



6. The way forward

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 situational analysis of childhood cancer care services in India reiterates a concentration on the availability of childhood cancer care services at the tertiary level of health care.

Childhood cancer policy

Based on the findings from the situational analysis, formulating a childhood cancer policy is essential to ensure the availability of exclusive pediatric oncology services and infrastructure to suit the unique needs of childhood cancer patients, such as supportive care and treatment adherence and address the barriers to diagnosis and treatment. Integration of childhood cancer as a part of the national cancer control response should be taken up as a matter of priority.

This calls for pro-active and collated efforts from all concerned stakeholders, including governing authorities, policymakers, health care providers, civil society organisations, families of the patient, patient groups and laypersons.

Early diagnosis

Intensive awareness is needed to sensitise health care providers and the community about childhood cancer symptoms and signs through concerted efforts between programme officers, providers, and the community. General physicians and primary care providers must be trained to identify signs and symptoms in children with cancer, enabling timely referral. IEC campaigns, integration of early diagnosis of childhood cancers with existing national health programmes such as Rashtriya Bal Swasthya Karyakram (RBSK), the reproductive and child health programme (RCH), NPCDCS and school health programmes could be explored for the integration and provision of such services. The WHO module on early diagnosis of childhood cancer uses the integrated management of childhood illness (IMCI) strategy to examine the presence of pediatric cancer and could be considered for integration into the currently implemented systems.

Besides histopathology, accelerating the availability of diagnostic biomarkers should be strengthened in public sector hospitals through intensive capacity building by institutions of excellence.



Developing applications that use machine learning algorithms for the early diagnosis of childhood cancers such as retinoblastoma can complement the efforts of a physician and thereby reduce the workload. Such deep learning tools for prediction and early diagnosis make implementation at primary health care levels feasible.

Strengthening pediatric oncology services and referral pathways

While setting up a specialised unit may not be feasible in every hospital, providing these services through existing infrastructure with the necessary facilities for diagnosis and treatment may be best. In the present survey, less than half of the tertiary hospitals had an entire pediatric oncology unit. Pediatric oncology service could be expanded by strengthening referral and back referral linkages between a tertiary nodal hospital and secondary health facilities. This could also be achieved through a robust end-to-end technological connectivity between the nodal cancer hospital and district hospital that can provide telemedicine services to enable early diagnosis and initiation of treatment. Oncology residents could be posted at district hospitals on a rotatory basis to overcome shortages in the health workforce. Secondary level health facilities could be upgraded into satellite facilities equipped with basic infrastructure with systemic therapy units. This would reduce travel time, ensure a continuum of care and be cost-effective.

Public-private partnerships would be very beneficial for addressing gaps in the availability of human resources, diagnostic and treatment services and supportive care. Medical social care workers' vital role in counselling and support to minimise treatment denial and adherence should be considered. Likewise, collaboration with CSOs could be explored to help maintain patient follow-up and treatment adherence.

Financing childhood cancer treatment is an essential matter of concern and requires concerted efforts to scale up the availability. The financial burden of treatment is compounded by out-of-pocket spending on accommodation and daily living expenses when the necessary treatment is available at a distant place. Besides successful treatment, a childhood cancer survivor also needs long-term rehabilitation and supportive care. Under the PM-JAY scheme, pediatric cancer treatment modalities have been included in broad oncologic specialities. A costing exercise of pediatric cancer care services would help develop specific childhood cancer treatment packages.



Palliative care and hospice services should be considered equal to cancer treatment. As described in the preceding sections, these required services could be sought through linkages with private and NGO health facilities.

Pediatric oncology training and research

Formal courses in Pediatric oncology for physicians and nurses need continuing and robust support for expansion and scaling up since these are available at limited centres. There is also a need for Paediatric oncology training programmes for primary care physicians, nurses, grass-root health workers, medical social workers and members of community-based organisations at periodic intervals.

Paediatricians should be encouraged to engage in research in paediatric oncology as they will best be able to identify the unmet clinical needs and gaps and work collaboratively as knowledge brokers with researchers from other fields. Forming a national pediatric oncology research group would be a significant step. The formation of a national childhood cancer registry would help promote pediatric oncology research. An electronic health record system would facilitate ease of case abstraction and data authenticity for running a successful childhood cancer registry. Pediatric cancer outcomes could be significantly improved by adopting evidence-based treatment guidelines and enrolling patients in multicentric clinical trials to evaluate optimal treatment interventions.

Pediatric cancers have a unique profile and health system needs than adult cancers. A multidisciplinary team effort involving coordinated efforts from all concerned players is needed to strengthen and scale up India's availability, accessibility, and quality of childhood cancer care services.