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Population-based cancer registration and the Punjab Cancer Registry

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Cancer registration is about systematic collection, storage, analysis, interpretation, and reporting of data on cancer. Cancer registries are of two main types: hospital-based and population-based. Hospital-based registries record information about patients diagnosed and treated in a particular hospital with each hospital having its own hospital-based registry. The main purpose of such registries is to contribute to patient care by providing readily accessible information on patients. The data are used mainly for administrative purposes and for reviewing clinical performances. However, for epidemiological purposes, such registries cannot provide measures of occurrence of cancer or trends in a defined population. A step beyond setting-up a hospital-based registry is a population-based registry, which is considered to be a great public health achievement, as it reflects a joint effort on the part of professionals representing different facilities of a region to establish a registry of this kind. In contrast to hospital-based registries, population-based registries monitor the frequency of new cancer cases diagnosed in a specified population, living in a geographically demarcated area, over a specified period of time and produce statistics on the occurrence of cancer in the population. This assists in providing a framework for assessing and controlling the impact of cancer in the community; thus, the emphasis is on epidemiology and public health.

For population-based cancer registration, data are captured, by the cancer registry staff, from different sources as hospital and laboratories. Data are collected both on the demographic features of the patients and clinical characteristics of the disease and are based on the minimum data requirement standard set by the International Agency for Research on Cancer (IARC), a sub-office of the World Health Organization. The method of data collection can either be through active collection or passive reporting. Active collection involves registry personnel actually visiting different sources and abstracting the data on special forms. Passive reporting involves health-care workers completing the notification forms developed and distributed by the registry or sending copies of discharge abstracts to the registry. A mixture of both the procedures is usually adopted by most registries of the world. In certain countries, notification of cancer cases is mandated by law, although this does not necessarily ensure completeness. Although, in Pakistan, the reporting of cancer is not a requirement by law, we cannot ignore the importance of having a cancer registry in any part of the world. In the absence of a

proper cancer registry, we can neither ascertain the cancer incidence or trends, nor can we conduct suitable research that can help us in taking appropriate measures toward the diagnosis and treatment of this disease.

In our part of the world, the Punjab Cancer Registry (PCR) was set-up in the year 2005 by an enthusiastic group of professionals, who realized the importance of cancer registration in the country and took it up as a challenge to establish the Registry. When they started working on this project, the only recognized population-based cancer registry in the country was the Karachi Cancer Registry, representing Karachi South district and being managed by Dr. Yasmin Bhurgri. Dr. Bhurgri passed away in January 2012 and since then, there is no information publicly available as to who is taking care of the data she collected. Despite that, it is hoped that her work is being carried forward.

PCR is also a population-based cancer registry, which was set-up a decade back to record cancer statistics in the province of Punjab, in Pakistan. The Registry is being sponsored by the Shaukat Khanum Memorial Cancer Hospital & Research Center (SKMCH & RC), Lahore, where its Central Office is located as well. The staff of the Cancer Registry and Clinical Data Management unit of SKMCH & RC oversees data collection, ensures data entry into software specifically designed for this purpose, and collates results to be presented to professionals and agencies, on request. Further, the Registry is recognized by IARC in Lyon, France, and registered under the Societies' Act of Pakistan, 1860, wherein, the registration has to be renewed every year. PCR has around 15 collaborating centers in Lahore district, a nine-member Governing Council, and 38 professionals serving as members of the Registry. Professionals represent both private and government facilities of the district. Of the members and collaborating centers mentioned above, some are more active in reporting their cases to the Central Office than are others.

Till recently, the Registry was collecting information on cancers being diagnosed among the residents of Lahore district only calling it the Lahore Chapter of the Registry. The Registry is now expanding its role to capture data on cases being diagnosed among the residents of districts adjoining, and close to, Lahore district, which include Kasur, Sheikhpura, Nankana Sahb, Gujranwala, Hafizabad, and Faisalabad. As for the Lahore district, although the cases are still being under reported to the Registry, the data from PCR between 2008 and 2010 were used by the World Health Organization, along with data from two other sources ((late) Dr. Bhurgri's paper and the Federal Bureau of Statistics, Pakistan), to provide cancer estimates for Pakistan. The report that was released in December 2013 is called 'Globocan 2012' and provides estimates on incidence, mortality, and prevalence for the year 2012, for the adult population of the country. The details related to the report can be accessed by visiting the website: <http://globocan.iarc.fr/>.

The Registry has now released its 2014 report for Lahore district and posted it on its official website: <http://punjabcancerregistry.org.pk/>. The numbers reported are likely to change as PCR is still receiving information on cases diagnosed between 2012 and 2014 from one of the main collaborating centers in the region. According to the report, in

all age-groups and both genders combined, 5,521 new cancer cases have been diagnosed in Lahore district in the year 2014. Of these, 5,138 (93.06%) have been recorded in adults and 383 (6.94%) in children less than or equal to 18 years of age. Further, of the total, 57% were seen in female and 43% in male population. The five most common cancers seen in the population were: breast (25.8%), Non-Hodgkin's Lymphoma (NHL) 4.9%, lip and oral cavity 4.8%, brain 4.7%, and gastro-intestinal cancers (colon, rectum, and anus) 4.6%; in males: prostate 9.2%, NHL 7.5%, lip and oral cavity 7%, colorectal 7%, and urinary bladder 6.9%; in females: breast 44.3%, corpus uteri and uterus 4.1%, ovary 3.9%, lip and oral cavity 3.2%, and gastrointestinal cancers 3.1%; and in children: Acute Lymphoblastic Leukemia 18.8%, Gliomas 14.1%, NHL 9.9%, Hodgkin's disease 8.6%, and Retinoblastoma 4.7%.

Setting-up a registry and keeping it up and running is a herculean task in a developing country like ours, given all the competing demands upon the limited resources allocated to health, and the fact that the country is marred by problems such as infectious diseases, natural calamities, and political unrest. Nevertheless, since cancer is already being seen as a significant health problem in our country, cancer surveillance is a public health priority and is required to determine statistics on cancer incidence, mortality, and prevalence in the region and, eventually on survival. This would be the way forward in developing cancer prevention, early detection, and control programs in the country and in improving the quality of life of patients suffering from this disease.

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