

Review Article

The importance of pediatric cancer registries in childhood cancer control

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Abstract

Cancers in children, as the major cause of pediatric deaths, account for one percent of all cancers. Cancer control program is intended to diminish occurrence, morbidity and mortality and to improve the life quality of people with cancer. A key element of any reasonable cancer control program is cancer registry. A registry which serves as the backbone for any treatment plan in childhood oncology. Given the importance of pediatric cancer, the present paper explores the importance of pediatric cancer registry in childhood cancer control.

Keywords: childhood cancer, cancer registry, control and planning

Cancer incidence in children is rare, but it factors are associated with increased risk of constitutes the second major cause of death in childhood cancers, though these factors affect children younger than 15 years of age after only less than 5 percent of all cancers (5, 6). accidents (1, 2). With the improved control of Also, cancer incidence rates vary in diverse contagious diseases, today childhood cancer is national groups both in a single country or in considered as a serious illness in children (3). countries with shared national community (7). The causes of most pediatric cancers are not About 75 to 150 people in every one million are known, but they may be induced by affected by this disease annually (8). Such environmental risk factors, exposure to chemical diversities could be attributed to environmental substances or common infectious agents, ABO agents, early or delayed exposure to infectious blood type and genetics (4). Many genetic disorders and genetic predisposition (7, 9).

Childhood cancers are different from adult cancers In developing countries, with improved control of (10). This type of cancers is not limited to a single infectious diseases and current population growth, disease and takes a variety of forms and infant mortality rates has dropped, but the pathogenic causes with diverse histopathology prevalence of cancer in child is expected to morphologies, which may affect various parts of increase by 30 percent by 2020 (15).

human body (11-13). According to the International Classification of Childhood Cancer (ICCC), there are 12 major types of cancers. The most common childhood cancers are leukemia and lymphoma followed by central nervous system (CNS) tumors (14).

Child cancer registries are essential tools to monitor and assess the impact of health system and cancer treatment (3). Given the role of pediatric cancer registry in childhood cancer control, this paper sets out to explore its importance.

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Overview of cancer registries

A cancer control plan is proposed as a public health plan formulated to reduce the occurrence and cancer-related mortality and to improve the quality of life of cancer patients in a particular state or country by systematic execution of the program based on evidences for early diagnosis, prevention, treatment and sedation, and utilization of the accessible resources (16). Gathering information about occurrence, type and cancer status is the first step to manage cancer burden, which is conducted by the frame of cancer registries (1).

Cancer registry is an integral part of health information which can be utilized to monitor cancer types in certain areas and to adjust useful cancer control programs (17). The registries allows improved programming of cancer plans, providing an effective vehicle for observation and assessment of the health system performance (18, 19). The chief role of cancer registries is calculating incidence rates, which enables the comparison of different cancer types in various

demographic groups. Studying the cause and methods of preventing cancer is another function of these registries (16). However, there suffer from drawbacks such as inaccurate information about population, limited diagnostic and treatment abilities, cultural barriers, instability of economic or political conditions and large population movements, which can lead to imperfect registration and inaccurate estimation of cancer incidence (7).

The classification of cancer registries are usually population-based (PB) or hospital-based (HP). PB registries identify all cases of cancers that occur in a certain population. HB registries focus on patients of a specific type of cancer, which can provide detailed information. Since PB registries cover a certain population in a geographical location, they are considered as the gold standard for cancer registry (18). According to reports released by the World Health Organization (WHO) in 2002 and 2011, PB cancer registries are the cornerstone of national cancer plans. PB registries collect data from several sources in which cancer is probably recognized or treated.

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These sources include records of diagnostic centers such as histopathology or cytopathology departments and hospital records. Furthermore, death certificates suggest that cancer is a major or synergistic cause of death (20).

HB cancer registries provide an opportunity to start a recording process by offering data about the clinical epidemiology of cancer. It also allows gathering important information about all patients referred to hospitals during their disease under various treatment conditions. It should be noted that HB registry cannot replace the PB registry, but this type of registry constitutes the first step for organizing a PB cancer registry (18). To set up a registry, whether PB or HB, it is vital to identify suitable resources, seek assistance from the government, policy makers and professionals and collect relevant data. Long-term support and cooperation are essential to set up a registry (18).

Some of the key criteria of registry records can be categorized into identification and demographic information (including sex, date and place of birth and address), diagnostic information (including date of the first visit, diagnostic tests, date of

diagnosis, primary site, histopathological type, size and stage of tumor), the first course of treatment (including presence/absence of an open surgery resection, chemotherapy and radiation) and follow up information (including vital status and date of last follow-up) (16, 18, 21).

The role of cancer registries in pediatric oncology

Cancer in people below the age of 20 is relatively rare, and its occurrence can raise a series of psychological, medical, societal and ethical concerns. Furthermore, particular treatment methods should be applied for these cancers (22).

About 200,000 children and teenagers are diagnosed with cancer worldwide every year, of whom 80% live in low-income and middle-income countries (LMICs), which account for nearly 90% of cancer-induced deaths in childhood (7). Furthermore, due to the effects of cancer itself or its treatment methods, this type of cancers is associated with long-term inability (7).

Epidemiology plays a major role in unraveling pediatric cancer causes (23).

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). Updating information about pediatric cancer incidence is pivotal to epidemiologic research, disease supervision and establishment of a foundation for service delivery programming (24).

Child cancer registries for specific populations are essential to monitor and evaluate the efficacy of health systems and cancer treatment and provide records on time-corrective activities (3). They represent the first step in managing cancer burden to gather information about type, frequency and sites of cancer incidence (4).

However, setting up a childhood cancer registry for a population group, particularly in limited-recourses settings, is a challenge, but it is possible to set up a high-quality childhood national cancer registry due to the low rate of child cancer cases, particularly in countries where child cancer treatment is focused in certain hospitals (3).

The various spectrums of child cancers, relative scarcity of childhood cancers and their classification based on histology, as compared with site-specific classifications, to evaluate cancer incidence and death in adults, are among factors that distinguish childhood cancer registries from adult registries (7). Furthermore, despite a number of PB cancer registries, scant attention has been paid to gathering data about pediatric cancers. As these registries demonstrate a small

portion of all cancers, more sources of information might be requires and final statistics should be taken into account for precise quality control, considering their sensitivity to inaccurate or missing data (7). In view of the costs, problems and uncertainties associated with true PB cancer registries, HB registries constitute an accurate dataset for childhood cancer, as well as the first step to possible PB evaluation of cancer incidence rate (7). **Overview of pediatric cancer registries in the world**

Childhood Cancer International (CCI), formerly known as the International Confederation of Childhood Cancer Parent Organizations, which was established in 1994, acts as a worldwide umbrella organization that covers paediatric cancer grassroots and national parent organizations. CCI has proposed the reasons why childhood cancer should be a global child health priority, which include:

Statistics does not tell the whole story: The estimation of total cases of new paediatric cancer is 175,000-250,000 each year, which is a considerable underestimate. It could be due to the deficiency of most cancer registries in LMICs, prevalent misdiagnosis and under diagnosis and/or under-registration of LMIC children with cancer. It is estimated that about 90% of children with cancer live in developing countries (LMIC).

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Paediatric cancer does not have border:

Child deaths due to infectious diseases has dropped dramatically worldwide, but the mortality rate of paediatric cancer is on rise. An increasing share of child mortality in both developed countries and LMIC is related to non-communicable diseases (NCD), particularly child cancer. Most public health practitioners are concerned about this increasing rate.

Paediatric cancer is treatable, but there is**vast difference between countries and continents in terms of survival rates:**

At the present, more than 70% of paediatric cancers are treatable using novel therapeutic methods. However, the survival rate depends on the type of cancer and factors such as medical culture, health system of a country and socioeconomic situation. In LMICs, the health care systems suffer from serious limitations and problems and survival rate of pediatric patients in these countries is 10-20% (that is, only 1-2 child out of 10 diagnosed with and treated for cancer will survive) while this rate is 80–90% in HICs (that is, only one or two child diagnosed with and treated for cancer will die).

Child are our future and they serve to live:

With the death of each child, families, communities and nations lose a wealth of their potentials and talents. Furthermore,

many survivors often experience depression and anxiety, which can have a huge bearing on their well-being.

No family should lose its assets and go bankrupt when a child develops cancer**Access to best possible care for children****with cancer is their right as a human****not a privilege:**

children with cancer deserve to live life to the full. The future of children with cancer should not rest solely on the shoulder of parents and friends who have lost their loved kids, or the kindness of strangers who feel their pain. The leaders of societies should be held accountable and serious and decisive measures should be taken to meet the demands of children with cancer, survivors and their families.

This type of cancer is relatively rare so that cancer incidence in children (under 15 years of age) in industrialized countries is less than 1% of all cancers. In developed countries, despite considerable therapeutic advancement, cancer is the second most common cause of death in children (7).

It is difficult to identify sources and determinants of pediatric cancer despite growing information acquired about child cancer incidence during the past decades (25). Chow et al. conducted a population-based case control study on race-related cancer incidence among children in five

states of America. The results demonstrated that whites, black and mixed white/black children were different in this regard, which could be attributed to ethnic, socioeconomic and genetic factors (7). In 1971, the National Pediatric Cancer Registry was established by Hungarian Pediatric Oncology Network. Data recorded in this registry is based on epidemiology, treatment status and follow-up of child cancers. An Internet-based child cancer registration and connection system was introduced by National Pediatric Cancer Registry in 2010 (8). In Europe, over 200 child cancer registries for different stages of development have been set up for data collection (26). The number of these registries has been on rise even in areas where common cancer registries are already in place (26). The establishment of Pediatric Cancer Registry indicates a step forward in the realm of pediatric cancer to evaluate the effectiveness of childhood cancer treatments and maximize utilization of medical assets (8). Unfortunately, in LMICs, the epidemiology of childhood cancer is not taken seriously (18). In these countries, pediatric cancer is considered as a "candidate cancer with controlling cancer manage opportunities" the results of which offer an ideal analysis of defense and function (27). However, research on causes and treatment of cancer is limited, which could be due to scarcity of resources and training, financial limitations, lower priority of cancer control program, improper infrastructure and limited experience (18, 28). In these countries, the lack of high-quality PB cancer registries limits access to data on the epidemiology of childhood cancer (7). The establishment of a cancer registry in these countries poses a major challenge due to problems that must be addressed to enhance the quality and exhaustiveness of information (18).

In developing countries, due to their particular socioeconomic situation, the convergence of both PB and HB provides an apt opportunity. In this context, PB and HB can be established to gather various data on cancer, but their cooperation will surely yield positive results for present and future patients with cancer (18).

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Conclusion

In general, cancer registries are crucial for monitoring and planning cancer to identify public health preferences. Data collection and interpretation along with operationalization of results are among the goals of cancer registries. They are used to ensure cancer surveillance, thereby laying the ground for further investigation and policy decisions. Setting up cancer registries for children is essential to monitor and assess the impact of health system and cancer treatment. Such information can be obtained by fostering cooperation between low-income and high-income countries. The effect of this strategy on cancer outcomes is providing resources and intellectual skill to report cancer prevalence in LMICs and formulate universal plans. However, given that the incidence of pediatric cancer is unknown in many LMICs, greater attention should be paid to the development of pediatric cancer registries in LMICs.

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