



Chapter 1: Introduction

The burden of childhood cancer in India

Childhood cancer is a physically and cognitively debilitating disease, leading to short-term fatal consequences or long-term adverse effects of prolonged illness and treatment. According to the recent NCRP report based on data from hospital-based cancer registries (HBCRs), Childhood cancers (0-14 years of age) comprise 4% of all reported cancers in India. The proportion of children affected may be higher owing to “missed cases” due to low coverage, lack of awareness, delayed diagnosis and a fledgling electronic referral system.

The age-adjusted incidence rate (AAR) of childhood cancer (0-14 years) worldwide is 140.6 per million person-years. The age-adjusted incidence rate per million (AARpm) is an important metric to monitor the new cancer cases in a defined population. There are variations among different parts of the country, with New Delhi showing the highest AARpm among boys (203.1) and girls (125.4). From southern India, Chennai ranks second among boys (146.7) and third among girls (52.7) in childhood cancer incidence. In the northeast, the AARpm was the highest in Aizawl among boys and girls (133.9 and 91.4, respectively).

A noticeable difference in the incidence rates between genders is observed in countries worldwide and India. There is a higher incidence in males compared to females, which is stark in low-income countries (LIC) compared to high-income countries (HIC).

The most common primary sites of pediatric cancers include the 3B’s, namely “blood, bone, brain”. Some of the most common malignancies include leukaemia, lymphoma, central nervous system (CNS) tumours like glioma and medulloblastoma, tumours of the bone and soft tissue like Ewing’s sarcoma, rhabdomyosarcoma and “blastomas” that affect different solid organs. Childhood leukaemia is followed by lymphomas which rank second in their prevalence after leukaemia. Unlike in the west, Hodgkin’s lymphoma is more prevalent than non-Hodgkin’s lymphoma in India.

In contrast to the adult counterparts, childhood cancer variants may be characterized by atypical or nonspecific disease presentation and non-traditional pathognomonic disease markers, which calls for specialized training programs in paediatric oncology for early disease recognition and effective implementation of the treatment protocol.



The long-term physical and psychological effects of the treatment can become lifelong stressors. The physical effects of childhood cancer treatment could result in frequent hospitalizations among survivors in adult life; epilepsy, pituitary hypofunction and abnormal menstruation, non-infective enteritis, colitis, pneumonia and upper respiratory infections. They can also be affected by psychological stress due to physical effects (amputation, hair loss). Therefore, it is imperative to understand that the burden of childhood cancer could be long-term. Special attention needs to be given to the physical and psychological stressors to improve the quality of life of these patients and prevent long-term morbidity.

Childhood cancer care services

The first paediatric oncology unit in India started in the 1960s, and the number of such units has increased since the 1980s. A national survey of childhood cancer services was conducted in 1988. In 50% of the surveyed centres, paediatric oncology cases were handled by adult oncologists, and only 10% of the centres had paediatric oncologists primarily trained abroad. A scarcity of specialists in paediatric oncology could be attributed to a lack of training programmes in this area. However, the last decade has seen an improvement in paediatric oncology education with the initiation of fellowship and super speciality courses for trained paediatricians and short-term training programmes for primary care paediatricians and nurses, facilitating early recognition and referral to higher education centres.

Most paediatric cancer care centres in India are in urban areas, leading to delayed access by the rural population. It is seen that children with cancer often present with an advanced-stage disease which worsens the outcome. The lack of sturdy referral systems is one of the reasons for late-stage presentations and delayed diagnosis.

For early treatment initiation, accessibility to anticancer drugs and availability of adequate drug stock are essential. In addition to the essential medicine list for children published by the World Health Organization (WHO), a working group was created by the Societe Internationale d'Oncologie Pediatrique (SIOP) to identify the essential medications for childhood cancers in low-income countries, taking into account the logistics of accessibility and accountability. A total of 51 drugs spanning three categories of antineoplastic, antimicrobials and supportive care medications were included. Such lists can guide the development of nation-specific essential medicine lists, which need to be periodically updated and improved based on updated treatment guidelines. India published 'The national essential drugs list' in 1996, later revised and renamed 'The national list of essential medicines, which was last updated in 2015. Although



most childhood cancer drugs have been included, as enlisted in the essential medicine list for Children by WHO, it does not mention paediatric formulations and dosage. The states of India have drawn up their list of essential medicines based on their patterns of cancer epidemiology in adults.

Government hospitals offer high-quality medicines for childhood cancer or are highly subsidised. The central and state governments launched health insurance schemes to provide financial packages that offer coverage for various childhood cancer care health expenditures. The Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PM-JAY) was launched in 2018 to provide financial assistance for secondary and tertiary care hospitalization. Oncology benefit packages are provided in four specialities: medical oncology, surgical oncology, radiation oncology, and paediatric cancer.

Lack of essential infrastructure for diagnosing and treating childhood cancer is one of the major causes of treatment abandonment, ranging between 10-63%. A survey of the diagnostic facilities in low-income countries revealed significant gaps in the availability of essential laboratory diagnostic infrastructure, which hinder an accurate diagnosis in suspected paediatric oncology cases.

The rationale of this study

The role of programmes and policies in childhood cancer control cannot be stressed enough. Currently, the national-level programmes and policies mainly focus on adult cancer and related cancer risk factors primarily implemented through the NPCDCS. There is, however, a need for a well-defined evidence-based national-level policy dedicated to childhood cancer.

Developing evidence-based policies for childhood requires a situational analysis of childhood cancer services' present state. Such interventions will enable high-quality care within limited health care resources, culminating in improved survival and quality of life of pediatric cancer patients in India.



Aim and Objectives

Aim:

To assess the status of childhood cancer care services in India

Objectives:

Primary: To assess the

- (i) Availability of childhood cancer care services
- (ii) Facility preparedness, treatment-related practices and referral linkages in childhood cancer care
- (iii) Barriers and facilitators in the provision of childhood cancer care services