

Pediatric cancer surveillance in China: A hospital-based introduction

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Background

In recent years, increasing numbers of families have been affected by childhood cancer. According to data from the International Agency for Research on Cancer (IARC) of the World Health Organization, approximately 279 000 new cases of cancer were predicted in children and adolescents aged 0–19 years worldwide in 2020. The global incidence of childhood cancer is 10.9 per 100 000 (global standard rate) and the mortality rate is 4.2 per 100 000.¹ According to data from the China National Cancer Center, the incidences of cancer in 2017 were 9.9 per 100 000 in children aged 0–14 years and 11.5 per 100 000 in adolescents aged 15–19 years.² There are estimated to be approximately 22 000 new cases of childhood cancer in China each year, and the incidence of malignant tumors in children aged 0–14 years has increased by 2.5% annually in the past decade.³

The cancer registration report is a statistical mechanism to collect, store, collate, analyze, and evaluate information concerning cancer incidence, mortality and survival in an organized manner. Cancer registration is divided into population-based, hospital-based, and special types. Hospital-based registration involves registration and reporting of relevant information regarding patients with cancer who visit one or a few hospitals. The targets of

registration are all cancer patients who visit the hospital, regardless of whether they are registered residence or not. Hospital-based registration is also the basis of population-based registration. The data sources of population-based registration are extensive; thus, they can macroscopically reflect epidemiological data (e.g., the incidence and mortality rates of different sexes, ethnicities, and regions in the target population). This enables oncologists and public health scholars to study cancer incidences and formulate appropriate public health policies. Hospital-based registration emphasizes the recording of diagnostic data and treatment information, as well as patient outcomes for various diseases, stages, and pathological types. This facilitates evaluation of the effectiveness of cancer diagnosis and treatment in hospitals and provides basic data concerning clinical cancer research.

In China, population-based cancer registration has developed from its initial stage in the 1950s to a registration system covering 438 million Chinese population.⁴ The population-based cancer registration only collects the basic information of cancer patients and lacks detailed information regarding treatment and prognosis. In addition, because of the limitations of various objective conditions, hospital-based cancer registration has been

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limited, especially with respect to the registration system for childhood cancer. The childhood cancer registration carried out thus far only focuses on single type of cancer (e.g., a leukemia registration system) or a single medical institution/area, and the registration coverage is limited. Therefore, the establishment of hospital-based cancer registration is an important task for the control of childhood cancer in China.

Most countries and regions worldwide have gradually established a whole-population cancer registration system that focuses on hospital-based cancer registration. Most developed countries (e.g., the United States, Australia, Switzerland, Denmark, France, Germany, and Singapore) have specific registration systems for childhood cancer. In Denmark, 98% of children with cancer are treated at one of the four regional childhood cancer centers in Denmark. These four regional childhood cancer centers also participate in childhood cancer registries.⁵ In Switzerland, “The Cancer Registration Act” became effective in January 2020; this modified the Swiss Childhood Cancer Registry from a population-based registry to a hospital-based registry (i.e., the Childhood Cancer Registry of the Federal Government). The Cancer Registration Act requires doctors and hospitals to report all cases of cancer diagnosed and treated in children and adolescents under 20 years of age to the Childhood Cancer Registry. Meticulous registration enables reliable conclusions to be drawn regarding the development of different types of cancer, their courses, and the efficacies of treatments.⁶

In China, the lack of a comprehensive childhood cancer registration system is a limiting factor in assessing the current status of childhood cancer treatment, as well as the childhood cancer prevalence and growth trends. In June 2019, the National Health Commission of the People’s Republic of China allowed the National Center for Children’s Health, Beijing Children’s Hospital, Capital Medical University to establish the National Center for Pediatric Cancer Surveillance (NCPCS), which serves to build a childhood cancer surveillance system and carry out national child cancer surveillance. Concurrently, the National Health Commission of the People’s Republic of China issued multiple relevant policies concerning the treatment and surveillance of childhood cancer nationwide, thus providing an important policy foundation for the development of childhood cancer surveillance. The establishment of the NCPCS marks the existence of a comprehensive and specialized surveillance system for childhood cancer nationwide, it will also provide an important basis for key data regarding the prevention and control of childhood cancer.

Target registrants

The national pediatric cancer surveillance is hospital-based, with pediatric cancer medical institutions as pediatric cancer surveillance sites. The surveillance

sites directly report to the NCPCS for two-level case information registration. Target registrants include Chinese children aged between 0 and 19 years with cancer who are discharged from hospital. Diseases include all cancers, benign tumors, carcinoma in situ, dynamic undetermined, or unknown tumor. The first three ICD-10 digits of the main or other diagnosed diseases of archived hospitalized cases represent anatomical sites within C00–C97, D00–D09, D32–D33, and D37–D48.

Surveillance sites

Pediatric cancer surveillance sites are established in medical institutions that perform diagnosis and treatment of childhood cancer. The National Health Commission of the People’s Republic of China has designated specific institutions and cooperative groups for the diagnosis and treatment of children with cancer; it has also required the designated institutions and members of the cooperative groups (i.e., designated surveillance sites) to be incorporated into the surveillance system for cancer with children, along with regular reports of pediatric cancer cases (i.e., report cards).

In accordance with the national policy requirements, the NCPCS divides the surveillance sites into designated and non-designated surveillance sites. As of April 2021, there are 389 surveillance sites. Thus far, the sites are distributed in 31 provinces, autonomous regions, municipalities directly under the central government, and the Xinjiang Production and Construction Corps; the sites include 199 designated surveillance sites and 190 non-designated surveillance sites. According to their specialties, the surveillance sites are divided into 299 general hospitals, 63 children’s hospitals, child and maternal healthcare institutions, 22 cancer hospitals, and ophthalmic hospitals. The distribution of pediatric cancer surveillance sites in China is shown in Figure 1.

Registering variables

The NCPCS has designed short-list pediatric cancer report cards (Table S1) and long-list pediatric cancer report cards (Table S2). The long-list report cards add more detailed diagnostic information to information already present in short-list report cards. The NCPCS requires designated surveillance sites to fill long-list report cards; non-designated surveillance sites are encouraged to fill short- or long-list report cards.

Data collection and quality control

Surveillance sites are responsible for the registration and reporting of the report cards each month. Surveillance sites may use various forms to fill in report cards. The surveillance sites with a small number of report cards use a manual filling and file import method; the surveillance sites with a large number of report cards and good



FIGURE 1 Distribution of pediatric cancer surveillance sites in China. Each dot represents a surveillance site.

hospital information infrastructure use an information port docking method to perform automatic data reporting. The surveillance sites have two staff members responsible for the sorting, quality control, and reporting of report cards.

The usefulness of cancer registries is dependent on the quality of the data: specifically, reporting timeliness, comparability between registries and over time, data recording accuracy, and case ascertainment completeness.⁷ The NCPCS has formed a complete set of quality control plans by referring to the docking standard for the collection of first page information of inpatient medical records in the performance appraisal and medical quality management of national tertiary public hospitals (2019), as well as the quality control standard for cancer data registration of the International Agency for Research on Cancer (IARC) of the World Health Organization. These standards mainly include uniqueness verification, integrity verification, validity verification, and logic verification, as described below.

For uniqueness verification, each report card must have a unique identification number, composed of the organization code, medical record number, and discharge time. If the three information items are identical between any two records, staff at the surveillance sites and the NCPCS identify them and decide whether to delete or merge them, thereby verifying the uniqueness of the report cards.

For integrity verification, key report card information must be complete. The report cards contain compulsory variables, such as organization code, medical record

number, name, sex, date of birth, name of contact, admission time, discharge time, diagnosis code and type of cancer, medical payment methods, and total hospitalization expenses. If required information is missing from the report card, the NCPCS will return the report card to the surveillance sites and record the card again after the report is completed.

With respect to validity verification, key report card information must be accurate and reliable. For example, the ID number will be verified by ID number encoding rules and the parity bit checking algorithm. Furthermore, consistency will be checked in terms of the ID number, date of birth, sex, and disease diagnosis will be verified. ID numbers that fail to pass the verification step will be reexamined or eliminated.

Concerning logic verification, information on report cards must be consistent and authentic. For example, consistency between sex and disease (e.g., whether a disease only present in boys has been diagnosed in a girl) will also be verified. Additionally, chronological consistency will be verified, with respect to admission time and date of birth, admission and discharge times, and discharge time and date of operation. If report cards fail to pass verification, they will be returned to the surveillance sites and recorded again after verification and modification by registrars.

Pediatric cancer surveillance database

The national pediatric cancer surveillance database is a cancer database formed on the basis of hospital-based childhood cancer surveillance, which is managed

by the NCPCS. Although the database is currently not accessible to the public, the NCPCS plans to publish cancer surveillance results in the form of an annual report. In February 2021, the NCPCS officially released the “National Pediatric Cancer Surveillance Annual Report,” which is the first special report in China regarding the distribution of childhood cancer treatment. The first published annual report analyzed the surveillance information of childhood cancer in terms of six dimensions: cancer spectra, age/sex composition, distribution of medical treatment, composition of medical payment method, average hospitalization expenses, and average length of stay. The report showed that, among all discharges of children with cancer, the top five diseases were leukemia (57.21%), unknown and other cancers (16.21%), lymphoma (8.15%), brain tumor (5.63%) and bone cancer (3.31%). In addition, according to the distribution of provincial-level regions receiving children with cancer from outside the provincial-level regions, approximately half of children with cancer were treated in Beijing, Guangdong, Shanghai, Chongqing, and Jiangsu.⁸ Pediatric cancer surveillance is relatively new in China; at this stage, the surveillance sites have not yet achieved full coverage of pediatric cancer medical institutions, although the current surveillance system covers approximately 85% of the intended institutions. Surveillance data regarding the distribution of medical resources for children with cancer in various provinces indicate that most areas continue to lack high-level and sufficient medical resources, thus causing children with cancer to seek medical treatment in other provinces or regions. With respect to regional distribution, Beijing is part of North China, Guangdong is part of Central and Southern China, Shanghai and Jiangsu are part of East China, and Chongqing is part of Southwest China. Compared with the other four regions, medical resources for children with cancer are generally scarce in the Northeast and Northwest. The findings of surveillance data suggest that the allocation of medical resources should first be optimized for children with cancer in the Northeast China and Northwest China. Pediatric cancer specialization efforts should be strengthened, thus improving the level of relevant treatment and infrastructure construction, which will reduce the frequency of cross-regional diagnosis and treatment of children with cancer. Solving the cross-regional medical treatment problem will help to solve the cross-provincial medical treatment problem for children with cancer. Provinces with extensive medical resources should gradually play the role of discipline and talent training to improve the diagnosis and treatment levels of surrounding provinces. Provinces with minimal medical resources should gradually increase the efforts toward relevant health-related resources, including infrastructure construction, talent training, and financial support. Thus, provinces with minimal medical resources can be fully improved, leading to an increased ability to adequately treat children with cancer in their home provinces.

This provides a valuable basis for optimizing the allocation of medical resources for children with cancer.

Prospect

Compared with adults, pediatric cancers are rare; each year, they affect 50 to 200 children per million worldwide. Because there are 16 different major types and many subtypes, no cancer center encounters large numbers of patients with the same diagnosis.⁹ The greatest difficulty in childhood cancer prevention and treatment research is therefore the insufficient number of cases. The population of children aged 0–17 years in China is approximately 271 million, comprising 13% of the world’s pediatric population (the second-highest number worldwide).¹⁰ With the support of China’s health administration, hospital-based pediatric cancer surveillance can fill a vital gap in medical diagnosis and treatment. The pediatric cancer surveillance network will gradually achieve full coverage of pediatric cancer medical institutions and provide a foundation for improving the pediatric cancer surveillance database. The national pediatric cancer surveillance database will become one of the largest and most comprehensive sources of childhood cancer records worldwide. In the future, the NCPCS will gradually publish more valuable information for use by researchers in related fields.

There is a critical need for hospital-based pediatric cancer surveillance. The primary tasks of the NCPCS are to provide the nation with indicators such as incidence, mortality, prevalence, and survival rate of children with cancer. It also aims to provide data regarding diagnosis, therapeutic methods, effect evaluation, adverse reactions, and survival information, thus helping to understand the disease burden and changing trends of pediatric cancers in China. The secondary tasks of the NCPCS are to provide information regarding the general status and developments regarding childhood cancer among medical institutions in each region; to provide a basis for suggestions regarding the allocation of medical resources to manage pediatric cancer, (e.g., medical personnel, hospital beds, and other related facilities); and to improve the accessibility of cancer diagnosis, treatment, and care for children in the region. The tertiary tasks of the NCPCS are to provide data concerning the diagnosis, treatment, and nursing status, as well as the quality and effects of diagnosis and treatment, at institutions that care for children with cancer. It also aims to investigate new technologies and methods implemented by hospitals, scientifically evaluate their development and effects, and provide evidence for monitoring and evaluating the effects of measures to control pediatric cancer. The final tasks of the NCPCS are to provide a foundation for clinical data analysis and large-scale cohort studies, as well as early diagnosis and early treatment of pediatric cancer; to provide data regarding the etiology, clinical diagnosis, treatment, prognosis,

and prevention of pediatric cancer; and to provide data support for the formulation of standardized guidelines for diagnosis and treatment of pediatric cancer, training for specialized talents, and continuing education programs.

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CONFLICT OF INTEREST

None

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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