Pediatric Cancers in India: Burden & Challenges

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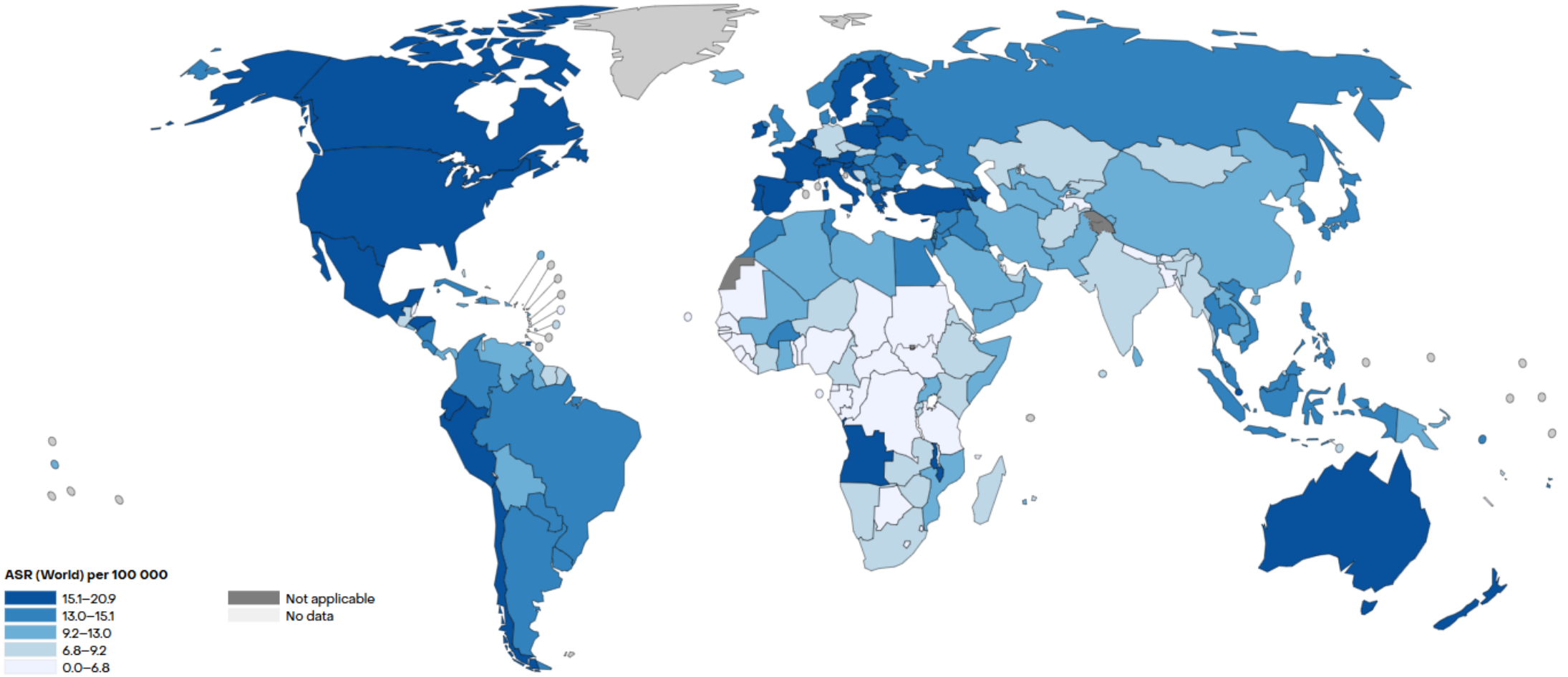
Age-Standardized Rate(World) per 100,000, Incidence, Both sexes (0-14 yrs) in 2022- All cancers



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Data version: Globocan 2022 (version 1.1) - 08.02.2024

International Agency for Research on Cancer
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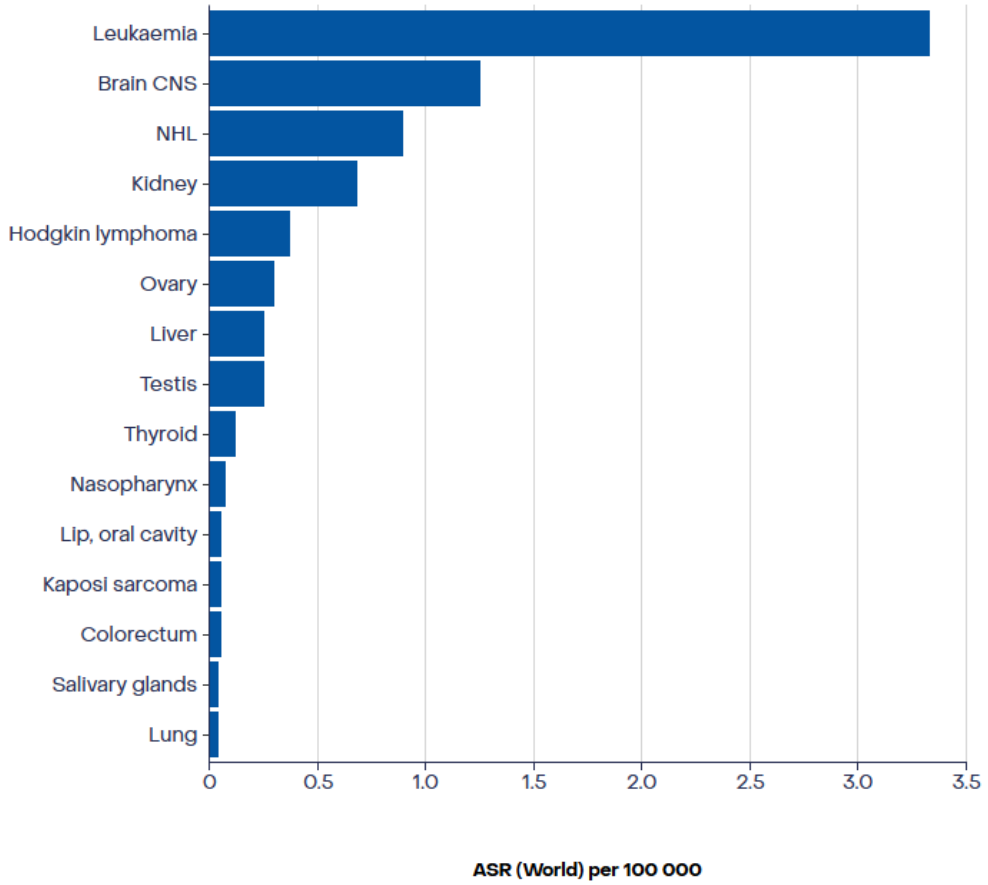
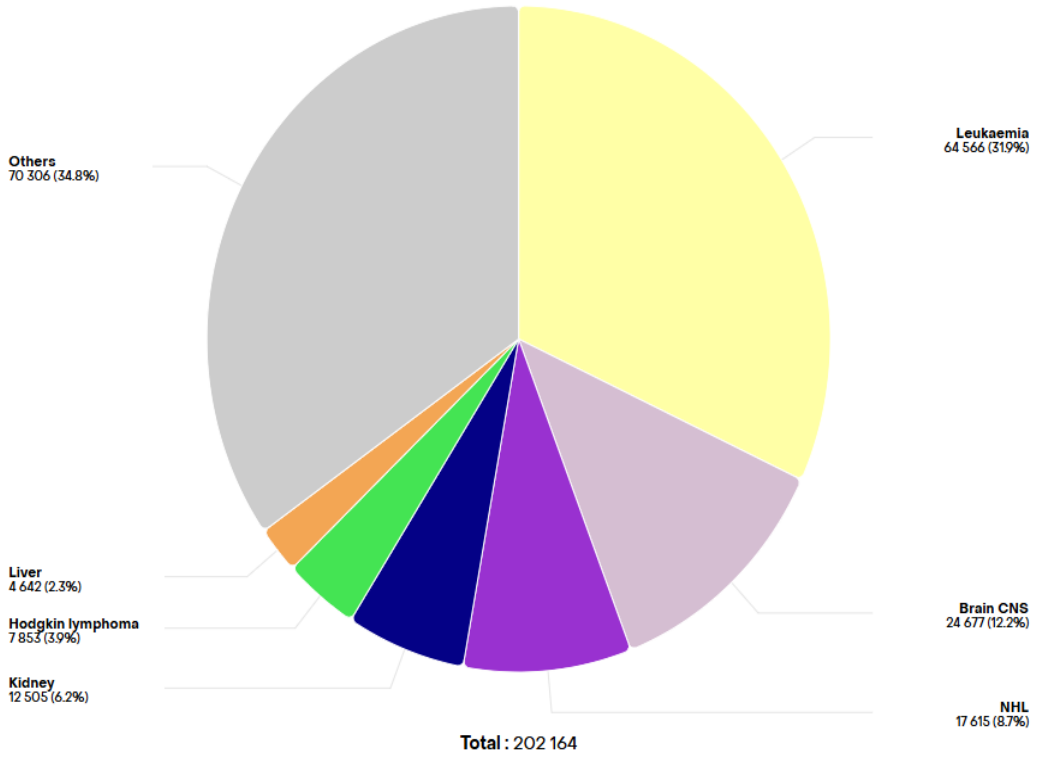


Absolute numbers, Incidence, Both sexes, age [0-14], in 2022



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Burden of Pediatric Cancers in India- What we know now?

- Childhood cancers (0-14 yrs) account for 4% of all cancers in India
- Nationwide incidence varies widely by region
- India's 1st dedicated Population-Based Cancer Registry- Greater Chennai Zone (2022-2023)

  Incidence: 136 cases per million

  2 yr OS 60-70%

Table I Childhood Cancers Relative to Cancers Across All Ages: Data from 96 Hospital-Based Cancer Registries, India, 2012-2019

Age (y)	*Boys (n = 705395)*		*Girls (n = 626812)*		*Total (n = 1332207)*	
	n	*% of all cancers*	*n*	*% of all cancers*	*n*	*% of all cancers*
0-4	9320	1.3	5764	0.9	15084	1.1
5-9	8883	1.3	4728	0.8	13611	1.0
10-14	8668	1.2	5164	0.8	13832	1.0
15-19	11589	1.6	6604	1.1	18193	1.4
0-14	26871	3.8	15656	2.5	42527	3.2
0-19	38460	5.5	22260	3.6	60720	4.6

INDIAN PEDIATRICS

VOLUME 61—JANUARY 15, 2024

Profile of Childhood Cancers From Hospital-Based Cancer Registries in India, 2012-19

Gauri Kapoor,[1] Ramandeep Singh Arora,[2] Venkatraman Radhakrishnan,[3] Anita Nath,[4] Payal Malhotra,[1] Sunu Lazar Cyriac,[5] Gangadharan VP,[6] Sadashivudu G,[7] Thilagavathi Ramamoorthy,[4] Sudarshan KL,[4] Prashant Mathur[4]

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[2]Department of Pediatric Oncology, Max Super Speciality Hospital, New Delhi.
[3]Department of Medical Oncology, Adyar Cancer Institute, Chennai, Tamil Nadu.
[4]ICMR - National Centre for Disease Informatics and Research, Indian Council of Medical Research, Bengaluru, Karnataka.
[5]Department of Medical Oncology and Hematology, Amala Institute of Medical Sciences, Thrissur, Kerala.
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- 60720 cancer cases in 0–19-year age group
- 96 hospital-based cancer registries
- Examined distribution of cancer by five-year age groups, sex and ICCC diagnostic groups and subgroups

Burden of Pediatric Cancers in India

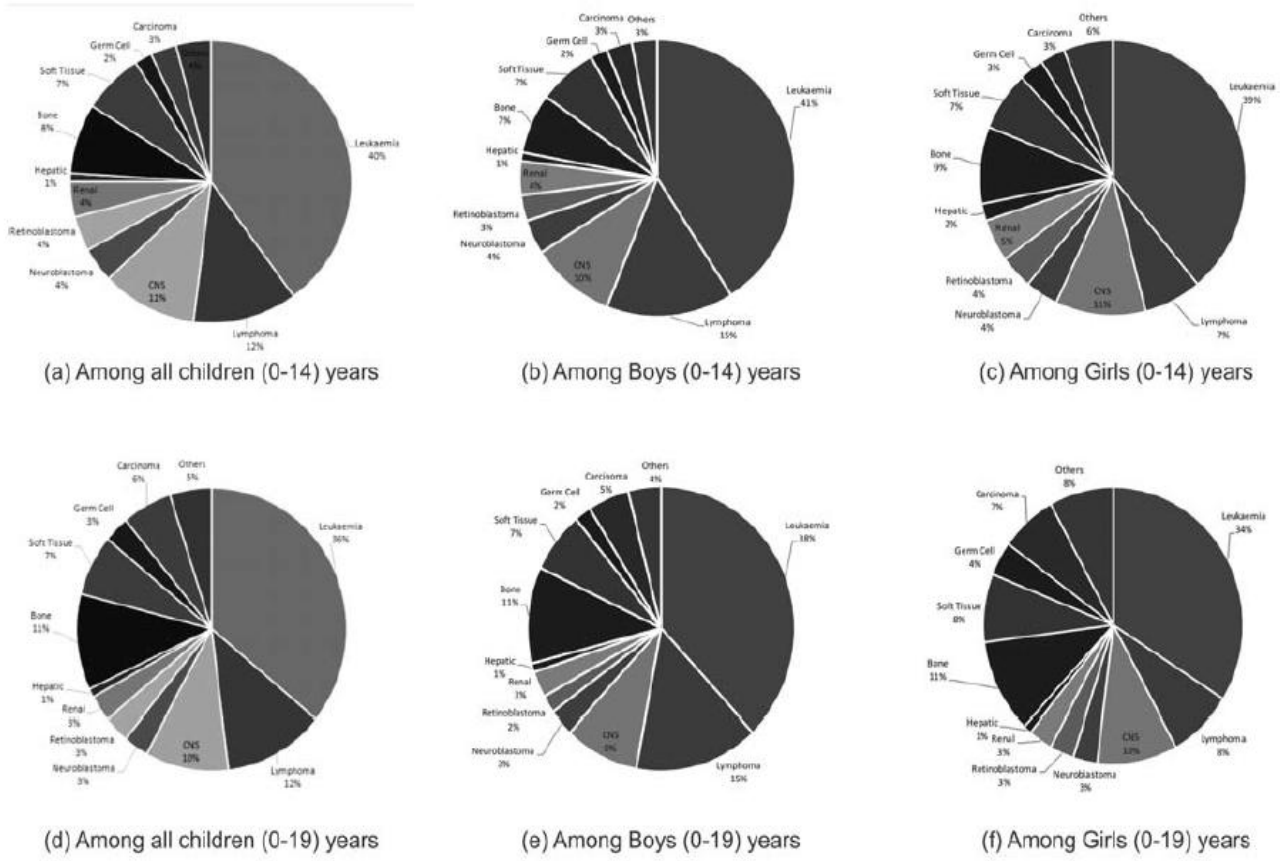

Fig. 1 Relative contribution of the 12 diagnostic groups of childhood cancer in (0-14) and (0-19) years.

- Cancers in 0-14 & 0-19 age groups accounted for considerable proportion of all cancers with significant male preponderance
- This information helps to fine-tune research & planning strategies
- 4 leading groups of cancers among 0-14 year olds were leukemia (40%), lymphoma (12%), central nervous system tumor (11%) & bone cancer (8%)
- 4 leading cancers among 0–19-year age group were leukemia (36%), lymphoma (12%), bone (11%) & central nervous system tumor (10%)

INDIAN PEDIATRICS
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Pediatric Cancer Burden in Different Regions of India: Analysis of Published Data From 33 Population-Based Cancer Registries

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Initial review: Jan 14, 2023;
Accepted: Mar 28, 2023.

Objective: To provide the regional pediatric cancer (age-group 0-14 years) burden and pattern in India utilizing published data of population-based cancer registries established under the National Cancer Registry Programme and Tata Memorial Centre, Mumbai. **Methods:** Based on the geographic locations, the population-based cancer registries were categorized into six regions. The age-specific incidence rate was calculated using the number of pediatric cancer cases and population in the respective age-group. Age-standardized incidence rate per million and 95% CI were calculated. **Results:** In India, 2% of all cases were pediatric cancer. The age-standardized incidence rate (95% CI) for boys and girls is 95.1 (94.3-95.9) and 65.5 (64.8-66.2) per million population, respectively. Registries from northern India reported the highest rate; while the lowest rate was in northeastern India. **Conclusion:** There is a need to establish pediatric cancer registries in different regions of India to know the accurate pediatric cancer burden.

Keywords: *Incidence, Leukemia, Lymphoma, Surveillance.*

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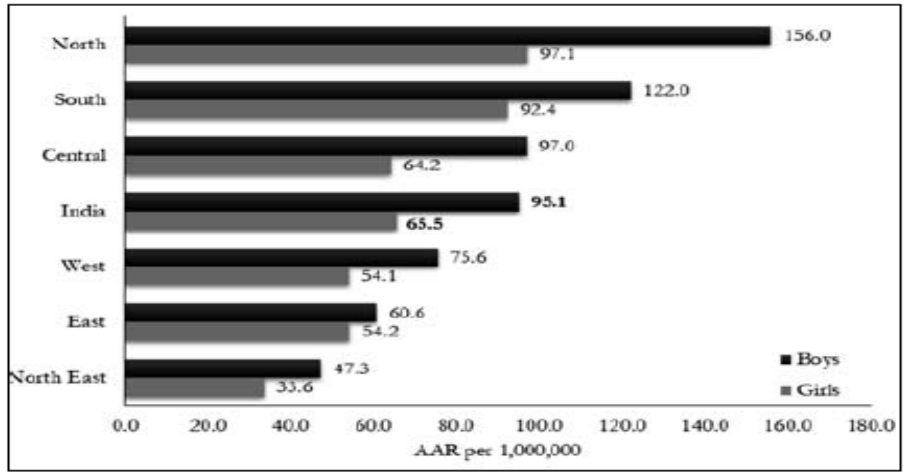
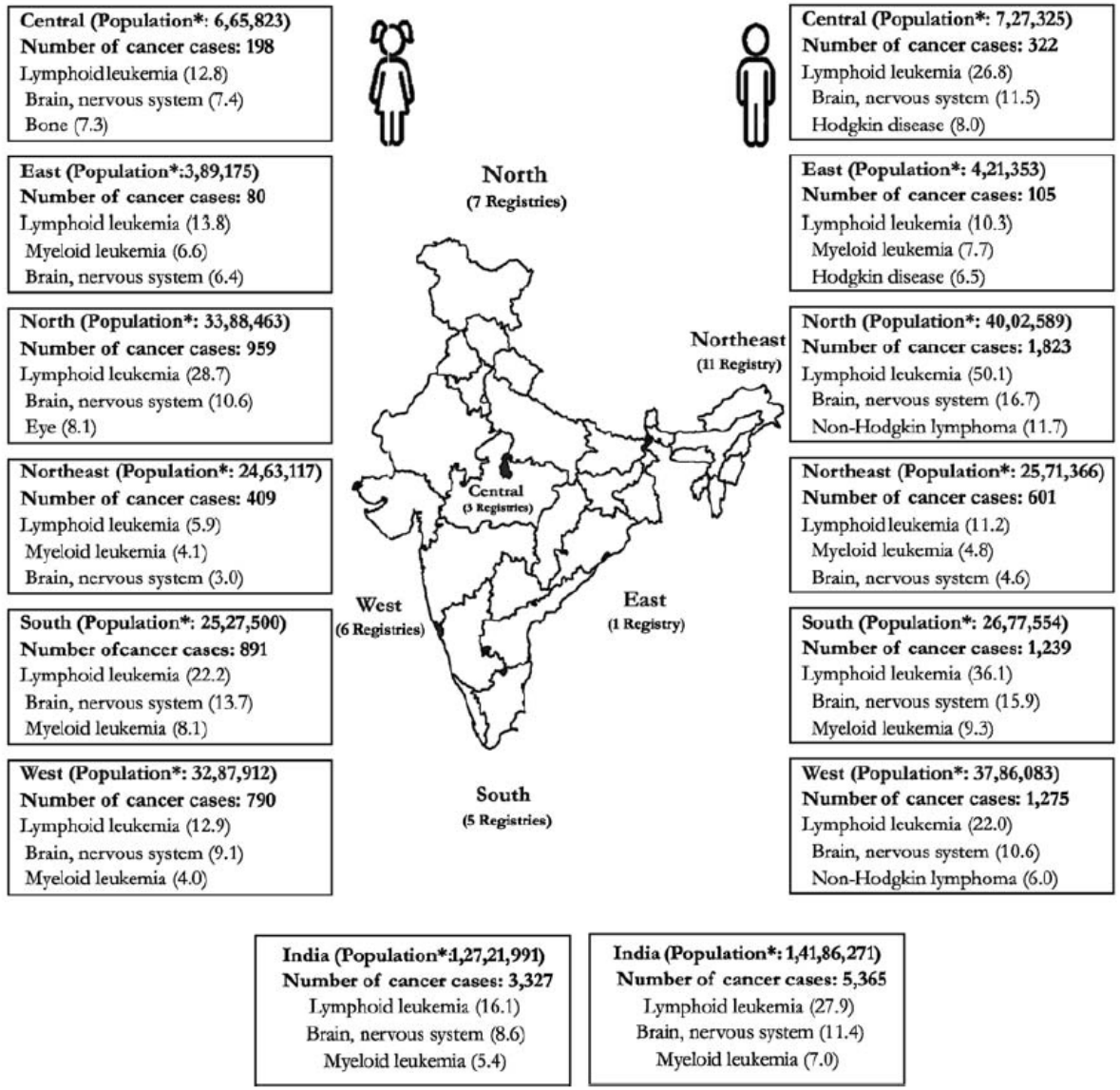


Fig.1 Pediatric cancer burden as per registries from respective regions from India (2012-2016).



**Population of respective region registries for the 0-14 age group.*

Fig. 2 Leading cancer sites in boys and girls as per registries from respective regions in India (2012-2016).

Survival Outcomes & Treatment-related mortality (TRM)

- Survival outcomes have improved; however, in uneven pattern- as per recent registry data (Chennai: 2022-2023) shows 2-year survival of 60-70%
- **Treatment-related mortality (TRM):** in high-income countries is 3–5%;however, in LMICs, it has been reported in 45%

Treatment-related mortality in children with cancer in low-income and middle-income countries: a systematic review and meta-analysis

Bella S Ehrlich, Michael J McNeil, Linh T D Pham, Yichen Chen, Jocelyn Rivera, Carlos Acuna, Liz Sniderman, Firas M Sakaan, Alejandra Mendez Aceituno, Cesar A Villegas, Lisa M Force, Nancy S Bolous, Parima P Wiphatphumiprates, Jeremy S Slone, Angela K Carrillo, Srinithya R Gillipelli, Caitlyn Duffy, Anita V Arias, Meenakshi Devidas, Carlos Rodriguez-Galindo, Sheena Mukkada, Asya Agulnik

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- Treatment-related mortality in high-income countries is 3–5%;however, in LMICs, it has been reported in 45%
- Articles: 2010- 2021 (13269 identified abstracts, 501 studies representing 68351 pediatric patients)
- Assessed treatment-related mortality in pediatric patients (aged 0–21 years)

	Included cohorts (n=506)
Mid-year* of data observation	2009 (2006–2012)
Years of follow-up	3·6 (2·3–5·0)
Age range (years)	
Starting age (lower limit)	1·0 (0·3–2·5)
Ending age (upper limit)	15·9 (13·0–18·0)
Median sample size (IQR)	59 (28–152)
Type of cancer-directed treatment	
Surgery	219 (43·3%)
Chemotherapy	469 (92·7%)
Radiotherapy	179 (35·4%)
Other†	22 (4·3%)

Data are median (IQR) or n (%), unless otherwise stated. *Defined as the midpoint year between initial and final years of study conduct. †Other cancer-directed treatment includes modalities such as immunotherapies and gene therapies.

Table 2: **Characteristics of included cohorts**

	Included studies (n=501)
Type of study	
Single-centre	431 (86·0%)
Multicentre (1 country)	56 (11·2%)
Multicentre (≥2 countries)	14 (2·8%)
Study design	
Randomised controlled trial	9 (1·8%)
Prospective cohort or case-series	98 (19·6%)
Retrospective cohort or case-series	367 (73·3%)
Unspecified cohort or case-series	22 (4·4%)
Other	5 (1·0%)
Country income level*	
Low income	20 (4·0%)
Lower-middle income	207 (41·3%)
Upper-middle income	286 (57·1%)
WHO region†	
Western Pacific region	124 (24·8%)
South-East Asia region	99 (19·8%)
Region of the Americas	72 (14·4%)
Eastern Mediterranean region	100 (20·0%)
European region	63 (12·6%)
African region	46 (9·2%)

Data are n (%). *12 studies involved more than one country income level. †One study involved four WHO regions.

Table 1: **Characteristics of included studies**

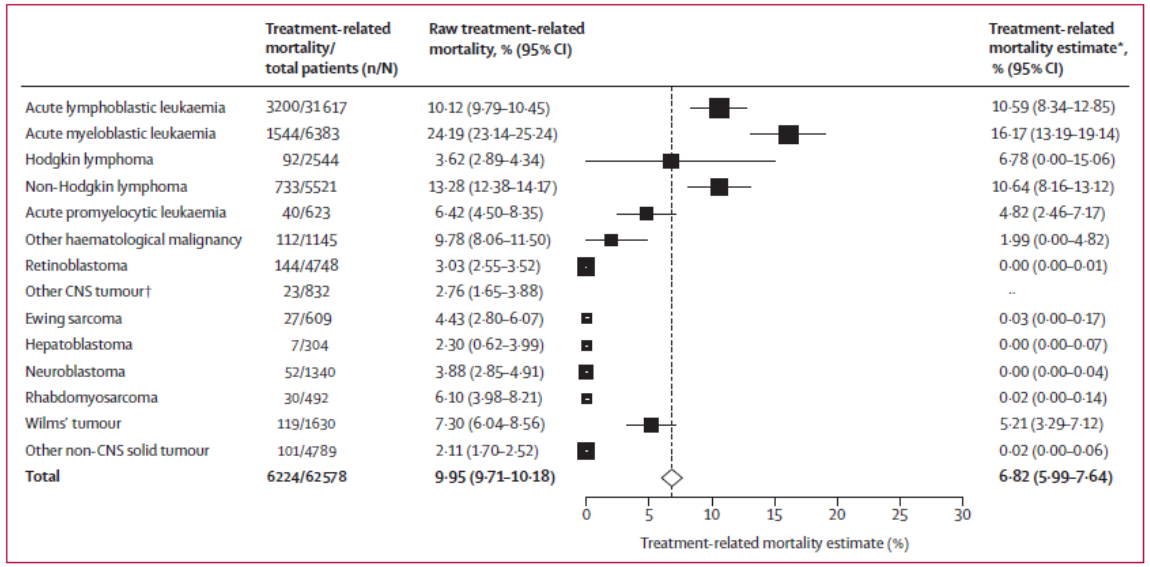


Figure 3: **Estimated treatment-related mortality by cancer diagnosis**

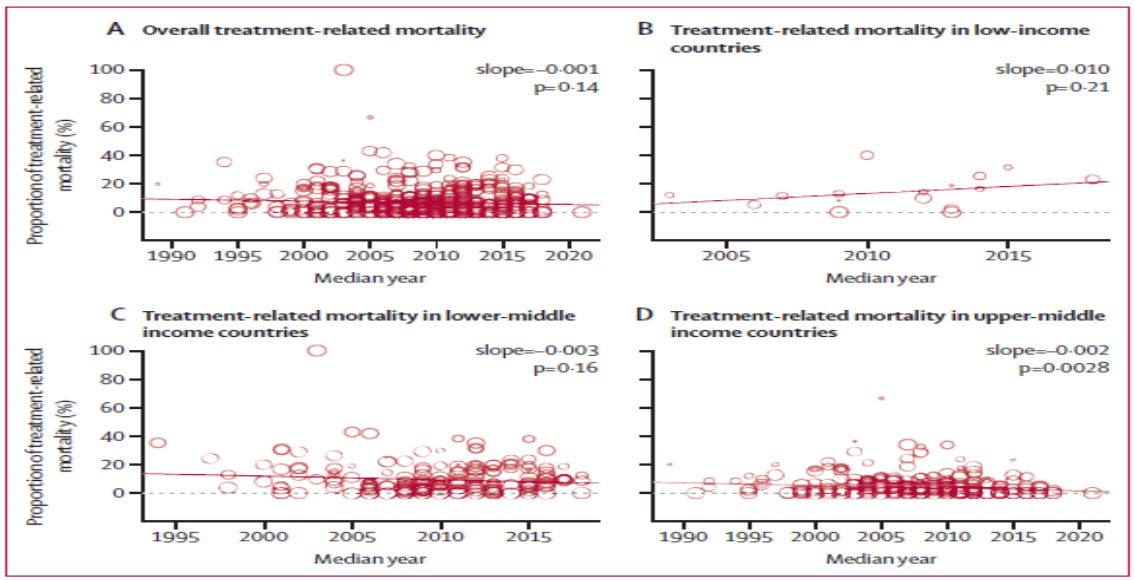


Figure 4: **Trends in treatment related-mortality over time**
The figure depicts treatment-related mortality by study mid-year, calculated as the middle year of study conduct (average between start and stop of study inclusion years). Treatment-related mortality rates are depicted for all study patients (A), patients receiving treatment in low-income countries (B), patients receiving treatment in lower-middle-income countries (C), and patients receiving treatment in upper-middle-income countries (D). The size of the circle represents the size of the study sample. Mixed-effects model was used to explore the relationship between treatment-related mortality estimates and the year of study conduct (as depicted by the trend line shown).

	All cancers (n=3569)	Haematological malignancy (n=2798)	CNS solid tumour (n=50)	Non-CNS solid tumour (n=199)
Total number of patients*	68351	51186	6240	10785
Sepsis or infection	2560 (71·7%)	2069 (73·9%)	28 (56·0%)	101 (50·8%)
Haemorrhage	379 (10·6%)	306 (10·9%)	4 (8·0%)	4 (2·0%)
Metabolic causes (tumour lysis syndrome)	174 (4·9%)	162 (5·8%)	0	1 (0·5%)
Disseminated intravascular coagulation	13 (0·4%)	12 (0·4%)	0	0
Surgical complications	51 (1·4%)	2 (0·1%)	7 (14·0%)	25 (12·6%)
Neurological complications (encephalopathy or raised intracranial pressure)	26 (0·7%)	21 (0·8%)	1 (2·0%)	1 (0·5%)
Seizures	4 (0·1%)	2 (0·1%)	2 (4·0%)	0
Cardiac failure	43 (1·2%)	17 (0·6%)	0	15 (7·5%)
Respiratory failure	99 (2·8%)	80 (2·9%)	0	6 (3·0%)
Superior vena cava syndrome	5 (0·1%)	5 (0·2%)	0	0
Hyperleukocytosis	8 (0·2%)	8 (0·3%)	0	0
Other chemotherapy toxicity	90 (2·5%)	32 (1·1%)	6 (12·0%)	33 (16·6%)
Other organ failure	98 (2·7%)	72 (2·6%)	1 (2·0%)	6 (3·0%)
Other	19 (0·5%)	10 (0·4%)	1 (2·0%)	7 (3·5%)

Data are n (%), unless otherwise stated. *Due to the inclusion of studies with multiple diagnoses across several diagnostic categories, the total number of patients with any malignancy is greater than the sum of patients in the given categories.

Table 3: **Identified causes of treatment-related mortality**

- **Results:**
- Treatment-related mortality was inversely related to country income
- Treatment-related mortality was 14·19% (low-income countries), 9·21% in LMIC & 4·47% in UMIC
- In UMIC, incidence of treatment-related mortality decreased over time; however, outcomes remained unchanged in low-income & LMIC
- 1 in 15 children receiving cancer treatment in LMICs die from treatment-related complications
- There is an urgent need for targeted supportive care interventions to reduce global disparities in childhood cancer survival

❖ HISTORY OF PEDIATRIC ONCOLOGY:

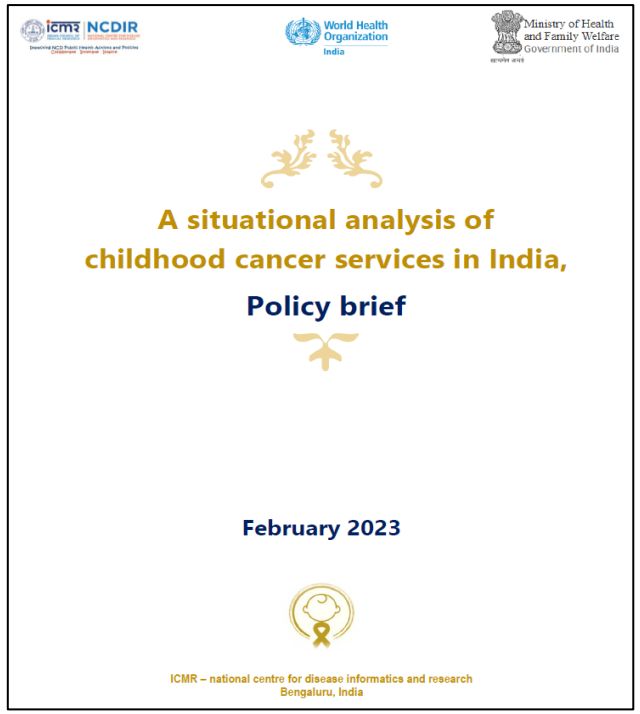
- First Pediatric oncology unit in India was started in 1960s by Smt. Indira Gandhi at Cancer Institute (WIA), Chennai
- First dedicated pediatric cancer unit was started in Tata Memorial Hospital, Mumbai in 1985
- A national survey of childhood cancer care services (CCCS) conducted in 1988 observed that pediatric oncology cases were handled by adult oncologists in 50% centers
- Most pediatric cancer care centers in India located in Urban areas leading to delayed access by rural population
- Indian children often present with an advanced-stage disease which worsens outcome

Systemic Challenges: Understanding the Persistence of Gaps

1) Late diagnosis & referral delays
2) Uneven infrastructure & workforce
3) Financial burden leading to abandonment
4) Supportive care gaps
5) Registry coverage & quality of data

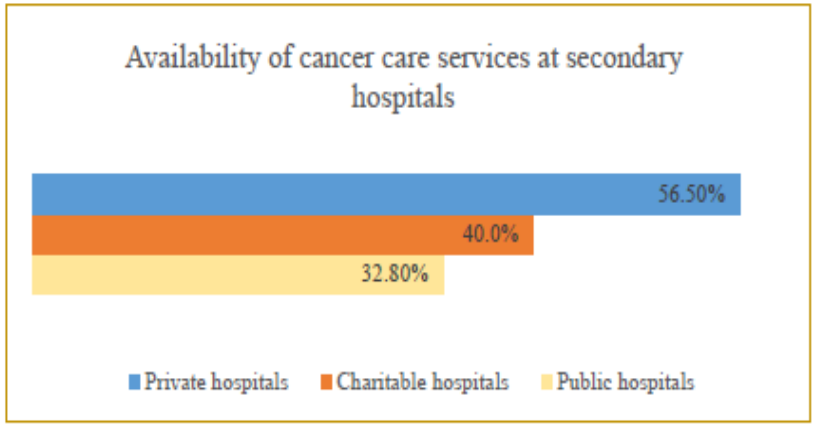
Late diagnosis & referral delays

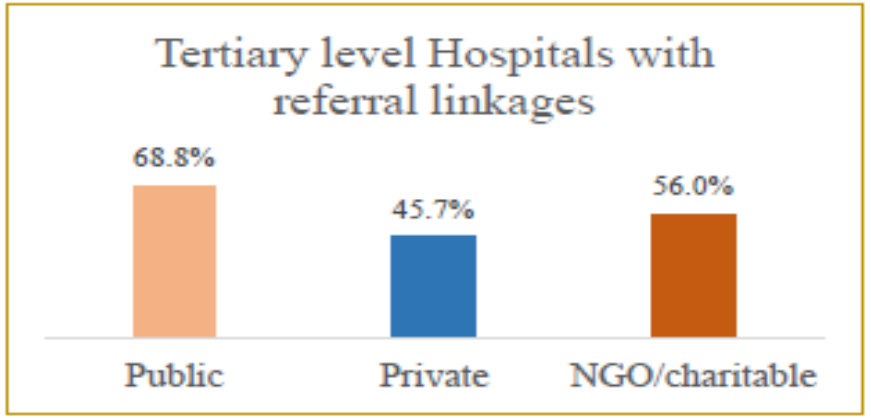
- Majority of patients are from rural areas and present in advanced stage to hospital
- A situational analysis of childhood cancer services in India by ICMR-NCDIR at Bengaluru
- ICMR-NCDIR has been operating National Cancer Registry Programme (NCRP) since 1981
- It gives a bird's- eye view on 'Situational analysis of childhood cancer services in India until 2021

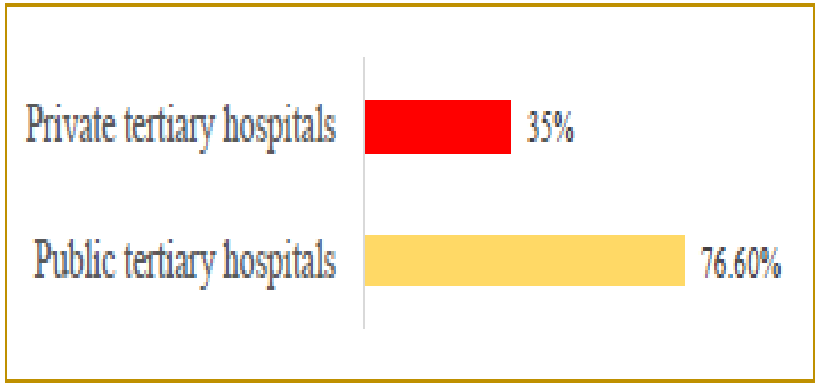


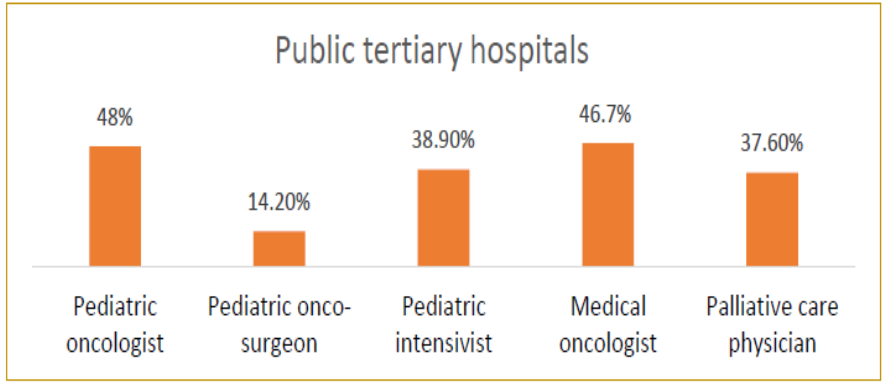
Major challenges encountered in addressing childhood cancer care

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


Availability of cancer care services at secondary hospitals
56.50%
40.0%
32.80%
Private hospitals
Charitable hospitals
Public hospitals


Tertiary level Hospitals with referral linkages
68.8%
45.7%
56.0%
Public
Private
NGO/charitable


Private tertiary hospitals
35%
Public tertiary hospitals
76.60%


Public tertiary hospitals
48%
14.20%
38.90%
46.7%
37.60%
Pediatric oncologist
Pediatric onco-surgeon
Pediatric intensivist
Medical oncologist
Palliative care physician

RESEARCH ARTICLE Open Access

Access to care for childhood cancers in India: perspectives of health care providers and the implications for universal health coverage

Neha Faruqui[1*], Sarah Bernays[1,2], Alexandra Martiniuk[1,3,4], Seye Abimbola[1,3], Ramandeep Arora[5,6], Jennifer Lowe[5], Avram Denburg[7,8] and Rohina Joshi[1,3,9,10]

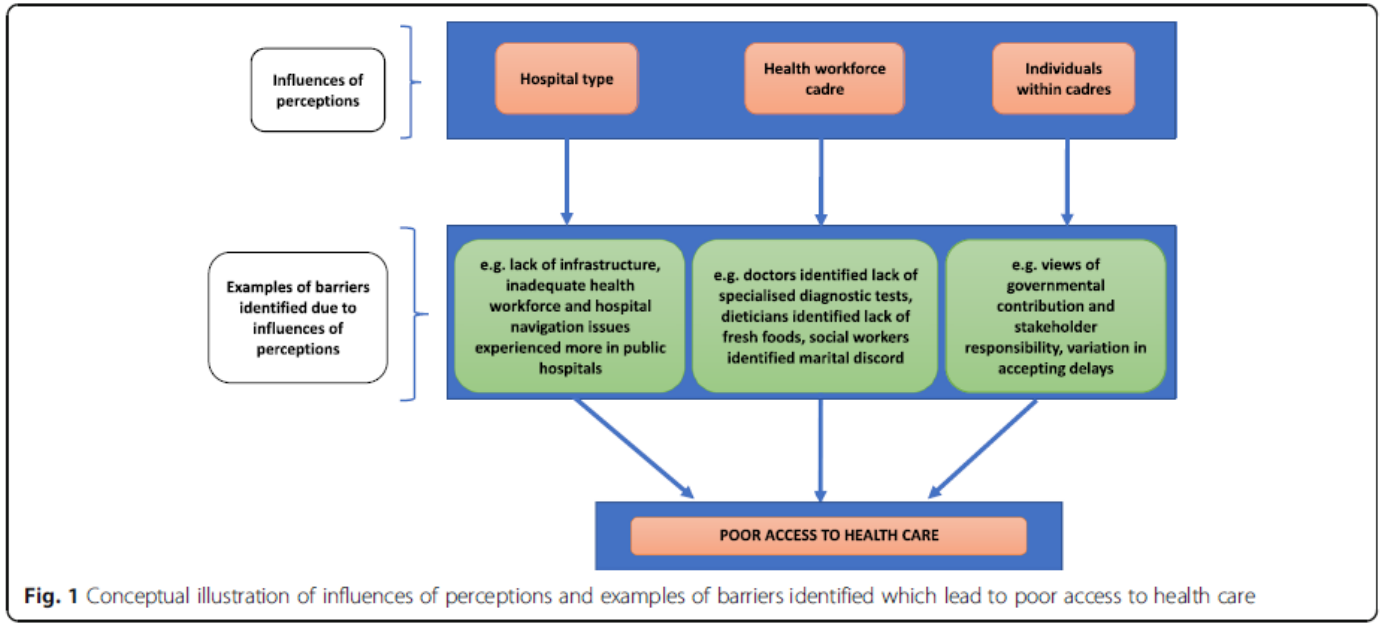


Fig. 1 Conceptual illustration of influences of perceptions and examples of barriers identified which lead to poor access to health care

- Conducted in 7 tertiary cancer hospitals (3 public, 3 private & 1 charitable trust hospital) across Delhi & Hyderabad
- Recruited 27 healthcare providers involved in childhood cancer care
- Semi structured interviews were audio recorded after obtaining informed consent
- Although participants acknowledged that accessing childhood cancer care in India is limited by several barriers, perceptions of these barriers varied
- Inference: health care provider perceptions are shaped by their experiences, interests & standpoints, which are useful towards informing policy for childhood cancers within UHC

An assessment of childhood cancer care services in India - gaps, challenges and the way forward

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- Cross sectional study design
- Described childhood cancer care services available at secondary & tertiary-level hospitals in India
- Conducted in 137 tertiary-level & 92 secondary-level hospitals in 26 states & 4 Union Territories

Type of hospital	Public		Private		NGO-managed		N	%
	n	%	n	%	n	%		
Tertiary level hospitals								
Medical college hospital	53	68.8	11	31.4	6	24.0	70	51.1
Super speciality (oncology)	12	15.5	8	22.8	12	48.0	32	23.4
Multispecialty with dedicated oncology unit	12	15.5	16	45.7	7	28.0	35	25.5
Total number of tertiary hospitals	**77**	**56.2**	**35**	**25.5**	**25**	**18.2**	**137**	**100**
Secondary level hospitals	**64**	**69.5**	**23**	**25.0**	**5**	**5.4**	**92**	**100**

Table 1: Categorisation of hospitals according to the major source of financial support.

S. No.		Public		Private		NGO/ charitable	
		n = 77		n = 35		n = 25	
		n	%	n	%	n	%
Cancer treatment departments							
1	Pediatric Oncology	32	41.6	17	48.6	16	64.0
2	Medical Oncology	35	45.5	22	62.9	15	60.0
3	Radiation Oncology	52	67.5	24	68.6	17	68.0
4	Surgical Oncology	41	53.2	24	68.6	17	68.0
5	Pediatric medicine	60	77.9	24	68.6	16	64.0
6	Medicine	47	61.0	20	57.1	11	44.0
7	Haematology	33	42.9	20	57.1	13	52.0
8	Pediatric surgery	48	62.3	20	57.1	11	44.0
9	Surgery	55	71.4	19	54.3	11	44.0
10	Ophthalmology	50	64.9	21	60.0	9	36.0
11	Musculoskeletal oncology	7	9.1	7	20.0	9	36.0
12	Orthopaedics	61	79.2	23	65.7	12	48.0
13	Neurosurgery	47	61.0	23	65.7	10	40.0
14	Radiology	66	85.7	31	88.6	22	88.0
15	Nuclear medicine	27	35.1	18	51.4	11	44.0
16	Pathology	71	92.2	31	88.6	24	96.0
17	Palliative medicine	37	48.1	20	57.1	18	72.0
Supportive care facilities							
1.	Blood bank	72	93.5	30	85.7	18	72.0
2.	Nutritional rehabilitation	54	70.1	32	91.4	20	80.0
3.	Physiotherapy	72	93.5	34	97.1	21	84.0
4.	Psychological counselling	61	79.2	27	77.1	22	88.0
5.	Parental education	58	75.3	25	71.4	17	68.0
6.	Occupational therapy	39	50.6	19	54.3	14	56.0
7.	Hospice care	26	33.8	13	37.1	6	24.0
8.	Dental care	69	89.6	32	91.4	14	56.0
9.	Play therapy	29	37.7	10	28.6	7	28.0
10.	Growth and development	60	77.9	29	82.9	16	64.0
11.	Immunisation	66	85.7	32	91.4	16	64.0
12.	Fertility Preservation services	14	18.2	11	31.4	4	16.0
13.	Parental groups	29	37.7	14	40.0	14	56.0
14.	Accommodation/lodging for patients and caregivers	40	51.9	15	42.9	17	68.0
Dedicated human resources for childhood cancer treatment							
15	Pediatric oncologist (Pediatrician working exclusively with childhood cancer)	37	48.0	19	54.3	16	64
16	Pediatric oncosurgeon	11	14.2	6	17.1	7	28.0
17	Nurses trained in pediatric cancer	32	41.5	17	48.6	18	72.0
18	Occupational therapist	32	41.5	17	48.6	13	52.0
19	Social worker	59	76.6	24	68.6	20	80.0
20	Counsellor	50	64.9	24	68.6	19	76.0

Table 2: **Availability of childhood cancer treatment-related departments at tertiary hospitals.**

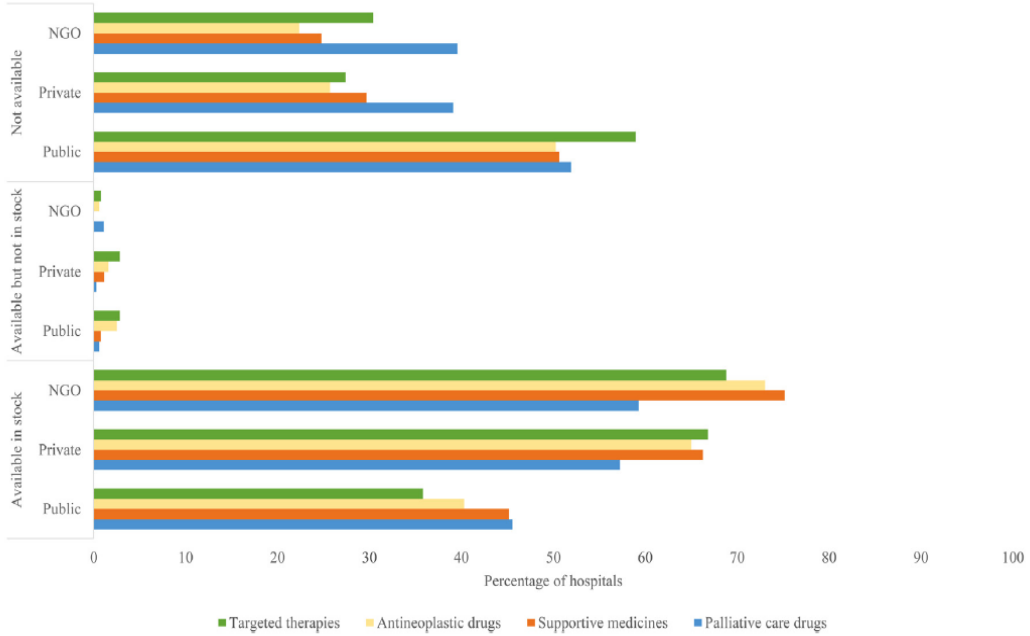

Fig. 1: Availability of childhood cancer treating drugs at tertiary hospitals (%).

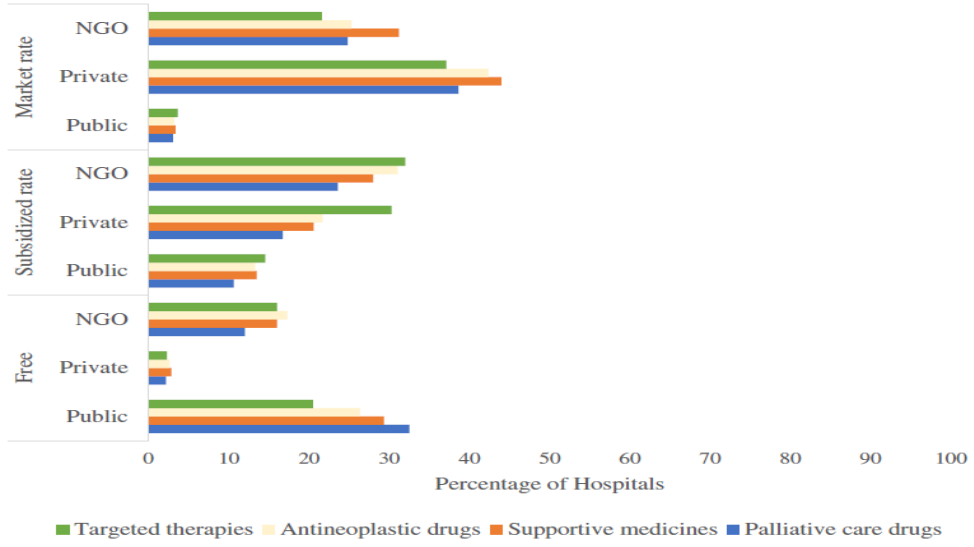

Fig. 2: Cost of childhood cancer treating medicines available at tertiary hospitals (%).

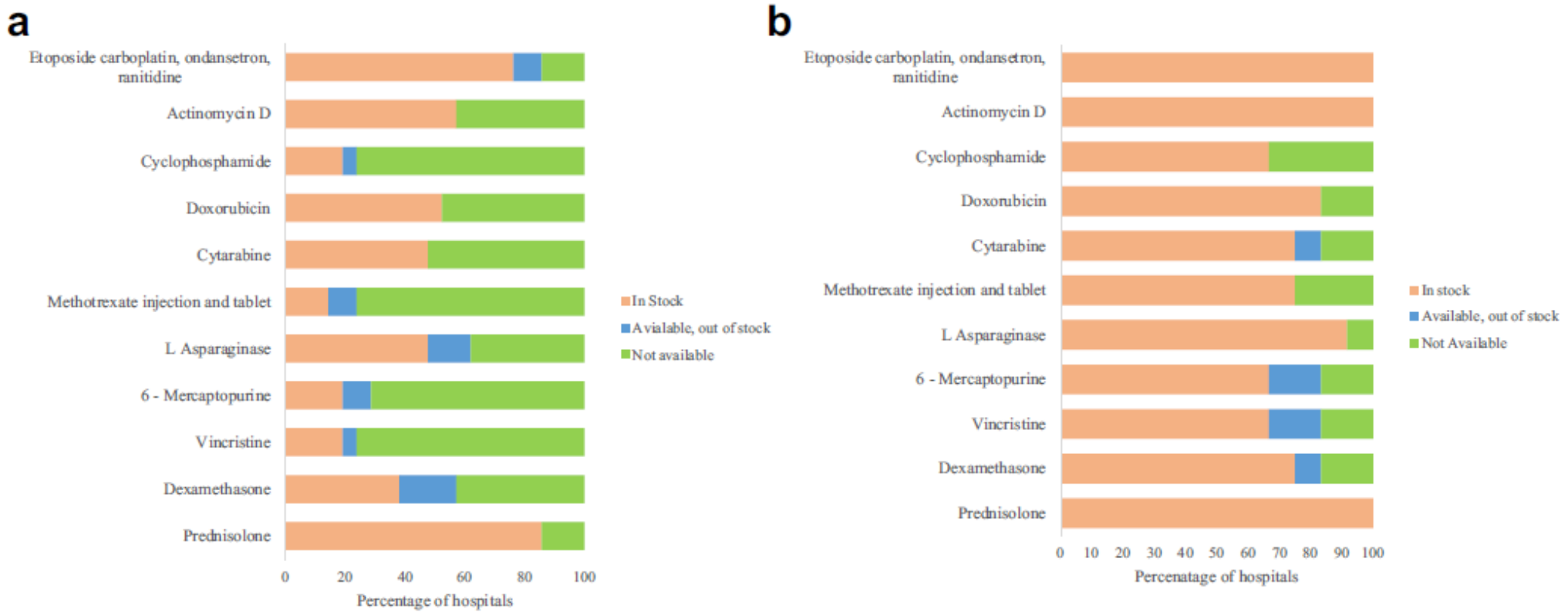

Fig. 3: a) Availability of drugs for treating childhood cancers at secondary level public hospitals (%). b) Availability of drugs for treating childhood cancers at secondary level private hospitals (%).

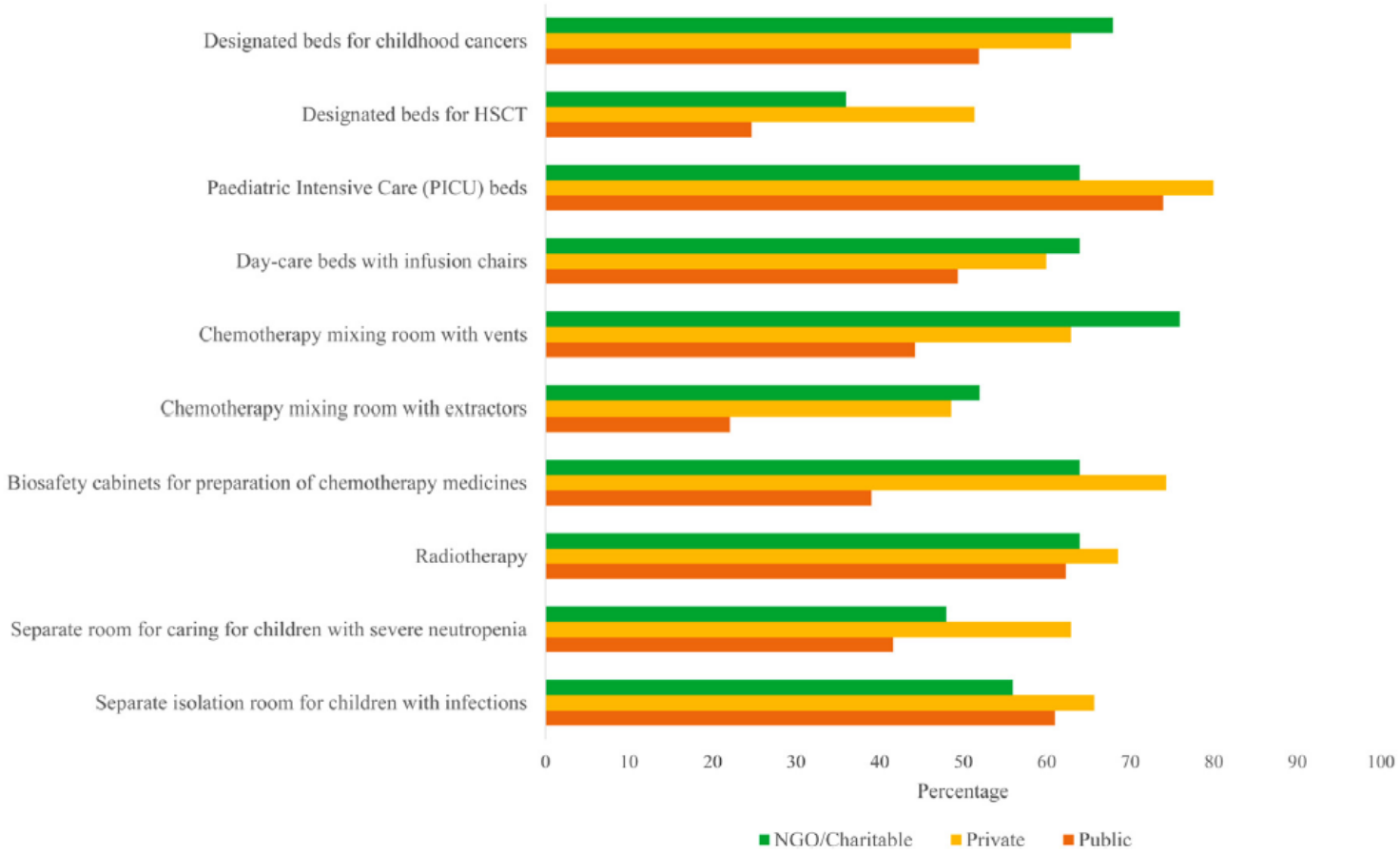

Fig. 4: Availability of infrastructure relevant to managing childhood cancer services at the tertiary hospitals.

This study demonstrated

a) Concentration of CCCS at tertiary level of health care

b) Gaps in availability of specialized pediatric oncology care in all tertiary hospitals

c) Availability of CCCS was higher in private & NGO-managed hospitals than in public hospitals

- ❖ Integration of childhood cancer as a part of national cancer control response should be taken up as a matter of priority
- ❖ The need of the hour is to formulate a childhood cancer policy that will enable timely access to care universally

ecancermedicalscience

Changing paradigms in pediatric cancer care – the contemporary landscape and perspectives for India

Badira Cheriyalinkal Parambil[1], Nirmalya Roy Moulik[1], Venkata Rama Mohan Gollamudi[1], Shyam Srinivasan[1], Chetan Dhamne[1], Akanksha Chichra[1], Gaurav Narula[1], Mukta Ramadwar[2], Sumeet Gujral[7], Tanuja Shet[2], Epari Sridhar[2], Poonam Panjwani[2], Uma Sakhadeo[2], Siddhartha Laskar[3], Nehal Khanna[3], Jifmi Jose Manjali[3], Sajid Qureshi[4], Vasundhara Patil[5], Akshay Baheti[5], Sneha Shah[6], Kunal Gala[5], Pappagudi Subramanian[7] , Prashant Tembhare[7], Nikhil Patkar[7], Gaurav Chatterjee[7], Sweta Rajpal[7], Dhanlaxmi Shetty[8], Maya Prasad[1] and Girish Chinnaswamy[1]

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- Parambil et al. (Published: 24/06/2025)
- Review article for major shifts in pediatric oncology care & current perspectives, especially for India & LMICs- in fields of cancer predisposition syndromes, precision medicine, immunotherapy & survivorship

Table 1. Immunotherapeutic agents approved for use in pediatric cancers.

Agent	Disease indicated	Year of approval	Key studies/findings	Availability in India
Pembrolizumab (anti-PD-1)	Hodgkin lymphoma (relapsed/refractory), tumors with MSI-H or dMMR	2020 (MSI-H/ dMMR approval for pediatrics)	Shown to improve outcomes in relapsed/ refractory Hodgkin lymphoma and MSI-H/ dMMR tumors like high-grade gliomas. Key trials: keynote series.	Marketed in India
Nivolumab (anti-PD-1)	Hodgkin lymphoma (relapsed/refractory)	2020 (pediatrics)	Demonstrated high response rates and durable remissions in pediatric Hodgkin lymphoma. Studies indicate safety and efficacy in younger populations.	Marketed in India
Blinatumomab (BsAb)	B-cell acute lymphoblastic leukemia (relapsed/ refractory)	2016 (pediatrics)	Showed significant improvement in minimal residual disease (MRD)-negative remission rates. Major trial: tower.	Not marketed, access through humanitarian/compassionate access program, or imported against payment on a named patient basis
Dinutuximab (anti-GD2)	High-risk neuroblastoma	2015	Improved survival in combination with GM-CSF, IL-2, and isotretinoin. Key trial: COG-ANBL0032.	Not marketed, imported against payment on a named patient basis
Tisagenlecleucel (CAR T)	B-cell acute lymphoblastic leukemia (relapsed/ refractory)	2017	First CAR T-cell therapy approved for pediatric ALL. Achieved high remission rates in the ELIANA trial.	Not marketed, imported against payment on a named patient basis. Phase 2 study on children of an indigenous product currently ongoing.
Gemtuzumab ozogamicin (ADC)	Acute myeloid leukemia (CD33-positive)	2017	Demonstrated efficacy in pediatric AML in combination with chemotherapy. Key trial: AAML0531 showed improved event-free survival in younger patients.	Not marketed, imported against payment on a named patient basis.

Table 3. Impact of risk-adapted treatment in pediatric oncology on late effects profile in CCSs (66–68).

First author, Year	Disease	Change in management based on risk stratification	Impact
Hodgson [66]	Hodgkin lymphoma	Decrease in volume/field of RT: From extended field RT to IFRT and INRT Decrease in RT dose Response-adapted selection of patients for RT	Decrease in incidence of SMN (up to 20-fold higher risk on historic treatments using extended field RT) Decrease in cardiac morbidity (up to 2-4-fold increased risk on receiving 35–45 Gy RT)
Friedman *et al* [67]	Neuroblastoma	Risk-adapted treatment	SMR_{high}=27.7 (21.4–35.8) $SMR_{intermediate}$=3.3 (1.7–6.5) SMR_{low}=2.8 (1.7–4.8) Decrease in SMR in low and intermediate-risk SMN risk: SIR_{high}=28.0 (8.5–42.3) $SIR_{intermediate}$=3.7 (1.2–11.3) No increased SMN risk in low-risk Grade 3–5 Chronic health conditions: HR_{high}=16.1 (11.2–23.2) $HR_{intermediate}$=6.3 (3.8–10.5) HR_{low}=1.8 (1.1–3.1) Decreased HR in in low and intermediate-risk
Essig *et al* [68]	Acute lymphoblastic leukemia- standard risk	Less intense chemotherapy regimens Omission of cranial RT	Only 1% survivors developed SMN (SIR-2·6, 95%CI:1·0–5·7) No significant impact on educational attainment, rate of marriage, or independent living.

RT-Radiotherapy, IFRT-Involved field RT, INRT-Involved node RT, SMN- Subsequent malignant neoplasms, SMR-Standardised mortality ratio, SIR-Standardised incidence ratio, HR-Hazard ratio.

Uneven infrastructure & Workforce

- Less than half of health care facilities have a dedicated Pediatric Oncology Department
- This issue has been well addressed in World Cancer Day 2024: Close the care gap- Addressing cancer care in India- 4th Feb 2024

World Cancer Day 2024
Close the care gap- Addressing cancer care in India
4th Feb 2024

- 7757 sources of reliable data which provides insights on

a) New cancer occurrences

b) Trends over time

c) Changing patterns & their distribution

d) Management practices, outcomes and survival

- These inputs inform action and encourage relevant research

❖ **Burden of Childhood cancers in India**

In 2022, lymphoid leukemia emerged as predominant site (29.2%-boys and 24.2%-girls)

An estimated 12.8% increase in cancer incidence by 2025 is expected as compared to 2020

❖ **Cancer care in India**

- Key concern is existing care gap, where access to quality cancer care & treatment is not uniformly distributed
- Particularly seen in rural areas where healthcare facilities are limited
- Factors impacting survival rates- type of cancer, timing of diagnosis, gender, disease stage & nature of treatment received
- Rise of childhood cancers is becoming a significant issue in India, highlighting absence of a dedicated programme or policy to tackle & control childhood cancer
- 4% of all cancers in India are among children aged 0-14 years

- **<u>Situational analysis of childhood cancer care services in India-</u>**

  a) Public (41.6%) & Private (48.6%) health set up had a dedicated pediatric oncology dept

  b) CCCS were provided at one-third (40%) of secondary level charitable hosp

  c) Over two-thirds of govt tertiary hospitals had referral linkages with non childhood cancer-treating facilities

  d) Most tertiary-level hospitals had supportive care facilities

  e) 90% of tertiary hospitals had facilities for histopathology

  f) 80% of tertiary hospitals had radio diagnostic facilities

  g) Specialised manpower was low in public tertiary hosp

  h) <50% of public tertiary hosp had stocks of all four classes of cancer treating drugs

❖ Closing the care gap

The need of the hour is to deliver cancer care to those who need it the most, by breaking barriers of access overcoming disparities in cancer care availability

- Bridging this gap requires a multifaceted strategy involving multiple stakeholders- responsible communities, health care providers, key decision & policy makers
- The need to enhance healthcare infrastructure is crucial, ensuring that effective cancer diagnostics & treatment services are accessible to all
- Establishment of advanced cancer centers & concerted effort to extend reach of these facilities to underserved areas
- Efforts of public insurance programs- (AB-PMJAY) & collaborative efforts between public & private sectors to overcome financial barriers to essential treatments
- The journey through cancer is not just about medical interventions; it is about providing a holistic support system that addresses emotional & mental well-being of patients & their families throughout continuum of care
- Therefore, closing the care gap is not just a goal; it is a commitment to a more equitable healthcare in India

Universal Health Care for Childhood Cancer in India: Challenges and Solutions for Implementation

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Abstract

Introduction: The World Health Organization has declared a Global Initiative for Childhood Cancer which aims at achieving a cure rate of atleast 60% globally. To achieve this significant planning and policy making would be needed in most LMICs including India. In this setting, having a Universal Healthcare Scheme, that tracks patients from first symptom to diagnosis to treatment and provides free treatment is a laudable effort by the Government of India. **Aims and Objectives:** In this paper, we describe our experience of managing children with cancer on Pradhan Mantri Jan Arogya Yojana (PMJAY) or Ayushman Bharat scheme at our center over a period of 5 years. We also identify and report few suggestions for universal implementation of this scheme in order for better coverage for children with cancers. **Methods:** The data of children aged between 0-18 years who underwent treatment for cancer with financial support from PMJAY scheme between Jan 2018 to December 2022 (5 years) was analyzed from hospital records. **Results:** 59 out of 485 children treated for cancer were eligible for PMJAY (Ayushman Bharat Scheme). Only 12% of patients were found to be eligible, even when parent's card was taken as primary proof. Overall >85% of the families who enrolled in to this scheme were highly satisfied as there were no out of pocket expenses incurred due to early initiation into the program. All patients were enrolled on treatment and 57 children completed treatment successfully. We also identify and report few suggestions for universal implementation of this scheme in order for better coverage for children with cancers. **Conclusions:** PMJAY is a people-centric scheme which provides a complete package from diagnosis to completion of treatment. The program when implemented in its totality would continue to strengthen India's response towards the Global Initiative for Childhood Cancer.

Keywords: Cancer, India, universal health care

Financial burden leading to abandonment

- Even with public schemes, travel cost & loss of daily income increased treatment abandonment in many regions
- Data from India's largest cancer center, Tata Memorial Hospital in Mumbai in 2010:

  1 of 5 child dropped out by mid way of their treatment course

  Reasons- financial constraints, lack of belief in cure & gender bias against girls
- ImPaCCT foundation has created remarkable transformation in this aspect-

  Treatment Refusal & abandonment (TR & A): reduced drastically from 25% (2008)-> 2% (2022)

IMPROVING PAEDIATRIC CANCER CARE & TREATMENT

ImPaCCT Foundation

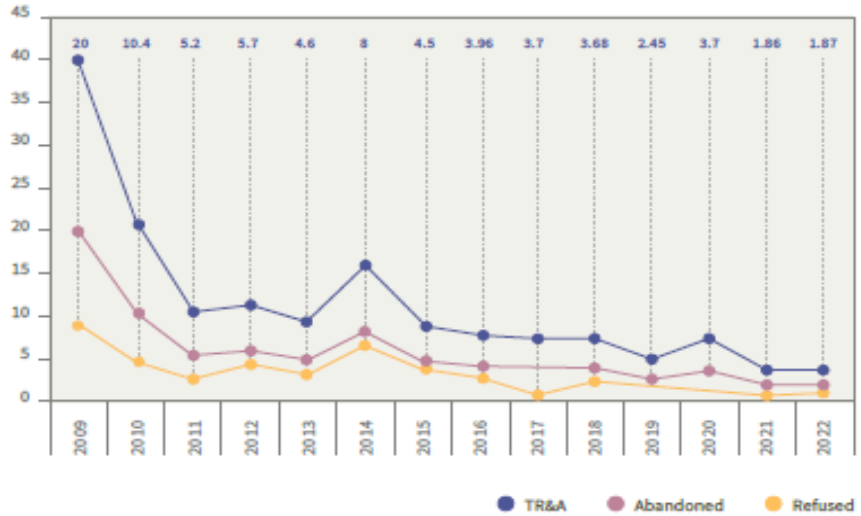
Annual Report
APRIL 2022–MARCH 2023

IMPACCT FOUNDATION - TATA MEMORIAL CENTRE

Impact of ImPaCCT Foundation

TR&A TRENDS 2009-2022

The Treatment Refusal & Abandonment (TR&A) rate has fallen drastically from a 25% in 2008 to a 2% in 2022



- Provided free treatment to 4500 children through the funds raised by donors, in 2022-23!
- Accommodation provided to more than 3500 children and families, through our NGO partners and other organizations, last year!
- 66,000 meals distributed to the children through the mid-day meal program sponsored by corporates!
- Providing education to all children coming to the hospital in the OPD and the ward!
- Hand holding each and every family and motivating them to complete treatment!
- Making the journey of each and every child a happy and memorable one - organized over 100 events in the year!

Supportive care- Gaps

- High infection burden (while on chemotherapy)
- Limited pediatric ICU access & blood products
- Anti microbial treatment-antibiotics policy
- All the above factors have contributed to significant treatment related mortality

	All cancers (n=3569)	Haematological malignancy (n=2798)	CNS solid tumour (n=50)	Non-CNS solid tumour (n=199)
Total number of patients*	68 351	51 186	6240	10785
Sepsis or infection	2560 (71·7%)	2069 (73·9%)	28 (56·0%)	101 (50·8%)
Haemorrhage	379 (10·6%)	306 (10·9%)	4 (8·0%)	4 (2·0%)
Metabolic causes (tumour lysis syndrome)	174 (4·9%)	162 (5·8%)	0	1 (0·5%)
Disseminated intravascular coagulation	13 (0·4%)	12 (0·4%)	0	0
Surgical complications	51 (1·4%)	2 (0·1%)	7 (14·0%)	25 (12·6%)
Neurological complications (encephalopathy or raised intracranial pressure)	26 (0·7%)	21 (0·8%)	1 (2·0%)	1 (0·5%)
Seizures	4 (0·1%)	2 (0·1%)	2 (4·0%)	0
Cardiac failure	43 (1·2%)	17 (0·6%)	0	15 (7·5%)
Respiratory failure	99 (2·8%)	80 (2·9%)	0	6 (3·0%)
Superior vena cava syndrome	5 (0·1%)	5 (0·2%)	0	0
Hyperleukocytosis	8 (0·2%)	8 (0·3%)	0	0
Other chemotherapy toxicity	90 (2·5%)	32 (1·1%)	6 (12·0%)	33 (16·6%)
Other organ failure	98 (2·7%)	72 (2·6%)	1 (2·0%)	6 (3·0%)
Other	19 (0·5%)	10 (0·4%)	1 (2·0%)	7 (3·5%)

Data are n (%), unless otherwise stated. *Due to the inclusion of studies with multiple diagnoses across several diagnostic categories, the total number of patients with any malignancy is greater than the sum of patients in the given categories.

***Table 3:* Identified causes of treatment-related mortality**

Registry coverage & quality of data

- Population-based cancer registry for children is expanding but is still incomplete
- The first dedicated Population-Based Cancer Registry- Greater Chennai Zone (2022-2023) is a big step but needs scale-up nationwide

From Burden to Action: Policies & Innovative approaches

Programs & Policy- What is changing?

- **<u>WHO Global Initiative for Childhood Cancer (GICC):</u>** India aligns with a goal of >60% survival by year 2030

Contents lists available at ScienceDirect

Pediatric Hematology Oncology Journal

journal homepage: https://www.elsevier.com/journals/pediatric-hematology-oncology-journal/

WHO Global Initiative for childhood cancer – India responds

Pediatric Hematology Oncology, Chapter of Indian Academy of Pediatrics (PHO IAP), Indian Pediatric Oncology Group (InPOG), Cankids Kidscan Representing Civil Society & Patient Groups

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ABSTRACT

Launched in 2018, the WHO Global Initiative on Childhood Cancer aims to reach at least 60% survival rate for children with cancers by 2030, while reducing suffering, altogether saving an additional one million lives. There is an opportunity for India to align with this Global Initiative and make progress. Over the last year several meetings at diverse platforms in India and abroad have engaged multiple stakeholders. This has led to an increased awareness of the Global Initiative, an agreement within the Indian community to be part of it, identification of key players, and initial discussions on the areas of focus and relevant organisations. In the next year, we aim to chalk out the details of the scope of the work, the structure of the activities, the timelines, the interim and final endpoints and the resources needed.

The first step (June 2019)

Fig. 1. Stakeholders at the meeting on June 24, 2019 in New Delhi.

Second meeting (September 2019)

Fig. 2. Breakout sessions for access to care taskforce and supportive care taskforce at PHOCON/PHOSSCON 2019 in Varanasi.

Third meeting (October 2019)

Fig. 3. WHO Childhood Cancer representative, Dr Andre Ilbawi with representatives from India at SIOP Annual Congress in Lyon.

Next steps

Creation of a Steering Committee proposed, which had representation from PHO IAP, In POG, National Cancer Grid, Cankids, WHO & national Government Declaration

Cankids & Max Healthcare provided funding & logistical support for 1st stakeholder meeting on June 24, 2019 in New Delhi.

PHO IAP & Cankids provided funds for second meeting in Varanasi during PHOCON & PHOSSCON in Sep 2019

Proposed Taskforce Groups for implementing the WHO Target for Childhood Cancer in India.

Proposed Taskforce	Related Problems	Stakeholders	Potential Solutions
Data & Registry	• Many children are not diagnosed and therefore not reported • Incomplete data capture in the existing registries • Regional disparity in the coverage • Non availability of survival data, most of the registries do not follow-up • Inadequate funds for registry and research	• National Cancer Registry Programme • State run registries (For example-Tamil Nadu Cancer Registry Programme) • Other hospital registries • Social support registries (For example-Cankids, Jiv daya Foundation) • Nutritional Registry (Eg. Cuddles Foundation) • Survivor Registry (Eg. Ugam, Cankids) • International Agency for Research in Cancer (IARC) • InPOG Epidemiology Subcommittee	• Collation of data from different registries • Mapping of the resources and the type of services offered by different organization in the country • Developing a standard data collection mechanism and reporting • Promoting data sharing practices • Making the data available for future clinical practice and policy change • Advocacy to make cancer as a notifiable disease to enhance coverage (For eg. Tamil Nadu [under the Tamil Nadu Public Health Act], Karnataka) • To explore funding opportunities for registry and research
Access to Care	• Late detection and diagnosis • Untrained local health professionals • No proper referral and absence of referral pathways • Lack of Facilities at Community/District hospitall/ Government Medical Colleges for shared care • No guidelines for pediatric cancer unit • Absence of treatment protocols • Lack of awareness • Lack of information and resource directories	• Central & State government • Print, broadcast & online media • Health Professionals • Hospital Administrative • Civil society and non-government Organisations • Parents, support groups & survivor groups • Indian Academy of Pediatrics (IAP) • InPOG Access to Care Subcommittee	• Mapping of hospitals, Referral Pathways and Shared care centres • Standard operating procedures for clinical practice • Standard protocols • Put the information in public domain • Advocacy with Govt. to make childhood cancer health priority • Guidelines for pediatric cancer unit and centres of excellence • Funding from Corporate Social Responsibility and Philanthropic Organisations • Sensitization of medical colleges for Paediatric Oncology Facility
Workforce, Training & Accreditation	• Inadequate manpower -medical and social • Variable to no standards of training • Only few trained pediatric oncologists/nurses • Limited systematic training for social support team, ASHA and anganwadi workers or other stakeholders • No funding for many training programs • No initiative to train at all level of stakeholders • No entity to monitor personal and institutional standards and accreditation	• IAP and Pediatric Hematology Oncology (PHO) Chapter of IAP • Indian Nursing Council • Other health professional and allied organisations • Social Support Organisations, Cankids • National Cancer Grid	• Map out centres and professionals and assess current status of facilities and training • Develop standard training modules and curriculums • Increase manpower
Protocols & Clinical Trials	• Absence of funding • Lack of training in research methodology and trial design • Lack of crosstalk/thought exchange with universities/ academia • Lack of dedicated research teams • Challenge of implementing the findings of trials • Lack of dedicated research time	• InPOG (Indian Pediatric Oncology Group) • ICMR (The Indian Council of Medical Research), • NCG (National Cancer Grid)	• Collaboration with international partners like SIOP, COG, etc • Seek funding for rexearh capacity building as well as for research studies • Increase portfolio of InPOG studies and promote culture of multicenter collaborative research • Develop training modules, courses, mentorship • Collaborate with universities
Drugs & Diagnostics	• Variability in quality of drugs • Affordability and accessibility • Lack of standardization of laboratory tests	• WHO • Government • Healthcare provider • Civil Society • Patients and survivor and family • Pharma industry • Laboratory centres • National Cancer Grid • The National Pharmaceutical Pricing Authority	• Identify & map what is available & gaps to fill • Start reporting the quality of drugs • Reporting reactions in patient and reporting it • Therapeutically equivalent essential list of anti-cancer drug • National list of essential medicine for childhood cancer treatment (first line and second line) • All drugs of anti-cancer and antibiotic available and cashless for childhood cancer • Centralised procurement and bulk purchase • Research in biosimilars and generics
Supportive & Social Care	• Unreliable supply of blood products • Lack of availability of blood component • Multi-drug resistant infections • Non-availability of accommodation • Paucity of train staff and funding for optimal supportive and social care	• Local Blood bank and relevant national organisations • Blood donor websites • Friends, Family and blood support groups • Local Infection Control Team and relevant national organisations • InPOG Supportive Care Subcommittee • PHO IAP	• Blood donation drives • Increased support for single donor platelet kits • Increase capacity of Home Away from Home • Develop mechanism to audit hospital infection rates and related mortality • Capacity building of dietitians

Table 1 (*continued*)

Proposed Taskforce	Related Problems	Stakeholders	Potential Solutions
		• NGOs like Cuddles, Cankids, St Jude Child Care Centres	
Financing & Policy	• Absence of government buy-in • No national plan, program or policy on childhood cancer – not part of the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) • Lack of medical insurance • Inadequate funding	• World Health Organization (WHO) • Central & State government • NHA (National Health Agency • Ayushman Bharat and other state government schemes • PHO IAP • National Cancer Grid. • NGOs and Patient Advocacy Groups • Corporate sector	• To bring the government as the stakeholder • To build our own capacity, acquire more knowledge and information so that we can be effective advocate so that patient voice is heard • Dialogue with all stakeholders • Define models of financing • Develop a National Cancer Institute for children
Patient/Family/ Community Engagement	• Unavailability of Single Window Information system • Stigma and mythsLack of patient groups and their engagement in policy, decision making and communication at all levels – hospital State, Regional or National • Lack of community support and engagement for pediatric palliative care, survivorship and reintegration and to improve access to care	• Parent and Survivor group • Non-governmental organisations • Community based organisations • Self Help Groups • Mass Media • Government Officials/ Administration	• Childhood Cancer should be the health priority in India (For Policy making) • Awareness Campaigns • Setting up of single window information center pertaining to childhood cancer • Helpline numbers should be made available • Survivorship should be part of cancer care program • Strengthening of parent and survivor groups and forums
Continuum of Care (including Palliation & Survivorship)	• Lack of palliation and end of life care • Access to opiods • Lack of trained physicians and nurses in palliation • Few dedicated survivor clinics • No India centric childhood cancer survivor guidelines	• Survivor groups – Kidskan Konnect, Ugam • PHO IAP • InPOG Survivorship & Late Effects Subcommittee • InPOG Palliative Care Subcommittee • Indian Association of Palliative Care and Pallium India	• Training of workforce in palliative and survivorship care • Develop relevant curriculum • Encourage utilization of hospices and home for end-of-life care • Develop late effects guidelines • Increase capacity of survivor clinics • Increase research in survivor issues • Involvement of survivors and caregivers in various campaigns, other medical/non medical forums and policy making

Programs & Policy- What is changing?

- **<u>Indian Childhood Cancer Initiative (ICCI-March 2023):</u>**

  National platform convening government, clinicians & civil society to deliver childhood cancer services
- **Goal:**

  To ensure equal access to patient-centered, holistic care & standardized treatment for all children
- **Key Objectives:**

  March 2023 launch focused on formalizing group, setting a 2030 survival goal

  Engaging stakeholders, establishing partnerships with organizations like St Judes Global

  Creating a robust framework for achieving its objectives

Programs & Policy- What is changing?

- UHC Momentum

Universal Health Care for Childhood Cancer in India: Challenges and Solutions for Implementation

Anukriti Srivastava, Nita Radhakrishnan, Archit Pandharipande, Zeenat Brar, Amit Pandey

Department of Pediatric Hematology Oncology, Post Graduate Institute of Child Health, Noida, Uttar Pradesh, India

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Stakeholder collaboration: Government, private sector and non-governmental organizations can build pediatric oncology services in India

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- Twinning programs between centers in developed & developing nations have shown to improve survival rates for pediatric cancer
- Patients twinning between centers within a state may help in establishing an effective pathway of care in pediatric oncology
- To strengthen pediatric oncology services, best way is through optimal utilization of existing infrastructure & by creation of a twinning program between centers already equipped
- Pediatric Oncology Outreach Clinic (POOC) was set up at Advanced Cancer Institute (ACI), Bhatinda & Pediatric Oncology Outreach Program was established for collaborative care

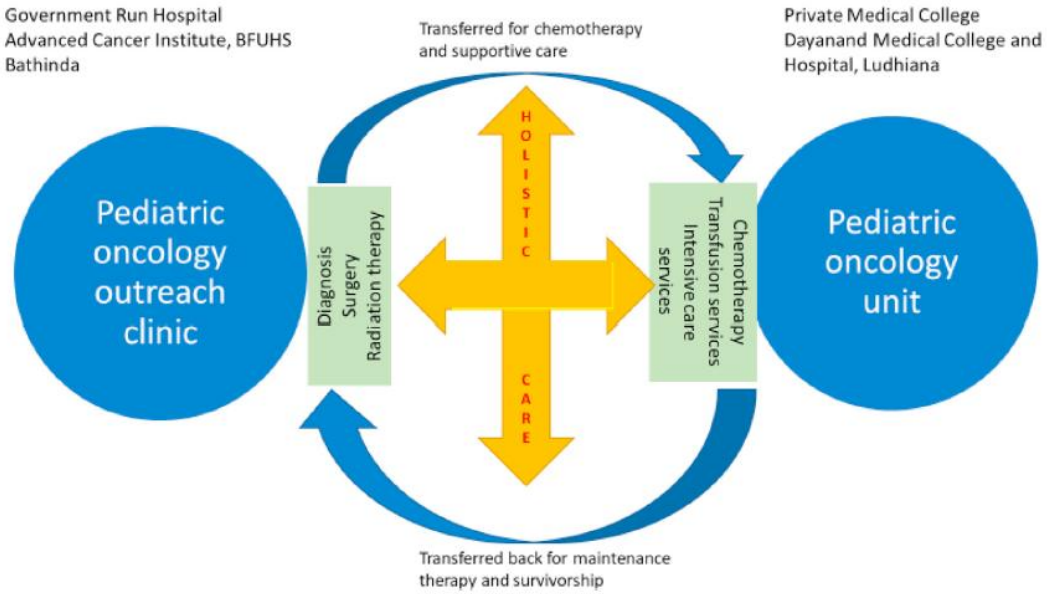

Fig. 2. Structural and functional organization of the Pediatric Oncology outreach program.

Spectrum of various malignancies seen at POOC.

	Type of neoplasm	No. Of patients
1	Leukemias, myeloproliferative diseases, and myelodysplastic diseases	
	Lymphoid leukemias	10 (2 relapsed after abandonment from other centre)
	Acute myeloid leukemias	1
	Chronic myeloproliferative diseases	2
	Unspecified and other specified leukemias	1
2	Lymphomas	
	Hodgkin's lymphoma	6
	Non Hodgkins's lymphoma (except Burkitt's lymphoma)	1
	Unspecified lymphomas	1
3	CNS and miscellaneous intraspinal and intracranial neoplasms	
	Ependymomas and choroid plexus tumors	1
	Astrocytoma	1
	Intracranial and intraspinal embryonal tumors	
	Other gliomas	2
	Other specified intraspinal and intracranial neoplasms	
	Other unspecifiedintraspinal and intracranial neoplasms	
4	Neuroblastoma and other peripheral nervous system tumors	
	Neuroblastoma and ganglioneuroblastoma	2
	Other peripheral nervous system tumors	1
5	Retinoblastoma	1
6.	Renal tumors	
	Nephroblastoma	2
7	Hepatic tumors	0
8	Malignant Bone tumor	
	Osteosarcoma	4
9	Soft tissue and other extraosseous tissue sarcoma	
	Rhabdomyosarcoma	1
10	Germ cell tumors	
	Malignant gonadal germ cell tumor	1
11	Other malignant epithelial neoplasms	
	Thyroid carcinoma	2
	Nasopharyngeal carcinoma	1
12	Other and unspecified malignant tumors	0

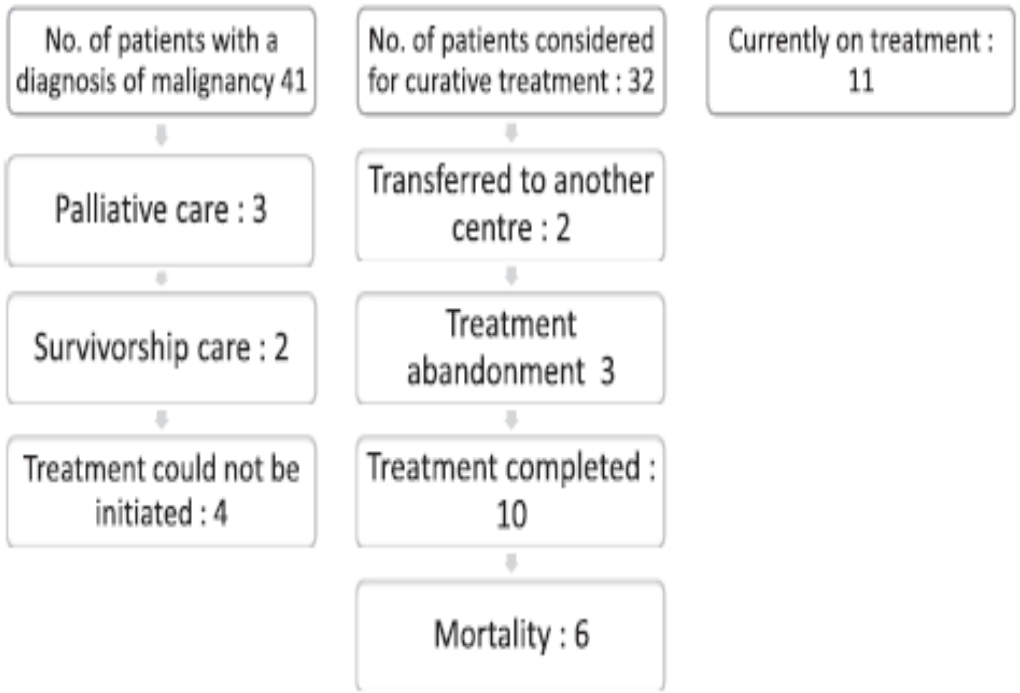

Fig. 3. Outcome of patients registered in POOC.

- **Results:**

- Twinning has proven to be extremely effective way to improve outcomes in pediatric malignancies in developing countries
- Provides advice & support from established pediatric oncology units to developing ones
- Effective in initiating treatment in 90% patients with childhood cancer
- POOC provided not only treatment, but also palliative & survivorship care
- POOC helped physicians to reach out to patients & gain their confidence
- Regular counselling sessions of children & parents were conducted by social worker & members of patient support group

❖ Refusal & abandonment are leading cause of treatment failure in children with cancer

❖ Twinning partnerships are highly effective at transferring skills & expertise to improve diagnosis, treatment & care for children with cancer

Addressing the Alarming Rise in Pediatric Cancer Prevalence in India: A Call to Action

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- Childhood cancers are global concern, impacting over 200,000 children annually & might escalate to 21 million by 2030
- Pediatric oncology in India faces challenges arising from limited rural healthcare access, resulting in delayed diagnosis & treatment
- Socio-economic factors hinder specialized pediatric cancer care, alarming need to bridge these gaps through targeted interventions, improved infrastructure & policies
- This requires public education, enhanced medical & research training, community-based cancer screening, & integrated medical care initiatives
- <u>Inference:</u> Despite recent efforts by Ministry of Health, Govt of India, childhood cancer lacks a specific policy in India

  Urgent collective efforts are needed to address challenges, invest in research, enhance awareness & advocate for policy changes

  It is time for healthcare professionals, policymakers, researchers & public to collaborate & ensure no child in India is left behind in its fight against pediatric cancers

- **Call to action**

- Formulating a childhood cancer policy to enable timely diagnosis, treatment, supportive care & follow-up through well-defined care pathways
- Integration of childhood cancer as a part of national cancer control response
- Financing mechanism and schemes for childhood cancer treatment
- Training of general physicians & primary care providers to identify signs & symptoms in children with cancer, which will enable timely referral
- Expansion of pediatric oncology units, training of physicians & paramedics in pediatric oncology
- Creating large-scale awareness of childhood cancer for its timely diagnosis, completing treatment, optimal cure rate & healthy survivorship

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Addressing The Shortage Of Pediatric Oncologists In India: Urgent Need For Action

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- **FACTORS CONTRIBUTING TO SHORTAGE**
- Limited Training Opportunities
- Lack of attractiveness of Specialization
- Infrastructure and Resource Constraints
- **STRATEGIES TO ADDRESS THE SHORTAGE**
- Strengthening Training Programs
- Incentives and Support
- Enhancing Collaboration

- **SOLUTION:** Comprehensive approach-
- Increasing number of healthcare professionals, enhancing infrastructure & resources
- Providing attractive incentives and support systems
- Collaboration between stakeholders is crucial to sharing resources, expertise & best practices
- By implementing these strategies, every child diagnosed with cancer in India receives timely, high-quality & specialized care, ultimately improving their chances of survival & quality of life

Assessment of Barriers and Enablers for Implementing a Population-Based Childhood Cancer Registry in Chennai, India

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Keywords: cancer registry | epidemiology | pediatric cancer | population-based childhood cancer registry

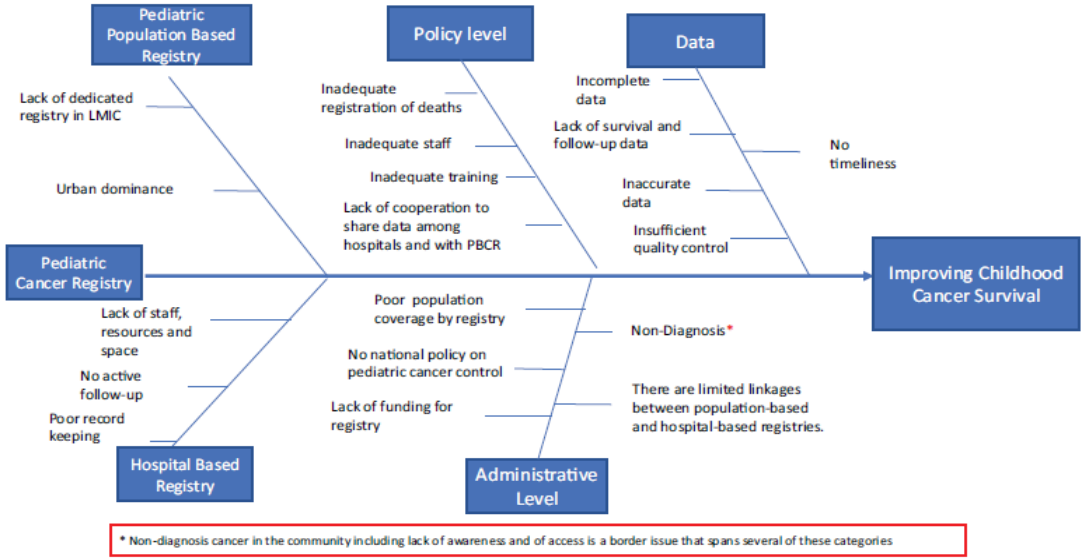

FIGURE 1 | Challenges facing childhood cancer registries in low- and middle-income countries (LMICs).

- India's first dedicated PBCCR in Chennai on October 4, 2022, covering children 0–19 yrs age
- Aim: to identify barriers & enablers to implementing Chennai PBCCR
- Between April 2023 and March 2024, a sequential explanatory mixed-method study was conducted across 10 of 16 centers in Chennai that agreed to support PBCCR
- A total of 25 professionals agreed to participate in quantitative phase using a structured questionnaire
- For qualitative phase, in-depth interviews were conducted with 23 participants

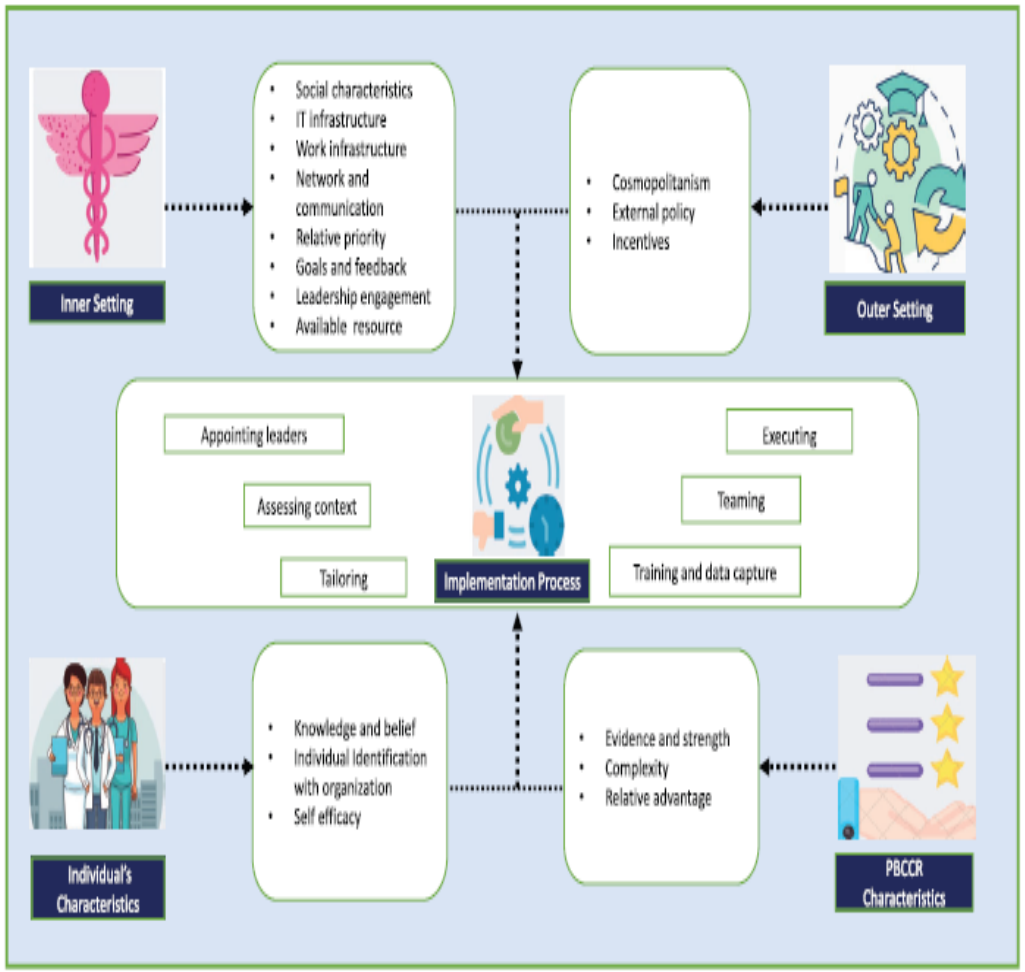

FIGURE 3 | Themes identified using the Consolidated Framework for Implementation Research (CFIR).

TABLE 2 | Summary of enablers and barriers in implementing Chennai Population-Based Childhood Cancer Registry (PBCCR).

Themes	Barrier	Enabler
PBCCR/HBCCR characteristics	• Missed cases due to undiagnosed pediatric cancer patients • Limited resources for diagnosis and treatment of pediatric cancer patients • Absence of pediatric oncologist in some centers	• Provides valuable data for improving outcome in childhood cancer • Assists in the development of policies
Outer setting	• Registry reports not shared with providers • Irregular periodic meeting between the PBCCRs core team and hospital administration	• Effective communication between the PBCCRs core team and hospital • Funds from other cancer registries support the development of technology and human resources
Inner setting	• Insufficient equipment, such as computer and office space • Lack of dedicated software for data collection • Lack of human resources to operate HBCCRs and PBCCRs • No financial incentives for data collection	• Dedicated HBCCRs • Regular meeting among registry staff • Strong leadership support for registry operations • Availability of electronic medical records • Utilizing NGO volunteer to address staffing shortage
Characteristics of individuals	• Concerns over data privacy and potential misuse • Inadequate training in cancer registration and data collection	• Training of registry staff and oncologist in pediatric cancer registration through courses and workshops • Individual's belief in the importance of cancer registration within the PBCCR for enhancing treatment plans
Implementation process	• Delays in hospital administrative approvals for data sharing with PBCCR • Multiple registries collecting overlapping data, leading to duplication of effort • Unclear guidelines on data sharing with PBCCR • Poorly stored or missing case records • Incomplete information in case records • High staff turnover due to low salaries and limited career growth • Insufficient or no funding to establish HBCCRs and PBCCRs • Lack of perceived benefit for centers contributing data to PBCCR	• State law mandating compulsory cancer registries • Previous experience contributing data to registries • Demonstrating the impact of PBCCR data to policymakers and stakeholders through reports and publications

Abbreviations. HBCCR, hospital-based childhood cancer registry; NGO, non-government organization.

❖ **Results:**

- Themes from qualitative analysis revealed technological constraints, poor record-keeping, insufficient details in case records & inadequate human resources as impediments
- Facilitators to successful implementation- knowledge, belief in sharing high-resolution data, requirement & advantages of implementing a childhood cancer registry, professional self-efficacy, work infrastructure & collaborative networks

❖ **Conclusion:**

- This study serve as a model for successfully implementing & operating PBCCRs in India & other countries
- Registry data are vital to improve understanding of childhood cancer burden & offer hope to children & their families

Actionable priorities- What will move the needle fastest?

1) Early detection & referral networks: Train front line health care personnel & establish fast track pathways to pediatric cancers
2) Hub-and-spoke Pediatric Oncology Units: Expanding Pediatric services & team to standardize treatment protocol
3) Anti-abandonment approach: alike ImPaCCT foundation
4) Comprehensive support model for pediatric care
5) Dedicated Pediatric Registeries

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Delivering psychological and social support to children with cancer in India and their families: a position statement from the social and psychological taskforce of the Indian childhood cancer initiative

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- ICCI Psychological & Social Support Taskforce

- 8 priority areas for addressing psychosocial needs of pediatric oncology patients & their families

1. Every child with cancer should have holistic care
2. Every child with cancer should have early assessment & intervention of their psycho-social needs
3. Promotion of interdisciplinary collaboration is essential for delivery of social & psychological care
4. Encouraging community outreach & education to raise awareness at community level
5. Advocate for policy to include psychological & social support services in pediatric oncology
6. Encourage research & innovation in psycho social aspects of pediatric oncology that are culturally sensitive & relevant
7. All children with cancer should have access to psychological & social support services
8. There should be standards for psychological & social support in pediatric oncology centers

Chemotherapy

Radiotherapy

Surgery