A situational analysis of childhood cancer services in India,

Policy brief

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ICMR – national centre for disease informatics and research
Bengaluru, India

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Improving lives: children with cancer

Executive statement/summary/aim

A significant chunk of the invisible and silent part of the entire "cancer iceberg" in India is childhood cancer. The country's paediatric cancers contribute substantially to the total cancer burden. This has driven attention to the state of childhood cancer care services in India, and that is clearly the best place to start if a transformative change has to be brought in. Delays in diagnosis and attendant delays in initiating treatment have been a significant cause of poor outcomes and survival. However, a primary prerequisite in determining a reformative course of action is complete knowledge of the current state of affairs.

The ICMR -National Centre for Disease Informatics & Research (NCDIR) at Bengaluru has been operating the National Cancer Registry Programme (NCRP), which was initiated in 1981. The cancer registries under the NCRP are of two kinds- population and hospital-based. Cancer registries are involved in the systematic collection, analysis, interpretation and dissemination of cancer data to facilitate cancer prevention and control programs. According to the recent reports of the NCRP, childhood cancers (0-14 years of age) comprise 4% of reported cancers in India. The age-adjusted incidence rate per million (AARpm) varies across the country. New Delhi recorded the highest AARpm among boys [203.1 per million] and girls [125.4 per million].

The ICMR NCDIR assessed the situation of childhood cancer care services in India. Such a situational assessment was considered essential to suggest the initiation of programmatic and policy interventions.

This policy brief presents a bird's eye view of 'A Situational Analysis of Childhood Cancer Care Services in India, 2021', sharing significant highlights and findings that can be utilised by policy and decision-makers, programme implementers and healthcare professionals on the ground to strengthen childhood cancer care services across the country. This would help achieve significantly improved treatment and survival outcomes for children with cancer – an invaluable milestone in the larger childhood health scenario of the country.

The Context & The Challenge

- Four per cent of all cancers in India are among children aged 0-14 years, and these are physically and cognitively debilitating conditions
- India's first paediatric oncology unit came up in the 1960s, and more began in the 1980s.
- Most such centres are clustered in urban areas, there is a lack of sturdy referral systems, smooth and undisturbed access to medications is a problem, and huge gaps are in the infrastructure required for efficient diagnostics and treatment services.
- There are issues with seeking timely and appropriate treatment, completion, and long-term care.
- All the above challenges are closely linked to the absence of a dedicated national policy and programme focusing on childhood cancers. The current cancer program focuses on adult cancers.

Introduction

The study was initiated to assess the status of childhood cancer care services in India, giving special attention to:

- Availability and distribution of childhood cancer care services
- Facility preparedness, treatment-related practices and referral linkages in childhood cancer care
- Barriers and facilitators in the provision of childhood cancer care services

As the central coordinating agency for the assessment, ICMR-NCDIR provided technical support, including overall supervision, study tools and an online portal, survey implementation, and data management. The situational analysis was conducted using a cross-sectional survey design and included 137 tertiary level hospitals, 92 secondary level hospitals, 16 State Nodal Officers/NPCDCS officers and 9 Civil Society Organizations/Non-Governmental organisations (CSOs/NGOs) in 26 states and four union territories (UT). A nodal hospital identified in each State/ UT is required to further identify a representative network of three to five childhood cancer treating hospitals (tertiary level) and two to three district/sub-district hospitals (secondary level), depending upon the geographical size of the region and covering public/private/NGO facilities. Descriptive statistics were used to analyse and present the final survey results. The World Health Organization (India and SEARO) Offices funded and supported the study.

Key findings

Availability of childhood cancer care services

- Less than half of the public and private tertiary hospitals had a dedicated paediatric oncology department. Childhood cancer care services were provided at over one-third (40%) of the secondary level charitable hospitals, which was higher in private (56.5%) secondary hospitals than public (32.8%) secondary hospitals. [Figure 1]

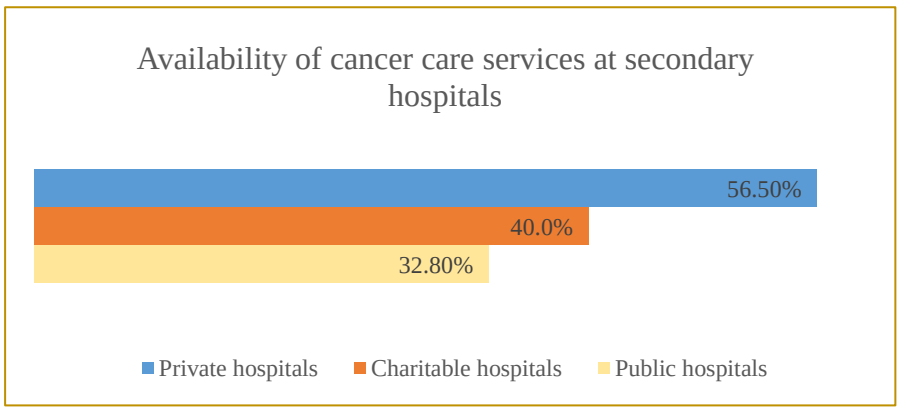

Figure 1

Referral

- Over two-thirds of the government tertiary hospitals had referral linkages with non-childhood cancer-treating facilities; however, such links were seen in less than half of the private tertiary hospitals. [Figure 2]

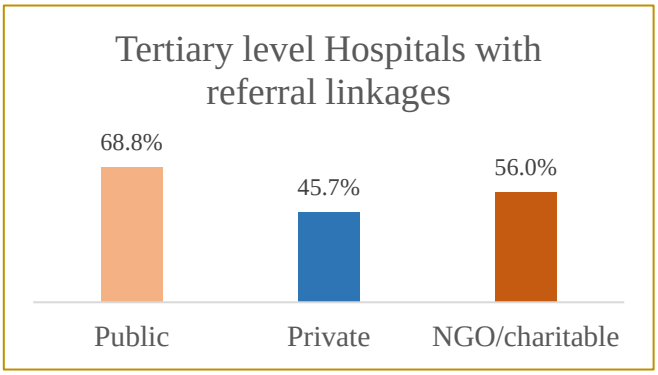

Figure 2

Approach to childhood cancer care

- Most tertiary-level hospitals had supportive care facilities. However, facilities for hospice care were available in less than half of the hospitals.
- 76.6% of the public tertiary hospitals adopted a multidisciplinary team approach for childhood cancer treatment, compared to 35% of the private tertiary hospitals. [Figure 3]

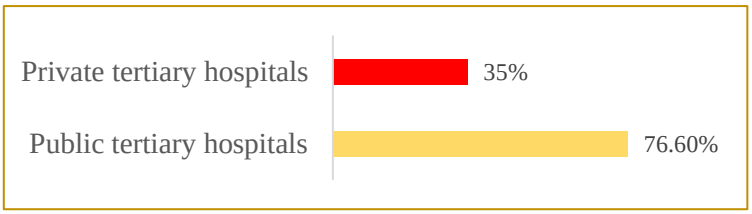

Figure 3

- Over 90% of the tertiary hospitals had facilities for histopathology.
- Fewer public tertiary hospitals had facilities for immunohistochemistry, flowcytometric immunophenotyping, cytogenetics, tumour markers and fluorescence in situ hybridisation (FISH) testing and diagnosis.
- Over 80% of the tertiary hospitals had radiodiagnostic facilities. The availability of bone scans and PET scans was lower, especially in public sector hospitals.
- Less than a quarter of the public hospitals had facilities for haemopoietic stem cell transplantation (HSCT) compared to half of the private hospitals (54.3%).

Availability of human resources for childhood cancer care

- Availability of specialised manpower was low in public tertiary hospitals; less than half of the hospitals had a paediatric oncologist (48%), paediatric oncosurgeon (14.2%), paediatric intensivist (38.9%), medical oncologist (46.7%), and palliative care physician (37.6%). Nurses trained in paediatric cancer and palliative care were available in less than 50% of the public and private tertiary hospitals. [Figure 4]

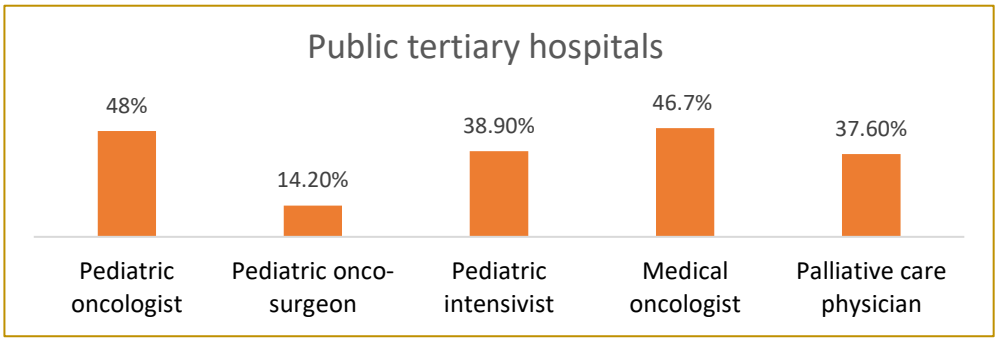

Figure 4

Availability of childhood cancer-treating medications

- Less than 50% of the public tertiary hospitals had stocks of all four classes of cancer-treating drugs. The availability of targeted therapies was the lowest. [Figure 5]

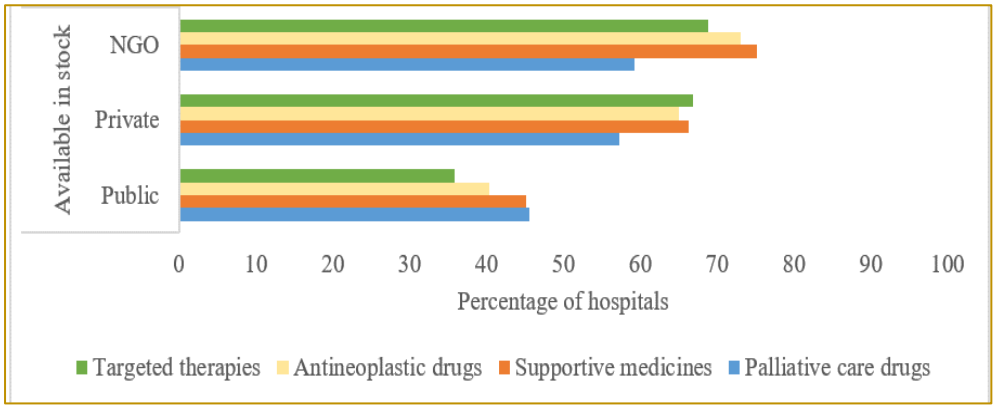

Figure 5

Financing mechanism

- The most commonly adopted financing mechanism comprised the Ayushman Bharat Scheme at public and secondary level hospitals and ESI/State specific schemes at private tertiary hospitals.

Research and Training

- About a third of the tertiary hospitals had active paediatric oncology clinical research programs

Major challenges encountered in addressing childhood cancer care

Public tertiary and secondary level hospitals	State Nodal Officers	Civil Society Organizations
• Shortage of beds/human resources/equipment	• ***Lack of*** • -Awareness among parents/caregivers about early signs and symptoms • -Expertise in grassroots healthcare workers in recognizing signs of childhood cancer • -Specialized diagnostic facilities (e.g., CT scan) in peripheral centres with lack of knowledge for interpretation	• Gender bias in seeking health care for female child • Lack of insurance • Poor accessibility due to geographic factors

Impact of COVID 19 pandemic on childhood cancer care

- The delivery of services was impacted at over half of the tertiary hospitals, indicated by low attendance in the outpatient department, reduced admissions and high rates of treatment abandonment.

Significant barriers in the diagnosis and treatment of childhood cancers as reported by state nodal officers and civil society organizations/NGOs

- Lack of awareness among parents and caregivers regarding early signs and symptoms
- Lack of expertise among grass-root level workers in diagnosis and poor accessibility to diagnostic centres due to geographical conditions.
- Shortage of childhood cancer diagnostic and treating health facilities
- Lack of referral pathways
- Treatment denial (non-acceptance or refusal to undergo treatment) and treatment abandonment (failure to complete treatment when the disease can be effectively controlled), for which financial constraints were the most commonly cited reason.

Call to action

- ❖ Need of the hour: Formulating a childhood cancer policy to enable timely diagnosis, treatment, supportive care, and follow-up through well-defined care pathways.
- ❖ Integration of childhood cancer as a part of the national cancer control response is to be taken up as a matter of priority.
- ❖ Financing mechanism and schemes for childhood cancer treatment.
- ❖ Training of general physicians and primary care providers to identify signs and symptoms in children with cancer, which will enable timely referral
- ❖ Expansion of paediatric oncology units, training of physicians and paramedics in paediatric oncology
- ❖ Creating large-scale awareness of childhood cancer, its timely diagnosis, completing treatment, optimal cure rate and healthy living.

Key guiding documents

- ICMR-NCDIR, Clinicopathological Profile of Cancers in India: A Report of the Hospital Based Cancer Registries, 2021, Bengaluru, India. Available on https://ncdirindia.org/All_Reports/HBCR_2021/
- Report of National Cancer Registry Programme (ICMR-NCDIR), Bengaluru, India 2020 https://www.ncdirindia.org/All_Reports/Report_2020/default.aspx

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More information

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