THE ROLE OF THE CANCER REGISTRY

MANUELA DRAGOMIR, F. BĂDULESCU

The University of Medicine and Pharmacy of Craiova

Abstract: The cancer registry plays a central part in all aspects of cancer control. The cancer registry collects information that can be used for research as well as for public health planning and evaluation. The data gathered from the registry (e.g. cancer incidence rates or the percentage of cases diagnosed in an advanced stage of the disease) can be used to identify areas requiring public health interventions. The data can also be used to evaluate the effectiveness of public health programs.
Keywords: cancer registry, public health, cancer control
Rezumat: Registrul de cancer reprezintă o componentă esenţială a oricărui program naţional de control al cancerului, furnizând singura oportunitate de evaluare corespunzătoare a extinderii şi naturii bolii neoplazice într-o populaţie. Datele pot fi utilizate într-o largă varietate de moduri în domeniul controlului cancerului, de la cercetarea etiologică, la profilaxia primară, secundară şi terţiară, până la planificarea asistenţei oncologice, de aceste date beneficiind atât individul, cât şi societatea. Înregistrarea bolii neoplazice poate fi definită ca procesul de colectare continuă şi sistematică a datelor despre apariţia şi caracteristicile cazurilor de cancer raportabile, cu scopul evaluării şi controlului impactului cancerului asupra comunităţii.
Cuvinte cheie: registru de cancer, prevenţie cancer, monitorizare cancer.

Information is an essential element in the cancer control and only by knowing well the real morbidity and morality rate due to cancer, the fight against cancer may be a sustained and an efficient one.

The importance of the cancer registries existence and the definition of their role: the cancer registry represents the service or the institution which collects, stores, analyses, interprets and reports all data regarding the patients with cancer.

The update statistics on the neoplazic localisations offer information on the real burden caused by cancer within the population health care system. In order to develop cancer long term control programmes, it is necessary to be able to predict the future specific care needs. In other words, it is necessary to have as precise estimations as possible regarding the incidence and the prevalence figures for the next years. The cancer registries represent important data sources necessary for such predictions to rely on. The simplest predictions for the incidence rates are based on the assumption of the continuity present aspect of variation of the temporal tendencies for each gender. The prediction may be improved if the birth cohort effect is also taken into consideration, by the use of the so-called *'age-period-cohort'* statistic models. A more sophisticated approach for the prediction of the future incidents rates may be used when the information on the temporal changes of the risk major factors is known and if appreciations on their behaviour in future may be given. This approach was used for predictions on the incidence of the lung cancer in relation with the prevalence of smoking or of the breast cancer with the changes occurred regarding fertility.

Evaluation of the cancer control programmes
1. Primary prevention.
The cancer registries may play an important part in monitoring and assessing the efficiency of the primary prevention measures. The tendencies of the cancer incidence may be influenced by the temporal changes within the risk factors exposure. Occasionally, when implementation has in view a well-defined area, it is possible to make comparisons on the changes occurred between the area of intervention and the control area. Nevertheless, we must not forget that it takes a long time (usually tens of years) to interpret such inter-relations, so that the effect of the change into exposure to be also reflected in the incidence rates of the respective localisations.

2. Screening and precocious detection
The cancer registries may be extremely important for evaluating and monitoring the screening programmes too, which aim at detecting certain pre-invasive states. The data taken from the cancer registration were used in routine studies which examined the tendencies of the illness rates in relation with the frequencies detected as a result of the screening in a well defined population, but also in comparing the illness rates between different populations and those taken from the best coverage figures offered by the screening programmes. For example, such studies sustained the idea that the regular use of the Pap test is efficient in reducing the incidence of the uterine cervix invasive cancer.

The cancer registries may also contribute to the certification of the cancer occurrence frequency within the interventional trials or cohort studies elaborated for the evaluation of the screening programmes, but also as a source of cases lacking in errors for the case-control research. As far as the screening programmes aim at the precocious detection of the invasive cancer (for example, the breast cancer), the last measure of assessing the efficiency should be the reduction of mortality and not of the incidence.

The statistic monitoring data taken from the cancer registries are the following:

a) *Incidence of the interval cancers* (for example, the cancers detected between the screening intervals) in comparison with the incidence of the population included in screening, but before its introduction;

b) *Distribution on stages* of the cancer cases detected after screening in comparison with the distribution of those undetected;

c) If the screening is efficient, the cases detected on this occasion should present better survival figures than those undetected.

However, we should emphasize the fact that the intermediary points are full of errors, so these may suggest that the screening methods are efficient even if the mortality data invalidate this.

3. Tertiary prevention

The statistics regarding survival may be produced from the populational cancer registries which actively or passively aim at the cancer cases. Although the analysis of these data cannot assess the specific treatments (this is possible only in the randomized clinical trials), it still offers a useful evaluation of the specialised care within the area monitored by the registry, taking into account that the cases of cancer are included, irrespective of the therapeutic modality they benefit from.

The methods used within the survival analyses are part of the well known *analysis of survival,* one of the most used methods of statistics regarding the modern oncology research.

The first requirement which must be accomplished for the implementation of these methods is the clear case definition. Thus, the topography of that particular case of cancer and/or the histology must be clearly specified, as well as the age of the patient, the gender, the stage of the disease in the moment of establishing the diagnosis, the nature of the case which is about to be registered. For example, it must be decided if the cases which were only clinically diagnosed should be included. Also, decision must be taken on the registration of the cases only based on the notification taken from the death certificate (DCO) with no information on the date of the cancer diagnosis.

The second requirement is *a clear definition of the research starting point.*

Regarding the populational cancer registries, the starting date (where the survival estimation starts from) is the incidence date.

The third requirement is *a clear definition of the aimed outcome.* Generally, death is the outcome of interest; a series of registries may correlate enough information in order to analyse the tumour recurrence or the first occurrence of a certain complication as outcomes of interest. It is also necessary to formulate specific criteria in order to decide who is to be considered "lost from the evidence". For example, a series of registries may consider those cases for which is no longer possible to obtain any information by pursuit after more than 15 months, should be considered lost from the evidence.

There are many problems regarding the interpretation of the temporal tendencies within the survival analyses. First of all, the improvements of the survival may be due partly to a better certification and registration of the new cases of cancer. Then, if there is a tendency for establishing a precocious diagnosis (for example, by introducing a screening programme), the survival may improve, but this may be wholly put on the account of the increase of the evidence period of time, without any changes regarding the mortality rates.

In spite of these, the temporal tendencies within the survival studies are very important in order to evaluate the extent to which the therapeutic progresses had an impact on the population. For example, the dramatic improvement in the survival observed within the clinical trials aiming at the treatment of cancer in children, accomplished in the years 60's, seems to be strongly reflected even in the entire community of the developing countries, especially taking into account the way in which the survival based on populational data of many of these localisations showed significant improvements in time.

Comparisons of the survival estimations in the illness by cancer, based on the populational cancer registries are more and more frequently used in order to compare the treatment efficiency in population. Although, the therapeutic progresses may have a reduced benefice in controlling the illness of cancer in comparison with the potential benefices of the primary and secondary prevention (for example, the control of the infection with the hepatitis B virus regarding the hepatic cancer, anti-smoking campaigns for the pulmonary cancer).

The drawing up of the cancer registries is indissolubly related to the elaboration of a computerised evidence within the oncology clinics, which is a necessity that has not been a general reality yet, although it is no longer required to be proved.

CONCLUSIONS

Populational cancer registries provide accurate information within a certain area and a well defined population. The target population for the activity of the populational cancer registry is established taking into account different criteria: geographical area, gender, age, race, emigrated population, disease. The way of establishing the target population represents the basis for denominating the population registry, the most frequently encountered method is the geographical criterion.

The areas for using the data taken from the territorial cancer registry are large: estimations made on of the extension of the neoplazic disease within the community, the establishment of the priorities regarding public health, monitoring and assessing the cancer control activities efficiency; all these represent a source of materials for the ethyologic studies.

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