

Trends in Pediatric Cancers over 10 years from a Hospital based Registry in Pakistan

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Abstract

BACKGROUND: In the absence of population based cancer registries, hospital records can only highlight the importance of collection and analysis of data to address the burden of cancer among children. For this purpose, a hospital-based registry's pediatric cancer data (individuals aged 0-18 at diagnosis) from 2010 to 2019 was compiled and analyzed at AKUH in Karachi, Pakistan. **METHODS:** A paper-based system is used to record all interactions with patients at the hospital. A dedicated team of Cancer Registrars transcribe this data onto a US based registry software; CNEXT. Registry data was extracted through software generated reports and compiled for analysis. **RESULTS:** The total number of children presented at our center was 2,694, out of which 1,673 were males while 1,021 were females. Top 5 sites were bone marrow (n=887), central nervous system (n=481), lymphoid tumors (n=294) bone (n=255) and soft tissues (n=145). All other sites contributed to 632 cases, 23.5% of the total patient population. Furthermore, 806 patients were aged 0-4, 627 were aged 5-9, 684 were aged 10-14 while 966 patients were 15-19 years old.. A consistent increase of 210% was noted during the 10-year period. **CONCLUSION:** Our database analysis shows that the top cancer sites are consistent with other databases around the world. Increase in numbers may reflect awareness and referral pattern emphasizing the need for capacity building at the national level to accommodate patients locally so families don't have to travel over provincial and international borders to receive treatment.

Introduction

Cancer is a rare event in the pediatric population with an estimated 280,000 new cases reported in 2020 among children and adolescents globally according to the International Agency for Research on Cancer (IARC). Yet it's one of the major causes of death. It accounts for over 100,000 deaths globally before the age of 15 with a majority of them in countries with limited resources¹. Most low and middle income countries (LMICs) do not collect data on the incidence and prevalence of cancer in the younger population thus the exact cancer burden, which can vary according to geographical regions, is unknown. In Pakistan, it is estimated that around 8000 children are diagnosed with cancer each year² which accounts for almost 10% of all reported cases for cancer in the country³.

In the absence of a national pediatric cancer registry in Pakistan, data can only be obtained from studies reporting regional cancer incidence through hospital based cancer registries⁴. Hence, planning of tailored national anti-cancer health policies and awareness campaigns is limited. This could be especially useful considering LMICs have a higher mortality compared to incidence for several cancer types therefore after prevention strategies, early detection and better treatment options would help decrease the cancer burden.

Several hospital based cancer registries exist in Pakistan such as Karachi Cancer Registry (for adults) and Punjab Cancer Registry maintained by Shaukat Khanum Memorial Cancer Hospital and Research Center. These collect clinical data and provide essential information to track incidence of cancer cases and the patterns of cancer care plans available over time that can be utilized to improve the quality of care and eventually, to

form the basis for coding, summarizing and analyzing population based studies. Environmental and genetic risk factors can also be detected to help identify and develop preventive strategies. They can also be used to assess implementation of standard guidelines and evaluate outcomes of protocols including long term effects of cancer treatment for a more tailored treatment approach since clinical practice guidelines, such as those provided by Children’s Oncology Group (COG), International Society of Pediatric Oncology (SIOP), National Comprehensive Cancer Network (NCCN), European Society for Medical Oncology (ESMO) and American Society of Clinical Oncology (ASCO), etc. that are available to standardize cancer care, are often adapted according to local evidence and patient outcomes.

This paper aims to report local data about the pediatric cancer patients presenting to Aga Khan University, Karachi’s largest tertiary care hospital and one of only five hospitals providing care to pediatric cancer patients in the province of Sindh. Since patients come to AKUH from all over the province for quality and specialized care, this registry can potentially provide an estimate of the epidemiology of cancer in Sindh. Data can also be consolidated with cancer cases from the other hospitals in the province equipped to deal with pediatric cancer to form a consolidated population based registry for this region. This would ultimately help with more streamlined research of causes and introduction as well as implementation of childhood cancer control practices.

Methods

Data sources, collection, storage

Primary data sources for our hospital based registry are patient lists from oncology and radiation oncology clinics and histopathology reports- medical record number lists are generated on a weekly basis and cases are selected by the cancer registrars based on a set criteria. Data is entered into CNExT registry software which is built according to the American College of Surgeons (ACS) cancer program and Commission on Cancer(CoC) standards; unique hospital medical record number, demographic information for each patient, and details of the disease which includes histologic and morphologic diagnosis, and treatment from the time of diagnosis to the time each case is abstracted, are recorded using ICDO-3 (International Classification of Diseases for Oncology-3) codes and AJCC (American Joint Committee on Cancer) 8th edition staging system. Cases are abstracted a few months after the patient’s diagnosis, hence cancer management till then is recorded only and follow up for long term survival or relapse is not maintained at the moment. Quality of the registry data is maintained through monthly audits by the senior registrars and cross checking is done to increase the consistency of the database.

Data Analysis

A descriptive analysis was performed using Microsoft Excel 2020 and STATA version 14 of the data for the time period 2010-2019 and frequencies of different types of cancer were assessed according to the year of presentation, sex and age categories.

The purpose of this study is to report the distribution of patients less than 19 years of age, presenting with different malignancies in a specific time period according to age group, type of cancer, gender, and year of diagnosis.

Results

Overall registry data

A total of 2694 patients between the ages of 0 and 19 were diagnosed with a malignancy at AKUH between January 2010 and December 2019, out of which 1673(62.1%) were males and 1021(37.8%) females. There was a trend for male gender predominance throughout the years. The frequency according to site are of oncologic cases are shown in Table 1.

Analysis of the distribution of reported cancers by age and gender

Cancer cases were most commonly seen in the 15-19 years age group (730 cases, 27.1%) and 0-4 years (624

cases, 23.2%), followed by 10-14 years group (522 cases, 19.4%) and 5- years (490 cases, 18.2%). Females accounted for 37.8%(n=1021) of all pediatric cancer cases and males 62.1% of the cases in the hospital based cancer registry. The distribution of cancer incidence by age categories is given in Figure 1.

Distribution pattern of reported cancers by site and year of diagnosis

Between 2010 and 2019, the highest number of recorded cases in a year was 343 in 2018 and 2019, and lowest was 163 in 2010. A consistent increase of 210% was noted over these 10 years. The five most common sites for cancer in the time period studied were bone marrow (887 cases, 33% of the total), CNS (481 cases, 17.8%), lymphoid (294 cases, 11%), bone tumors (255 cases, 9.5%) and soft tissue (145 cases, 5.4%). The trends in incidence of cancer according to site is shown in Figure 2 and the overall proportion of each cancer in Figure 3.

Discussion

Assessment of accurate incidence and prevalence of pediatric cancer is limited by the absence of a central registry since low and middle income countries like Pakistan lack the resources and organization needed to establish effective population based cancer registries; these can also serve as public health surveillance tools to plan, monitor and measure cancer related services, research and education⁵. However, hospital based cancer registries can provide information about common cancers, localization, age groups, and treatment options available for patients as well as their response rates and survival outcomes to establish the exact need for cancer care services and health policy planning in that particular region⁶. For a reliable hospital based registry, coordination between the local oncologists and trained cancer registrars is required to find, abstract and register cases in an organized database. Collaborations with other centers catering to pediatric cancer patients in Pakistan to combine validated databases can facilitate improvements in survival outcomes and cancer care in that region and eventually lead to the formation of a proper population based registry.

Aga Khan University Hospital is one of the largest tertiary care hospitals in the country and has been maintaining a pediatric cancer registry since 2009. It is one of the primary referral centers for quality pediatric cancer care, making the registry data capable of commenting on commonly seen cancers in the population. For the time period 2010 to 2019, there was an increasing trend in the cases of pediatric cancers presenting each year with numbers almost doubling over the ten year period- this implies an increase in pediatric cancer incidence and could also be attributed to increased awareness and accessibility to healthcare services leading to prompt diagnosis and treatment initiation. A higher proportion of male patients (62%) was observed in our hospital and this is commonly seen globally such as in the 18 registries included in SEER (Surveillance, Epidemiology and End Results) as well as 162 out of 183 national registries evaluated Globocan 2018- this could be attributed to hormonal variations particularly for bone tumors although a combination of immune related, genetic and social factors could play a role^{7, 8}. In the time period studied, leukemias(33%) were most commonly seen, followed by CNS tumors (17.8%) and lymphomas(11%); this proportion corresponds to Globocan's estimates for the most common childhood cancers- leukemia and CNS tumors accounted for 45% of cases and 57% deaths according to the 2018 report⁷. Patterns of site-wise case distribution are also somewhat similar within Pakistan- data from a study reporting pediatric cancer cases from 3 centers within Pakistan between 2016 and 2018 also showed a male predominance and leukemia, lymphomas and retinoblastomas as the top three cancers⁹. The Punjab Cancer Registry, which collects cancer incidence from 27 collaborating centers within Punjab province reported acute lymphoblastic leukemia, glioma and Hodgkins lymphoma as the most commonly occurring childhood cancers in 2020¹⁰. Globocan also reported most of the cases(42%) in the under-5 age group followed by the 5-9 age group- however, we had more patients (27%) between the ages of 15 and 19, followed by the under 5 age patients (23% cases).

Pediatric cancers mostly present with non specific signs and symptoms that can be easily attributed to more common, benign conditions, thus diagnosis and workup is often delayed, especially in resource limited settings like Pakistan where the sophisticated technology required to make accurate diagnoses is not available at most healthcare facilities coupled with a general lack of health awareness, cultural factors and financial constraints¹¹. This is particularly concerning since Globocan ranked South-central Asia and Eastern Asia

the highest for incidence of cancers in children (<19 years), with an incidence of over 143000 according to the 2020 estimates. Over the past few decades, overall survival of childhood cancer patients has improved from less than 30% to about 80% in high income countries¹². However this number is much lower in Pakistan and other low and middle income countries. This burden is complex due to the number of intrinsic hurdles negatively affecting outcomes such as malnutrition, social access, lack of infrastructure to gain access to healthcare as well as lack of capital to build and maintain proper facilities.

The Global Initiative for Childhood Cancer, announced by the World Health Organization (WHO) aims to reach a 60% survival rate for pediatric cancer by 2030 and this can only be done with a special focus on cancer care in LMICs. To improve cancer care delivery systems especially in low resource countries, a continuous quality improvement system could help streamline existing resources for better utilization while simultaneously improving infrastructure and caregiver knowledge. Collaboration between institutions to identify gaps and implement local research with careful monitoring of outcomes could also increase long term survival.

Conclusion

In the absence of a centralized cancer registry, hospital based registries can provide a starting point to assess cancer occurrence in the region or country. True incidence of pediatric cancer can only be determined with the establishment of a proper cancer registry using standardized, preferably web-based, forms for data collection at all hospitals throughout the country along with recruitment and training of personnel.

Declarations

The authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

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Cancer incidence according to age categories



