Editorial

The role of Cancer Registration in National Cancer Control Pakistan

Y. Bhurgri

Department of Pathology, Sindh Medical College, Karachi.

"Cancer registration is a process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms." A cancer registry attempts to collect, store, analyse and interpret data on persons with cancers. A population-based registry records all new cases in a defined population with emphasis on epidemiological research, and evaluation of health services for prevention, diagnosis and treatment of the disease. A hospital, institution or oncology-based registry records all cases in a hospital or in respective units, with emphasis on clinical-care and hospital administration. It submits the data to the central, population-based registry. Pathology-based registries records all cases of cancer in a given laboratory with emphasis on pathological diagnosis, grading and staging of cancers, thus maintaining the quality control of population registers. Large hospital or pathology series are sometimes used for monitoring of cancer control programs in the absence of population data.[1]

The data sources of population-based registries are medical facilities within a defined population or geographical area. Cancer cases who do not enter the health-care system in life are registered with the help of the death registration system. The cumulative data obtained from all data sources form the population-based data, provided residency status of patient is established and linked to the registry catchments. All cancer cases, residents of target-population should be included, without any restrictions to age, sex or diagnostic procedure. Duplication checks are essential in case of multiple data sources.

To facilitate comparison of data internationally, registry data fulfil some criteria of comparability and quality control. The rules are laid down or recommended by the International Agency for Research on Cancer (IARC) and the International Association of Cancer Registries (IACR).[2] These rules relate to comparability, standardization and completion of data.

Uses of Cancer Registry Data for Cancer Control

Population-based cancer registries provide demographic data and assessment of risk factors, essential for the assessment of the magnitude of the cancer burden of a population. The data provide accurate and relevant clinical information essential for basic research, starting point for etiological research, improve survival of cancer patients, monitor and evaluate cancer activities.

Age, gender and characteristics of malignancies show a geographical variation linked to racial, genetic and environmental pathogenic factors. Cancer rates of one population cannot precisely be used to develop a cancer control program of another population yet overenthusiastic stress and allocation of limited funds on cancer registration at the cost of the goal of cancer control should be essentially avoided.

"National Cancer Control Programme (NCCP) is a public health programme designed to reduce the incidence and mortality of cancer and improve the quality of life of cancer patients in a particular country or state, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, treatment, and palliation, making the best use of available resources. Epidemiological data on the occurrence of cancer, and knowledge of causative factors and of how to avoid those factors, provide a basis for determining where the emphasis of cancer control efforts should be placed".[3] NCCP can be organised independently or a cancer surveillance programme can be built around a stable population-based cancer registry.

Cancer patterns of any population change in a long period. Time trends in cancer are measured over decades not months or a couple of years. Dramatic changes are not observed in a short time period. Factors, which influence time trends maybe indirect viz. environmental factors or population change or direct intervention via the cancer, control programme. Environmental factors play an important role in oncogenesis and are more readily controlled then the genetic and racial factors. The emerging age structure of populations, improvement of living standards, control of communicable diseases and population control has improved life expectancy and also associated cancer susceptibility. Projection of the future cancer burden is based on cancer registry data, changing rates and observed trends. It provides the baseline for evaluation of cancer control programmes, as intervention in the form of primary and secondary cancer prevention, change the natural trends of the disease.[3]

Cancer Registration in Pakistan

Pakistan has been historically unsuccessful in sustaining the numerous population-based registries established in the past. In the last 5 decades published data of a few sporadic institution-based registries, provided the coun-

country with its only cancer database. This data had limited value as the demographic details of the patients were partially recorded; there was associated selection bias of different hospitals and there was a lack of continuity. This relative frequency data could not be used as a replacement for population-based data, neither as a guideline for a cancer control programme.

Population-based cancer data is a fundamental requirement of National Cancer Control Programmes. The Karachi Cancer Registry (KCR) data has acquired 9 years stability (1995-2003) for Karachi South, a sample population of Pakistan.[4,5] The city of Karachi is divided into 5 districts, South, Central, West, East and Malir. Karachi District South has a population of 1,724,915 with 929,394 (54%) males and 795,521 (46%) females, annual growth rate of 1.94 as calculated by the Federal Census Bureau.[6]

The population distribution of Karachi South (KS) is similar to the population distribution of Paksitan as regards age, gender, and religion. KS has the distinction of being the only district in the country with a representation of all ethnic and socio-economic groups of the country. It can thus be taken as a sample population of the country in the absence of other data sources. KCR has also calculated the incidence of Karachi Division (1998-2002), population of 9,802,134; 5,261,712 males and 4,540,422 females, annual growth rate 3.52 and Quetta (1998-1999) population of 759,245; 425,474 males (56%) and 333,771 females (44%).[6-8]

Cancer control based on the KCR data and WHO estimates would advocate identical strategies. Primary prevention in the form of tobacco and areca nut control could reduce 43.7% of the malignancies in males and 17.8% in females. This can be achieved by public health education, especially of school children, adolescents, healthcare providers and by mass education and media influence. Legislation in the form of taxation, ban on public smoking or chewing, ban on advertising and enforcement of non-tobacco industry. Regulation of tobacco exports and encouragement of alternative crops in tobacco areas will have the most dramatic effects on the trends of cancer.

Primary prevention in the form of diet control (colon, breast, gastric cancers), checks on preservatives, dyes, and pesticides; protection from occupational hazards (lung, pleural, peritoneum, skin, eye, scrotum, liver, lymphatic, haematopoietic malignancies), control of biological agents (hepatitis B vaccination - liver cancer, H.pylori treatment - gastric cancer and Maltoma, avoidance of aspergillus contamination - oral cavity and liver) and solar UV protection (eye and skin cancers) will help in the control of half the malignancies. Early detection of cancers of accessible sites could be warranted for oral, cervical and breast cancer. In females this could help target 47.6% (approximately half)

the malignancies and in men 13% of the total.

Pakistan falls into the low to medium resource countries by WHO classification. Resource restriction put high technology methods beyond the scope of Pakistan today. Cancer control activities should focus primarily on education to improve awareness. Self-examination of the oral cavity and breast, physician breast examination and cytology-based screening for high risk cervical cancer populations should be established. These initiatives along with model community programmes were successfully organised in Kerala and Trivandarum in India and need to be closely examined and reproduced in Pakistan as resource allocation, social-economic and cultural similarities suggest potential for success.[3] Establishment of equitable pain control and a palliative care network through-out the country is essential as more than 70% of cancer patients report in very advanced stages of malignancy.

Pathology-based cancer data can be utilized as a reflection of the patterns of cancer in the population it represents, provided the microscopic verification of malignancies is high and demographic data well recorded. Incomplete information gives either an over-registration of non-resident cases or a duplication of cases. The risk of associated selection bias of different hospitals and over-representation of more easily accessible sites are also present. Despite these drawbacks, if interpretations are made in the light of information on selective factors, invaluable scientific information may be derived from this data as approximately 70-90% (urban, rural variation) of the malignancies in Pakistan can be traced to pathology departments. The Aga Khan University pathology-based cancer registry is a good example.[9]

Oncology-based registries emphasize on clinical-care of cancer patients and submit the data to the central, population-based registries. Approximately 30-50% (urban, rural variation) of the malignancies in Pakistan can be traced to treatment centres. These are cases with early diagnosis and socio-economic security. National population-based registries though ideal are not practicable due to restrictions of finances and a lack of technical expertise. There is wastage of allocated resources, as desired completion rates cannot be achieved.

Unfortunately the vast majority of hospital-based and pathology based data in the country is recorded without establishing the residency status of the patient or without recording a retraceable address or telephone number or even the correct name. This invaluable data is therefore wasted as no conclusions can be made from the cancer data if the population from which the cases are drawn is not known. Duplication of data also cannot be avoided. In such circumstances, incidence rates cannot be calculated; the data when

circumstances, incidence rates cannot be calculated; the data when presented as proportions or relative frequencies is also not representative of the population. Ironically this deficiency of incidence data hinders the development of a well-organized cancer control programme.

Conclusion

Cancer registration is a public health profession and requires professionalism for success. It is not a hobby for the selected few, dependent on the availability of funds in particular time periods. Cancer registries are parameters of dignity for a country and play a major role in providing the data to justify the establishment, implementation and monitoring of a national cancer control programme, therefore stability in cancer registration is of pivotal importance. An erroneous assessment of the cancer burden can have long-term negative implications on the health resources of a country, especially a limited resource country like Pakistan. Cancer registries require atleast a decade of persistence and continuity for stabilization. Registries starting simultane-ously with the national cancer control programme cannot adequately be used for the planning, establishment and monitoring of the programme.

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