival after earlier treatment does not necessarily mean that life has been prolonged.

There was no appreciable difference in the ages of the two groups of patients but the histological types

of the tumours were different; those detected by the mass survey had a higher percentage of adenocarcinoma and alveolar (bronchiolar) cell carcinomata and a lower percentage of anaplastic small cell carcinomata.

The above examples illustrate the important function of the cancer registry in the evaluation of cancer detection programmes. In both instances an important task of the registry was to establish acceptable "standards" against which the group of cases detected during the special survey could be evaluated. In the last example, the series of patients needed for the study was readily available in the registry.

SUMMARY

During the past 30 years various types of cancer registries have been established in many countries. A brief description is given of the main types, with emphasis on the population-based registry, the characteristic feature of which is that it attempts to collect information about all recognized cases of cancer in a defined population. Experience in Norway indicates that, for many forms of cancer, the morbidity data of such a registry are superior to the official mortality statistics, as a source of information regarding cancer incidence in the population. The use of the cancer registry in evaluating cancer detection surveys is illustrated. In this context the main function of the cancer registry is to furnish suitable standards against which the observations made during the survey can be evaluated.

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