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A Situational Analysis of Childhood Cancer Care Services in India
2022

ICMR - National Centre for Disease Informatics and Research

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A Situational Analysis of Childhood Cancer Care Services in India

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ICMR – National Centre for Disease Informatics and Research, Bengaluru

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Section A **Status of childhood cancer care services at tertiary and secondary level hospitals**

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Message

Childhood cancers contribute to a reasonable quantum of morbidity and mortality among children and adolescents. The current childhood health programmes focus on infectious diseases and nutritional problems, while the cancer control programmes aim to prevent and control cancer in adults. Hence, childhood cancers have not received the due attention, resulting in delays in diagnosis and treatment with consequent poor disease outcomes since children with cancer often present with advanced-stage disease. Lack of sturdy referral systems is one of the reasons for late-stage presentations and delayed diagnosis.

The 'Situational Analysis of Childhood Cancer Care Services in India' conducted by the WHO and ICMR-NCDIR, MoHFW aimed to describe the status and challenges in delivering quality childhood cancer services. The survey has attempted to provide a nationwide presentation by including tertiary and secondary level hospitals in 27 states and 3 union territories and concerned state health officials and non-profit organisations engaged with childhood cancer care.

The findings in this report could be used to accelerate the preparedness and capacity of the health system to address childhood cancer in India. Multisectoral efforts to enhance awareness, treatment-seeking and treatment adherence, combined with robust policy implementation, would be of immense help in improving survival in patients of childhood cancer.

(Dr Sudarsan Mandal)

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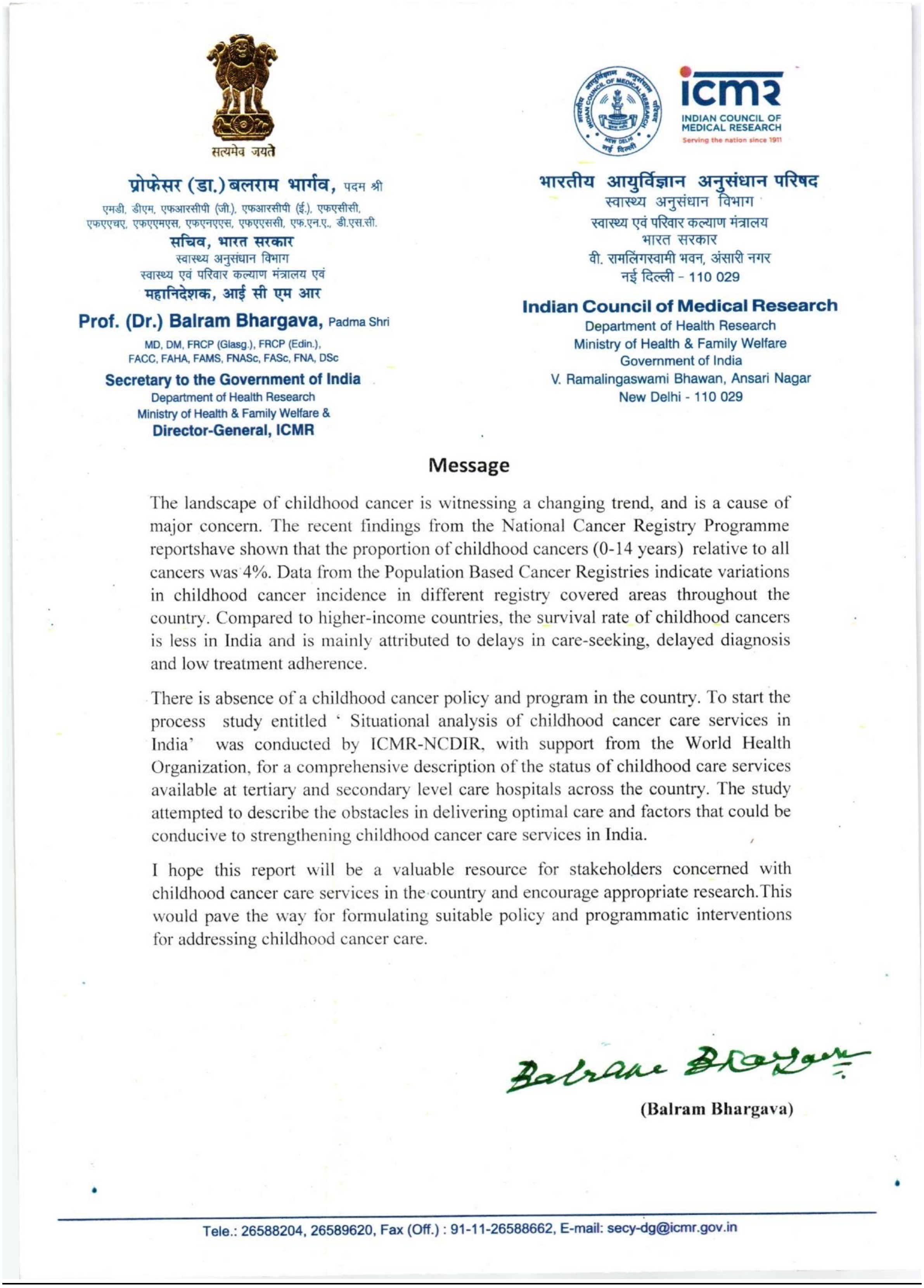

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Message

The landscape of childhood cancer is witnessing a changing trend, and is a cause of major concern. The recent findings from the National Cancer Registry Programme reportshave shown that the proportion of childhood cancers (0-14 years) relative to all cancers was 4%. Data from the Population Based Cancer Registries indicate variations in childhood cancer incidence in different registry covered areas throughout the country. Compared to higher-income countries, the survival rate of childhood cancers is less in India and is mainly attributed to delays in care-seeking, delayed diagnosis and low treatment adherence.

There is absence of a childhood cancer policy and program in the country. To start the process study entitled ' Situational analysis of childhood cancer care services in India' was conducted by ICMR-NCDIR, with support from the World Health Organization, for a comprehensive description of the status of childhood care services available at tertiary and secondary level care hospitals across the country. The study attempted to describe the obstacles in delivering optimal care and factors that could be conducive to strengthening childhood cancer care services in India.

I hope this report will be a valuable resource for stakeholders concerned with childhood cancer care services in the country and encourage appropriate research.This would pave the way for formulating suitable policy and programmatic interventions for addressing childhood cancer care.

Balram Bhargava

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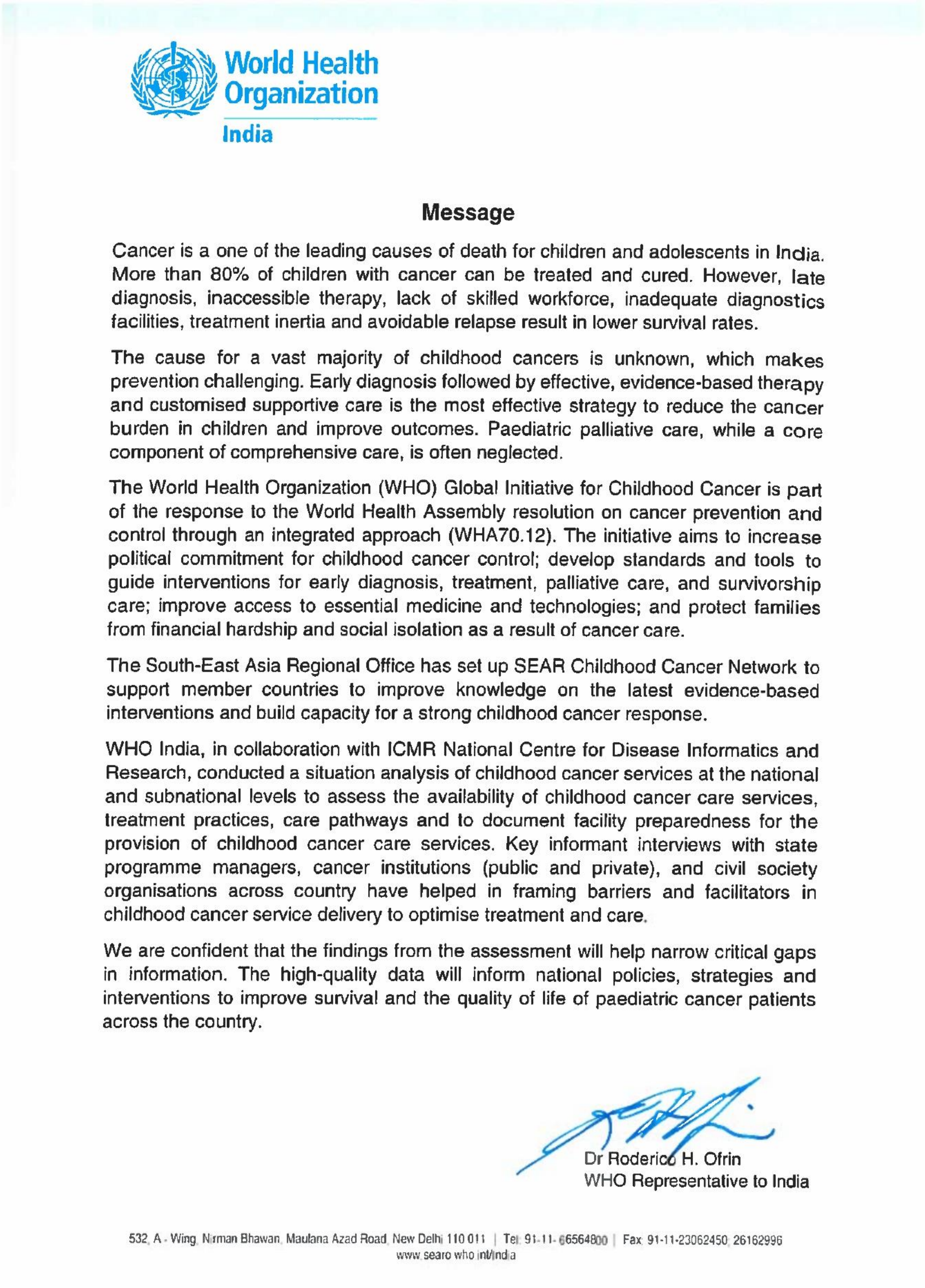

World Health Organization
India

Message

Cancer is a one of the leading causes of death for children and adolescents in India. More than 80% of children with cancer can be treated and cured. However, late diagnosis, inaccessible therapy, lack of skilled workforce, inadequate diagnostics facilities, treatment inertia and avoidable relapse result in lower survival rates.

The cause for a vast majority of childhood cancers is unknown, which makes prevention challenging. Early diagnosis followed by effective, evidence-based therapy and customised supportive care is the most effective strategy to reduce the cancer burden in children and improve outcomes. Paediatric palliative care, while a core component of comprehensive care, is often neglected.

The World Health Organization (WHO) Global Initiative for Childhood Cancer is part of the response to the World Health Assembly resolution on cancer prevention and control through an integrated approach (WHA70.12). The initiative aims to increase political commitment for childhood cancer control; develop standards and tools to guide interventions for early diagnosis, treatment, palliative care, and survivorship care; improve access to essential medicine and technologies; and protect families from financial hardship and social isolation as a result of cancer care.

The South-East Asia Regional Office has set up SEAR Childhood Cancer Network to support member countries to improve knowledge on the latest evidence-based interventions and build capacity for a strong childhood cancer response.

WHO India, in collaboration with ICMR National Centre for Disease Informatics and Research, conducted a situation analysis of childhood cancer services at the national and subnational levels to assess the availability of childhood cancer care services, treatment practices, care pathways and to document facility preparedness for the provision of childhood cancer care services. Key informant interviews with state programme managers, cancer institutions (public and private), and civil society organisations across country have helped in framing barriers and facilitators in childhood cancer service delivery to optimise treatment and care.

We are confident that the findings from the assessment will help narrow critical gaps in information. The high-quality data will inform national policies, strategies and interventions to improve survival and the quality of life of paediatric cancer patients across the country.

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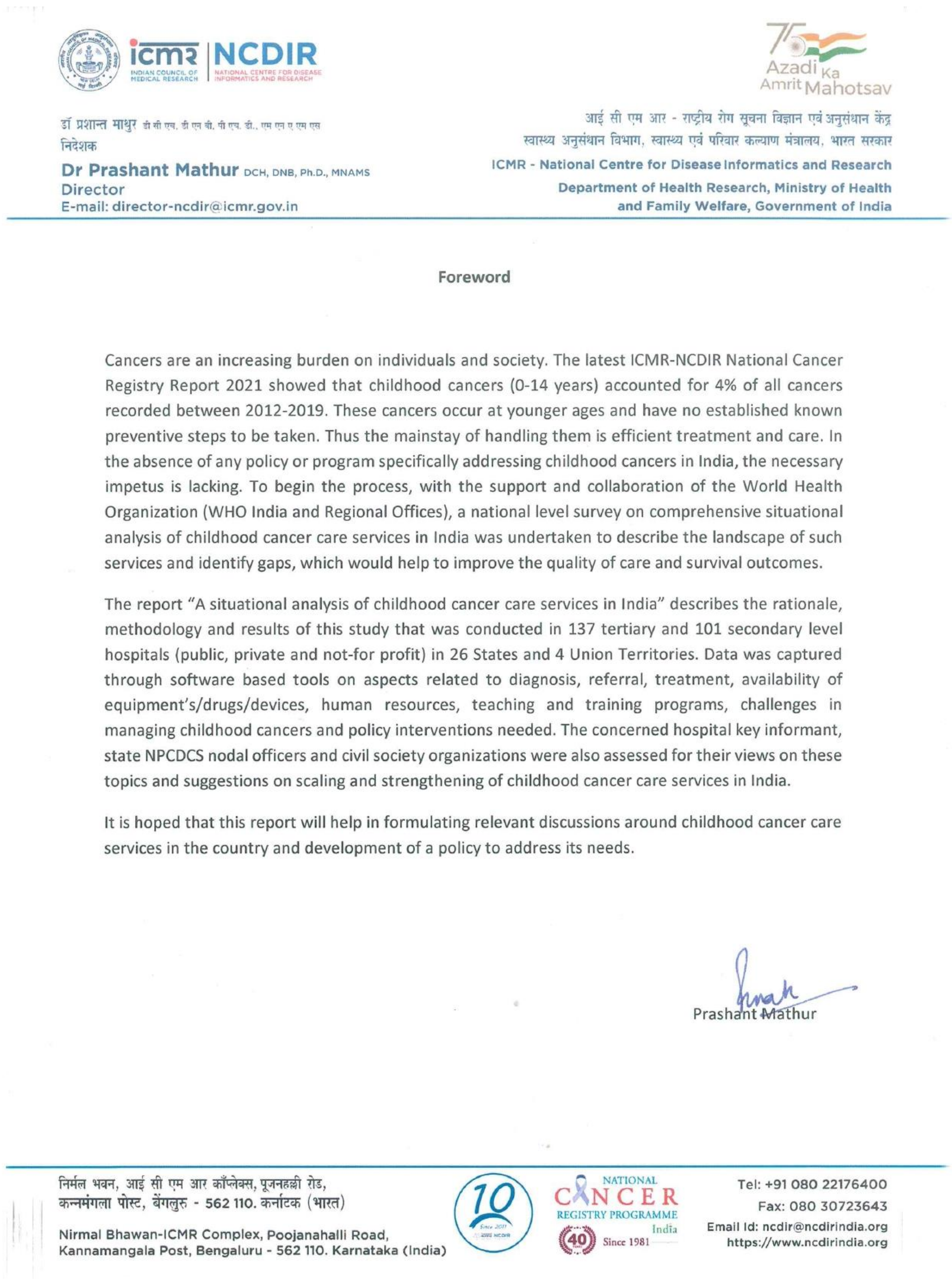

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Foreword

Cancers are an increasing burden on individuals and society. The latest ICMR-NCDIR National Cancer Registry Report 2021 showed that childhood cancers (0-14 years) accounted for 4% of all cancers recorded between 2012-2019. These cancers occur at younger ages and have no established known preventive steps to be taken. Thus the mainstay of handling them is efficient treatment and care. In the absence of any policy or program specifically addressing childhood cancers in India, the necessary impetus is lacking. To begin the process, with the support and collaboration of the World Health Organization (WHO India and Regional Offices), a national level survey on comprehensive situational analysis of childhood cancer care services in India was undertaken to describe the landscape of such services and identify gaps, which would help to improve the quality of care and survival outcomes.

The report "A situational analysis of childhood cancer care services in India" describes the rationale, methodology and results of this study that was conducted in 137 tertiary and 101 secondary level hospitals (public, private and not-for profit) in 26 States and 4 Union Territories. Data was captured through software based tools on aspects related to diagnosis, referral, treatment, availability of equipment's/drugs/devices, human resources, teaching and training programs, challenges in managing childhood cancers and policy interventions needed. The concerned hospital key informant, state NPCDCS nodal officers and civil society organizations were also assessed for their views on these topics and suggestions on scaling and strengthening of childhood cancer care services in India.

It is hoped that this report will help in formulating relevant discussions around childhood cancer care services in the country and development of a policy to address its needs.

Prashant Mathur

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Executive summary

Background

Childhood cancer constitutes the invisible portion of the “cancer iceberg” to a large extent. The proportion of childhood cancers in India contributing to the global statistics is significant. In this context, the narrative of childhood cancer care services gains importance. Delayed diagnosis and treatment initiation are the commonly proposed reasons for poor survival outcomes in childhood cancer. Assessing the present situation of childhood cancer care services is essential to suggest reforms and shape programmatic and policy interventions. The survey aimed to assess the status of childhood cancer care services in India regarding availability, facility preparedness and capacity, treatment-related practices, and perceived barriers and facilitators in diagnosing and treating childhood cancers.

Methodology

The ICMR- National Centre for Disease Informatics and Research (NCDIR), the central coordinating agency, provided technical support, including overall supervision, study tools and an online portal, survey implementation, and data management and statistical analysis. The situational analysis was conducted using a cross-sectional survey design. The participants included 137 tertiary level hospitals, 92 secondary level hospitals, 16 state nodal officers for NPCDCS and nine civil society organizations/non-governmental organizations (CSOs/NGOs) in 26 states and four union territories (UT). A nodal hospital was identified in each state/ UT and required to further identify a representative network of three to five cancer-treating hospitals (tertiary level) and two to three district/sub-district hospitals (secondary level), depending upon the geographical size of the region. The questionnaire was administered through an online portal. Descriptive statistics were used to analyse and present the final survey results.

Key findings

- Over two-thirds of the government tertiary hospitals had referral linkages with lower-tier non-childhood cancer-treating facilities; however, such links were seen in less than half (45.7%) of the private tertiary hospitals.
- Childhood cancer care services were provided at over one-third (39.1%) of the Secondary level hospitals, which was higher in private (56.5%) than public (32.8%) hospitals.
- A dedicated paediatric oncology department was available in less than half of the public and private tertiary hospitals.
- The majority of the tertiary level hospitals had supportive care facilities, including blood banks, nutritional rehabilitation, physiotherapy, psychological counselling and parental education. However, facilities for hospice care were available in less than half of the hospitals.
- Over three quarters (76.6%) of the public tertiary hospitals adopted a multidisciplinary team approach for childhood cancer treatment, compared to 35% of the private hospitals.
- More than 90% of the tertiary hospitals had facilities for histopathology; however, a lower proportion of public tertiary hospitals had facilities for immunohistochemistry, flowcytometric immunophenotyping, cytogenetics, tumour markers and fluorescence in situ hybridization (FISH), which about half of the public tertiary hospitals provided referral services for those investigations.
- Over 80% of the tertiary hospitals had facilities for CT scans, MRI and ultrasonograms; however, the availability of bone scans and PET scans was lower, especially in public sector hospitals.
- Less than a quarter (20.8%) of the public hospitals had facilities for Haemopoietic Stem Cell Transplantation (HSCT) compared to half of the private hospitals (54.3%).
- At public tertiary hospitals, less than half of the hospitals had a pediatric oncologist (48%), pediatric oncosurgeon (14.2%), pediatric intensivist (38.9%), medical oncologist (46.7%) and palliative care physician (37.6%).
- Nurses specialized in pediatric cancer, and palliative care was available in less than 50% of the public and private tertiary hospitals.
- Among palliative care medications, methadone and morphine oral liquid stocks were available in less than 30% of the public, private, and tertiary hospitals. A larger proportion

of targeted therapies were not available at the public tertiary hospitals compared to private hospitals.

- A higher proportion of private secondary level hospitals had cancer-treating medications in stock among the secondary hospitals.
- The most commonly adopted financing mechanism comprised the Ayushman Bharat Scheme at public tertiary level hospitals and secondary level public hospitals and ESI/State specific schemes at private tertiary hospitals.
- Only about a third of the tertiary hospitals had active pediatric oncology clinical research programs at Hospital or pediatric oncology unit/ward
- For public tertiary and secondary level hospitals, the major challenges faced included shortage of human resources, lack of beds, shortage of equipment and lack of physical space for extending facilities. Shortage of human resources was an essential concern for private tertiary and secondary hospitals.
- The most frequent challenge patients and their caregivers faced regarding treatment was treatment denial and treatment abandonment, for which financial constraints were the most commonly cited reason.
- The delivery of childhood cancer care services at over half of the tertiary hospitals was impacted by the COVID pandemic resulting in a decreased diagnosis of new pediatric cases in a majority of the hospitals and increased rates of treatment abandonment.

The situational analysis of childhood cancer care services in India reiterates a skewing in the availability of childhood cancer care services at the tertiary level of health care. Most childhood cancers are associated with non-modifiable risk factors. The key to a better prognosis and favourable outcomes is early and accurate diagnosis and timely initiation of effective treatment. The need of the hour is to formulate a childhood cancer policy that will enable timely diagnosis, treatment, supportive care and follow-up through well-defined care pathways.

A. Definitions

Availability of diagnostic and treatment services: Physical presence of the laboratory services, radiologic/nuclear investigation and specific procedures and treatment interventions for cancer. For the available services, service utilization was measured through tracer items that included average time to avail services, referral to other centres, and the means opted for making the referral.

Capacity building: Training and technical assistance that builds resources enabling communities to deliver evidence-based interventions

Cancer care facilities and coordination: Ability of the health facility to offer either diagnosis or treatment for childhood cancers in the hospital. The capacity to provide this was measured through tracer items that included availability of departments and average waiting time for getting an appointment, supportive care facilities, social support, multidisciplinary team approach, treatment decision and patient follow-up.

Continuing medical education: A continuing education process to learn about new and developing areas of a field, upgrade and maintain professional competence.

Chemotherapy: Type of cancer-treating modality that uses one or more anti-cancer medicines to halt the growth of cancer cells, either by killing or stopping the cells from dividing. Chemotherapy may be given orally or parentally, depending on the type and stage of cancer. It may be given alone or with other treatments, such as surgery, radiation therapy, or biologic therapy.

Financing of treatment: mode adopted for paying for childhood hood cancer care. This included government financing, state-specific financing, individual private insurance and employment-based group private insurance.

A formal agreement for patient referral: A signed acknowledgement between two health care facilities in which they agree to attend to a referred patient and coordinate patient care between the two facilities.

Health insurance is an agreement between the insured and the insurer that is effective when an adverse health event occurs. The insurer will reimburse the compensation either to the insured person or the health service provider.

Information, Education and Communication (IEC) is a "public health approach that aims to change or reinforce health-related behaviours in a defined target audience, concerning a specific problem using varied communication methods".

A medical oncologist is the "primary health care provider for an individual diagnosed with cancer. The doctor specialises in diagnosing and treating cancer".

The medical record system refers to the "availability of digital versions of the patient paper charts at the hospitals".

Multi-speciality Hospital offers "tertiary care and specialized care in multiple specialities through an expert team of medical specialists and allied health personnel".

Nutritional Rehabilitation Centers are care units where "severely acute malnourished (SAM) children below five years are admitted with their mothers/caregivers for treatment, stabilization and rehabilitation".

Physical infrastructure, equipment and medicines: Physical infrastructure relevant for managing childhood cancer services at the Hospital included the following services as broad categories; beds, systemic therapy and supportive care.

The medications were broadly classified as a medicine for palliative/supportive care, medication for other symptoms common in palliative care and supportive drugs. Each medication was checked for availability, stock-outs per year, and procurement.

Palliative care is a specialized area of medical care that aims to relieve patients from pain and other cancer-related symptoms.

Service availability: Physical presence of health delivery services, including health infrastructure, essential health personnel and features of service utilization.

Secondary level Hospital: Refers to hospitals at the second tier of the health system, which attend to patients referred from health centres at the primary level.

Treatment guidelines encompassed the recommended guidelines adopted at each hospital for leukaemia, lymphoma, brain tumours, neuroblastoma, Wilms tumour and bone cancer. It also included written protocols for administering chemotherapy, managing febrile neutropenia, and central venous access devices.

Tumour board meeting includes a group of doctors and other health care providers with different specialities that meet regularly at the hospital to discuss cancer cases and share knowledge.

Telemedicine: Health care services delivery using technologies for information and communication employed by health care providers in places where distance is critical. It helps to exchange meaningful information for the prevention, diagnosis and treatment of disease and injuries, enables research and evaluation, and helps in the continuing education of health care providers, all in the interests of promoting the health of individuals and communities.”

Tertiary level hospital: Includes hospitals at the third tier of the health system. Specialized treatment and care are provided, usually based on a referral from health facilities at the primary and secondary levels.

Treatment abandonment: Failure to complete treatment when the disease can be effectively controlled or missing therapy for a defined period affects disease prognosis.

Treatment denial: Non-acceptance or refusal to undergo treatment that the attending health care provider advises.

B. Abbreviations

AAR	age-adjusted rate
AARpm	age-adjusted rate per million
CBC	complete blood count
CGHS	Central Government Health Scheme
CNS	central nervous system
CSO	civil society organization
CT	computed tomography
ESI	Employees' State Insurance
FISH	fluorescence in situ hybridization
FNB	fellowship of the national board
HBCR	hospital-based cancer registry
HIC	high-income countries
HLA	human leukocyte antigen
HSCT	haemopoietic stem cell transplantation
IAP	indian academy of pediatrics
IMCI	integrated management of childhood illness
IEC	information education communication
LIC	low-income countries
MIBG	iodine-123 meta-iodobenzylguanidine
MRI	magnetic resonance imaging
NCD	noncommunicable Disease
NGO	non-governmental organization
NPCDCS	National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke
OOP	out-of-pocket
PBCR	Population Based Cancer Registry
PET CT	positron emission tomography and computed tomography
PHO	pediatric hemato-oncology
PICU	paediatric intensive care unit
PM-JAY	Ayushman Bharat Pradhan Mantri Jan Arogya Yojana
RBSK	Rashtriya Bal Swasthya Karyakram
RDBMS	relational database management systems
RT PCR	real-time polymerase chain reaction
SARA	service availability and readiness assessment
SIOP	societe internationale d’oncologie pediatrique
WHO	World Health Organization

Figures

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