

Need for a national cancer registry in Pakistan: Challenges and way forward

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Abstract

The incidence of cancer is rising globally at a remarkable rate. According to the global cancer Observatory, the total number of cases in Pakistan were 178,388 in 2020; and these figures were provided by the Punjab Cancer Registry which represents the population of Lahore and some parts of central Punjab. Considering the overall 220 million population, these figures are severe underestimation of the true cancer burden in Pakistan. Unfortunately, several attempts at establishing a national cancer registry in the country have failed in the past. Resource limitations, including funds, manpower and infrastructure, and the lack of interest on the part of the governments are behind the failure of the establishment of a national cancer database. There is a dire need for establishing a national cancer registry to understand the actual burden of disease, and to implement a national action plan for cancer prevention, and management strategies to control the growing epidemic.

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Introduction

The incidence of cancer is rising worldwide. It is considered to be the first or second leading cause of death in 112 countries in women aged <70 years, according to a World Health Organisation (WHO) report in 2019.¹ According to the global burden of cancer observatory (GLOBOCAN) report, 19.3 million new cancer cases were diagnosed and 10 million people died of cancer in 2020 around the world.² Growing incidence of cancer resulting in mortality has been attributed to a number of factors, including aging population, overall population growth and alterations in prevalence of risk factors related to socioeconomic development.³ The statistics provided by GLOBOCON rather seem to be the tip of an iceberg due to the absence of national databases or cancer registries for cancer estimation in most countries, including those in the

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developed world. A correct estimate on the incidence and prevalence of cancer is extremely essential to mitigate the adverse outcome of the disease, making the role of cancer registries exceptionally important. This is particularly crucial for the developing countries to ensure appropriate use of already scarce resources.

The current narrative review was planned to build up a perspective on cancer registries and to underscore the need in Pakistan.

History and evolution of cancer registries

Cancer registries are responsible for collection, storage, analysis, interpretation and reporting of data on cancer patients. Such registries have been deployed differently at different places and may be population-based, hospital-based or pathology-based. Population-based registries collect data from geographical regions in terms of disease burden, aetiological factors, and assessing the effectiveness of cancer care and prevention. Hospital-based registries gather clinical data of cancer patients regarding treatment and clinical outcomes in a clinical entity. Pathology-based registries record information from laboratories on histopathology of tumours, giving a snapshot of cancer profile. Although considered ideal, a national cancer registry, which aims at gathering data across an entire country, might not be feasible in each country due to the cost associated with its implementation. However, data collected from local population-based registries can be extrapolated at the national level.

The first attempt to establish a cancer database was made in Germany in 1900. Every physician treating a cancer patient was asked to record the data on a uniform questionnaire. Other European countries and the United States of America adopted the same approach, but poor physician collaboration led to the failure of such attempts. Later, the first population-based cancer registry was established in Hamburg Germany, in 1926. Three nurses were assigned to collect data about cancer patients from local hospitals and physicians at regular intervals, and to transfer the data to the central health database.⁴ In subsequent decades, population-based registries were established in parts of the world. More than 700 population-based cancer registries are working globally, covering 21% of the global population, while registries in Asia cover only 8% of its entire population.⁵ Developed

nations have established national cancer registries in collaboration with population-based registries to maintain a national cancer database.

Cancer registration, data collection and reporting methods

Population-based registries gather data regarding cancer cases for a specified population from healthcare facilities, including hospitals, private clinics and general practitioners as well as from diagnostic facilities, like pathology laboratories and imaging clinics. This data is either recorded actively by the registry personnel or passively by healthcare professionals on proformas issued by the registries. A unique registration number is assigned to each patient and the demographic details, the date of either diagnosis or first consultation, or date of death in cases when not diagnosed early, called the incident date, is recorded. The International Classification of Disease for oncology coding system is used to code the site and morphology of tumour, which is important to ensure comparability with the data from other registries.⁶ The four quality indicators of cancer data include comparability, completeness, validity and timeliness. Every case in the catchment population should be recorded and should be checked with hospital records and death certificates for completeness in a timely manner to avoid delays which negatively impact cancer prevention strategies. For population-based registries, The World Health Organisation's (WHO) International Agency for Research on Cancer (IARC) has developed an electronic ad hoc system, called CanReg5, for data collection and storage, and better quality control. This computerised database has helped developing countries in the implementation of cancer registries.^{7,8}

Role of cancer registries

1. Cancer epidemiology

Muir et al. first defined the cancer registry as an essential part of any cancer programme beneficial for both individuals and society for cancer control.⁹ However, Armstrong in 1992 described the extended role of tumour registries in cancer surveillance and prevention.¹⁰ Population-based registries are imperative in providing the statistics required to understand the epidemiology of cancers. The key objective of a cancer registry is to measure the incidence, prevalence and mortality rate of site-specific cancers in a predefined population. Cancer demographics demonstrate geographical variations linked to race, genetics and environmental factors, and this data is vital when considering primary prevention of cancers.¹¹ Mortality rate is a surrogate marker for incidence and a measure of serious outcomes and helps in evaluating the effectiveness of primary prevention, early detection, and treatment. Similarly, survival data is a useful tool in

evaluating the effectiveness of cancer treatment.¹²

2. Cancer research

The function of registries has developed far beyond the epidemiology and proved to be valuable tool in cancer research, forming a part of research institutions to provide data for scientific studies. Descriptive studies use this data in generating hypothesis regarding the aetiology of various cancers. For example, diet was considered a risk factor for colon cancer after comparison of data retrieved from different tumour registries around the world in terms of geographic variations, time trends and migrant studies.¹³ Similarly, cancer registries have been involved in identifying new cancers in specific cohort of patients, like susceptibility of a new cancer in surveillance group of another cancer due to common risk factor or because of side effect of cancer treatment. In interventional studies, the effect of suspected carcinogens can be studied by comparing the incidence before and after intervention. Similarly, the efficacy of chemotherapeutic agents can be evaluated in randomised controlled trials (RCTs) using registry data.¹⁴

3. Cancer prevention

Cancer registries play a vital role in planning and evaluation of cancer control programmes.

- A) Primary prevention: The assessment and monitoring of preventive interventions have been assessed by comparing the incidence rates of various cancers before and after the implementation of preventive measures. One of the striking examples is the dramatic reduction in the incidence of hepatocellular carcinoma (HCC) after the introduction of vaccination against hepatitis B virus (HBV), recorded by Taiwan cancer registry in 1980.¹⁵
- B) Screening and early detection: Cancer registries play a major role in evaluating and implementing the effectiveness of screening programmes for early detection of cancers in pre-invasive stage. The data is used to compare the incidence of cancer before and after the implementation of screening programmes.¹⁶ The best example is the screening programme for cervical and breast cancer which has dramatically improved the survival of patients worldwide.
- C) Tertiary prevention: Tertiary prevention aims at improving the quality of life and survival. Survival statistics provided by the registries facilitate valuable estimation of cancer care in terms of adjuvant and targeted therapies, and palliative care.¹⁷ This data is used in cancer research to improve the efficacy of the treatment strategies in adjuvant and palliative settings to improve the overall survival (OS) and disease-free survival (DFS) of cancer patients.

Perspective from Pakistan

According to the GLOBOCAN report, the total number of cancer cases in Pakistan were 178,388 against a total population of 220 million in 2020, compared to 173,937 in the year 2018.² However, the statistics were provided by the cancer registry in the Punjab province alone, which has a population-based registry only covering a few cities of the province and representing less than 10% of the total national population.¹⁸ Due to ethnic diversity, cancer statistics obtained from a specific region are peculiar and relevant to that ethnic background, and these figures cannot represent the cancer burden in other regions. With the rising trend of risk factors due to modernisation of lifestyle, aging population, and absence of a national cancer database, the actual number of cancer cases is severely underestimated in global surveys. Such erroneous estimation of cancer burden can have negative implications in resource-limited countries on cancer prevention programmes in the long term.

Cancer registries in Pakistan

Pakistan unfortunately has failed in establishing and sustaining a national cancer database although various attempts have been made in the past. The Armed Forces Institute of Pathology (AFIP) established the first pathology-based cancer registry in Rawalpindi in the 1960s. In the following decade, an attempt was made by the Pakistan Medical Research Council (PMRC) to establish a national cancer registry, but it could not function due to financial constraints.¹⁹ The first population-based registry was established in Karachi by Dr Yasmin Bhurgri in 1995 in collaboration with Sindh government, WHO and IARC. Out of five districts, South was selected due to its ethnically and socioeconomically diverse population having representation from across the country. Bhurgri et al.²⁰ published their first report in 2000, which provided valuable statistics on cancer patterns for cancer prevention despite limitations regarding data quality. This data was crucial as it led to the development of cancer control activities in terms of tobacco control and screening programmes for breast cancer. Unfortunately, after the death of Dr Bhurgri in 2012, this registry, too, became non-functional. Meanwhile, the Punjab Cancer Registry (PCR) was initially established by a public-sector hospital in 2005, but in the following years the registry was shifted under the umbrella of Shaukat Khanum Memorial

Cancer Hospital and Research Centre (SKMCHRC). PCR has been successful in collecting data from the major hospitals in and around Lahore, and is providing data to IARC (WHO) and GLOBOCON.²¹ Subsequently, Karachi cancer registry was established in 2017 in collaboration with public and private hospitals in Karachi which has published its three-year data recently.¹⁹ Till date, there is no national cancer database to record the statistics from all over the country to assess the true cancer burden. Recently, the Pakistan Health Research Council (PHRC) has been designated by the Ministry of National Health Services Regulation and Coordination (MoNHSRC) to establish a national cancer registry by linking all major private and public entities in the country. Reports produced by population- and hospital-based registries from Pakistan, since the inception of the first cancer registry, show that the numbers only represent population from a few urban areas of the country (Table).

Major challenges in establishing a national cancer registry

The problems faced by developing countries in establishing a national cancer registry were first described by the WHO in 1979 and Olweny in 1991.²² Even after four decades, Pakistan is facing similar challenges and has thus failed to develop a national cancer database. The most important factor is the lack of basic health facilities in rural areas, and the concentration of mainstream health facilities in the cities. Cancer registration usually involves these centres and the final cancer statistics do not represent the country as a whole.

Table: Published studies on the basis of population-based registries in Pakistan.

Study	Source	Years of study	Place	Total
Bhurgri et al, 2000 ²⁰	Karachi cancer registry	1995-1997	Karachi	4268
Bhurgri et al, 2002 ²³	Combined data from several public and private hospitals from Karachi	1998-1999	Karachi	14,243
Bhurgri et al, 2002 ²⁴	Aga Khan University Hospital	1998-1999	Karachi	11,368
Bhurgri et al, 2005 ²⁵	Aga Khan University Hospital	1998-2002	Hyderabad	
Bhurgri et al, 2006 ²⁶	Three hospitals from Karachi	2000-2002	Larkana	
Atique et al, 2008 ²⁷	Combined Military Hospital	2002-2007	Multan	930
Hanif et al, 2009 ²⁸	Allama Iqbal Medical College	1997-2001	Lahore	1500
Ahmad S et al, 2013 ²⁹	Ayub Medical College	2007-2012	Abbottabad	555
Badar et al, 2015 ³⁰	Shaukat Khanum Memorial Cancer Hospital	1994-2012	Lahore	55,974
Masood et al, 2015 ³¹	Pakistan Atomic Energy Commission	1984-2014	Lahore	80,390
Ahmad et al, 2016 ³²	Aga Khan University Hospital	2014	Karachi	10,000
Qureshi et al, 2016 ³³	Dow University of Health Sciences	2010-2015	Karachi	13,508
Badar et al, 2016 ³⁴	Punjab Cancer Registry	2010-2012	Lahore, Central Punjab	15,840
Registry Report, 2018 ³⁵	Pakistan Atomic Energy Commission	2015-2017	Eight small registries from different areas	102,022
Pervez S et al, 2020 ³⁶	Karachi Cancer Registry	2017-2019	Karachi	33,309
Globocon 2020 ²	Punjab Cancer Registry	2020	Lahore and Central Punjab	178,388

Even in the cities where cancer statistics are recorded, the geographical and ethnic factors and their relation to cancers is dubious due to the migration of rural population to these cities in search of job opportunities. Another obstacle is the lack of trained personnel for data recording, resulting in the utilisation of primary sources, like patients and nursing records, and operating room notes for data extraction which are usually insufficient for recording proper demographics and follow-up. This results in incomplete follow-up data which impacts survival analysis.

Furthermore, there is lack of electronic data recording and storage systems in most public-sector hospitals that require manual filling up of data on cancer questionnaires. This can result in potential delays in data transfer and processing, affecting the timeliness which is a quality indicator of data recording.

Population-based registries require data on the size of population served, which ultimately needs yearly census. This is infrequent in our part of the world due to several reasons. Also, there is lack of collaborative effort among the regional cancer databases to share the data for meaningful results which can have a powerful impact in terms of numbers when shared with international cancer associations and WHO in planning and implementing disease preventive strategies.

Last but not least, lack of funding sources for sustainability of cancer registries is the most important reason behind the failure to establish a national registry. Setting and sustainability require an enormous cost and developing countries have resource limitations.

Prospects and way forward

The need for a national cancer database in Pakistan cannot be over-emphasised. Before cancer becomes an epidemic, immediate action is required from both the government and the non-government organisations (NGOs) to implement a national action plan. It demands massive logistical support, including funds, human resource and the political will.

There is an urgent need for allocation of adequate funds for the establishment and sustainability of national registry in the annual health budget. It is important to seek help from international organisations, like WHO and IARC, for training and monitoring staff in recording and processing the cancer data on CanReg.⁵ MoNHSRC should take the lead to establish small registries at all district-level hospitals around the country and train staff in data recording and transferring the same to the large population-based registries of the respective provinces, which then should transfer the data to the national cancer database.

Conclusion

Setting up a national cancer registry will help in understanding the actual cancer burden with respect to age, gender, ethnicity and social status in both rural and urban areas. This is crucial in formulating and implementing a comprehensive national action plan for primary prevention, timely detection, screening and tertiary prevention of the disease.

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