THE UNDER-USED ROLE OF THE BULGARIAN NATIONAL CANCER REGISTRY IN CANCER CONTROL

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Information about cancer patients is captured by cancer registries that have been established for this purpose. Their role in planning and monitoring cancer control activities has been described in detail by many authors but whilst this function is generally acknowledged, it is not always fully applied in some countries. The Bulgarian National Cancer Registry (BNCR) has collected sufficient data to participate at each level of cancer control, but the use of such data by policy-makers is well below the potential opportunities that the data provides.

Cancer is a big challenge for people in all countries around the world. There are 12 million new cancer diagnoses every year and about 20,000 cancer deaths every day.[1] Information about cancer patients is captured and processed by cancer registries worldwide that have been established for this purpose. Cancer registry data is used to estimate the cancer burden in a given population, to monitor trends and to prepare projections and other analyses, assisting policy-makers, cancer researchers, patients groups and other users. The role of population cancer registries in planning and monitoring cancer control activities has been recognized and described in detail by many authors.[3-6] Their usefulness is demonstrated not only in the provision of cancer statistics on population level, but also in evaluating the effectiveness of the cancer control activities by the calculation of indicators such as the proportion of patients diagnosed at an early stage, the time interval until initiation of treatment, etc. This concept of the role of cancer registries, although acknowledged in general, is not fully applied in some countries.[4,6]

In this article, the potential role of the Bulgarian National Cancer Registry in cancer control is described and some of the obstacles preventing its expansion are identified.

Bulgaria is situated in south-eastern Europe with a land mass of 110,993 km^2. The population of 7.5 million people is predominantly urban and is concentrated mainly in the administrative centres of its 28 districts.

The Bulgarian National Cancer Registry (BNCR) started operation in 1952. It is population-based, covers the whole territory of the country and registers about 34,000 new cancer cases a year. Cancer registration in Bulgaria is compulsory and is regulated by orders and instructions from the Ministry of Health. The registration network consists of 13 regional cancer registries that collect data from their region (covering one, two or three districts) and record them on a regional database. These regional databases are sent regularly to the BNCR to form the national database, which contains over 600,000 cancer cases diagnosed between 1993–2013. Patient data gathered before 1993 is stored on paper only. The information for each case is structured in more than 75 fields with details about the patient, tumour, treatment and follow-up, which allows its use not only for calculating incidence, prevalence and survival, but also for different analyses and research projects in oncology, as well as for public health purposes.

A comprehensive assessment of data quality at BNCR for the period 1993–2010 shows that the registration of cases follows the rules recommended for European cancer registries regarding the coding of topography and morphology, date of diagnosis, multiple primary and stage. Cancer incidence in Bulgaria is lower than other countries in south-eastern Europe, but the trends in incidence by cancer site are similar. The curves of age-specific incidence are identical with other south-eastern European countries and childhood cancer incidence is within the expected range. Completeness of registration is 94.5–96.0% for men and 91.1–93.6% for women.

An analysis of the validity indicators for the data shows a

favourable trend for increasing the proportion of morphologically confirmed cases, a reduction of cases registered based only on information from death certificates as well as those with unspecified stages, and a relatively constant proportion of cases with unspecified cancer sites. These indicators are within the range defined for valid data in international studies.[8] This assessment shows that BNCR yields comparable data that are close-to-complete and reasonably accurate, especially in recent years, which is a prerequisite for valid conclusions drawn from them.[9]

There were 34,864 new cancer cases registered in 2011.[18] The most common cancer in males is lung cancer (18.9% of all cancer cases) and breast cancer in females (27.3% of all cancer cases). These two are also the most frequent causes of cancer death in males and females, respectively. Among the five most common cancers in males, besides lung cancer, are prostate, colorectal, bladder and stomach cancers. Among the five most common in females, besides breast cancer, are cancers of corpus uteri, colon-rectum, cervix uteri and ovary. About 40% of patients are diagnosed at advanced (III and IV) stages of the disease. Incidence (all sites) is increasing by 1.5% annually and mortality does not show any statistically significant trend. Cancer incidence (all sites, both genders) is lower, while cancer mortality is higher than the average European (eco.iarc.fr). Five-year relative survival is 39.7%, which is lower than the average for European patients (www.eurocare.it).

According to WHO, cancer control has the following components: prevention, early detection, treatment and palliative care.[2] The main goal of cancer control is to reduce incidence, morbidity and mortality and to improve quality of life of cancer patients with optimal use of available resources.

Even if Bulgaria does not have a national cancer control plan, some municipalities have initiated regional cancer control programmes, funded by local resources, and also there are several projects for specific cancer prevention and control activities.[7] The National Health Insurance Fund pays for prophylactic examinations of breast, prostate and the

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colon-rectum. A smoking ban for closed places was introduced in June 2012.

A pilot project for screening of breast, cervix uteri and colon-rectum started in 2013.

The role of BNCR in the planning of cancer control activities can be the assessment of the scale of cancer problems in the population in terms of the number of new cases, computation of incidence rates by gender, residence and age-groups, frequency distribution by stage at diagnosis, trend analysis and projections. Such description of cancer patterns allows the identification of the most frequent cancers, the most affected age groups or geographic areas, which is important for allocating resources.

The potential uses of BNCR data

The impact of prevention activities can be monitored using data from BNCR in the following ways:
➤ analyzing the trends in incidence of cancers associated with smoking, infections, radiation, occupational carcinogens, etc;
➤ comparison of trends in other populations and over other time periods.

The role of BNCR in monitoring the effect of activities directed at early detection of cancer can be used for:
➤ surveillance of stage distribution of cancers, subject to early diagnosis by site: breast, cervix, oral cavity, larynx, colon, rectum and skin;
➤ analysis of trends in incidence and mortality of cancers that can be screened for – cervical, breast, colorectal.

When monitoring the patterns and effects of treatment in cancer patients, the data from BNCR can be used for:
➤ surveillance of trends in mortality from curable malignant diseases (seminoma, acute lymphoblastic leukemia in children);
➤ analysis of survival by site, age-group, hospital for

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treatment and period of diagnosis;

➤ studying the proportion of patients who received different treatments, according to the guidelines for standard care;

➤ analysis of the time to initiation of treatment, which can be used in estimating the need for additional facilities (for radiotherapy, systemic treatment) in certain regions in order to ensure equal access to treatment.

The information provided by BNCR about patients diagnosed in advanced stages, can be useful in planning resources for palliative care. Through links with other data sources (hospital information systems, etc.) patients with progressions of the disease (metastases) can be identified in order to accurately assess the needs of palliative care.

Although BNCR has sufficient data to participate in each stage of cancer control, the use of such data by responsible state institutions and policy-makers is incidental and is well below the potential opportunities the data provides. At the same time, some changes that have taken place in recent years in the organization of health care in Bulgaria may affect data collection as regional oncology centres and university hospitals are no longer the only places where cancer patients can receive treatment. The decentralization of cancer care reflects negatively on the quality of data collected at the cancer registry, because the sources of information are more heterogeneous and very often incomplete which requires more effort for cancer registrars to ensure completeness. The legal framework for cancer registration is also outdated (it has not been updated since 1964) and does not reflect the current changes in the health care system. Funding from the Ministry of Health (which is the only funding source) is limited and not sufficient to cover all national and regional cancer

registry activities. An economic evaluation study of cancer registration in Europe performed by the EUROCOURSE project (www.eurocourse.org), showed that cost per inhabitant versus size of population under registration and cost per case by population covered in 2010 for Bulgaria was among the lowest in Europe. All these issues have been discussed at meetings with the participation of the cancer registry and Ministry of Health representatives, but the difficult economic and political situation in the country has taken them off the Ministry's priority list.

Despite these challenges, BNCR is participating in all major European and International projects based on cancer registry data: EUROCOURSE, EUROCARE (www.eurocare.it), CONCORD (http://www.lshtm.ac.uk/eph/ncde/cancersurvival/), Cancer Incidence in Five Continents (ci5.iarc.fr), International Incidence of Childhood Cancers (iicc.iarc.fr), RarecareNet (www.rarecarenet.eu), and EPAAC (www.epaac.eu). Every year BNCR publishes a "Cancer Incidence in Bulgaria" series (www.sbaloncology.bg), with the last report (for 2011) available in 2013. BNCR has initiated collaborations with clinicians for different projects, such as "Patterns of systemic treatment of colorectal patients in Bulgaria", "Adherence to standard care for breast cancer in Bulgaria", "Multiple primary tumours in familial breast cancer patients" and several others. BNCR data is also used in some recent publications based on population cancer registries information.[10-17]

Despite functioning with a very limited budget in a situation where the legal framework is outdated and cancer care is decentralized, BNCR has maintained its cancer registration system and upholds a proud tradition dating back over 60 years. With the support not only from the state institutions responsible, but also from medical and patient societies, and non-governmental organizations, interested in cancer prevention, treatment and research, BNCR has the potential to expand its role in cancer control. ●

Dr Nadya Dimitrova graduated from the Medical University in Sofia, Bulgaria, in 1997. She specialized in general medicine and health management and worked as a general practitioner for nine years. In 2007 she joined the Bulgarian National Cancer Registry staff and since 2010 has been the Head of the registry. Dr Nadya Dimitrova has additional qualifications in cancer epidemiology and population-based survival analysis. In 2013, she completed her PhD in Oncology.

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