

2023

FoodHeals™ :

Exploring Nutritional
Aspects of Childhood
Cancer in India



Foreword

With great pleasure, I introduce this report “FoodHeals™: Exploring Nutritional Aspects of Childhood Cancer in India” by Cuddles Foundation. This report not only includes information on nutritional status of children with cancer in India but also encompasses vital data on demographics, socio-economic status, food insecurity and cancer type thereby offering a holistic view of the state of childhood cancer in India.

As a paediatric and medical oncologist, I have witnessed significant progress in childhood cancer care, yet the burden remains pressing, especially in countries like India.

Cuddles Foundation has been working for the last 10 years to help solve one of the most important obstacles to cancer cure; Malnutrition. They have been supporting nutrition for paediatric patients with cancer through the FoodHeals™ programme at AIIMS, New Delhi and this I believe has resulted in significant impact in improving their outcomes.

This report highlights the landscape, guiding us to focus on critical areas for enhancement.

**Together, let us ensure a future where
cancer doesn't overshadow any child's life.**



PROF SAMEER BAKHSHI

Department of Medical Oncology,
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Section A: The Reality of Childhood Cancer in India

In February 2022, 12-year-old Reshma (name changed to protect the identity of the patient) fell unconscious and was diagnosed with anaemia. Despite multiple blood transfusions, her condition worsened. Seeking answers, her parents took her to Nepal from their home state in May but remained undiagnosed. She then started developing swelling in her feet and lumps in her neck and stomach. The struggle for a diagnosis continued as they consulted a traditional medicine practitioner in their home state, before finally getting diagnosed with Acute Lymphoblastic Leukaemia (ALL), at a cancer hospital in November – a challenging nine-month journey to find the cause of her symptoms. In addition, the child and her caregivers are likely to face even more obstacles when the treatment for this type of childhood cancer begins. These may very well change the trajectory of the child's and her caregivers' lives.

Childhood cancer is a significant public health concern that poses a considerable challenge to societies worldwide. In India, the exact incidence and prevalence rates of childhood cancer are not easily quantifiable due to the fact that population-based cancer registry data only covers 13% of the population.^[1] However, according to an article published in the journal *Indian Pediatrics* in 2021, approximately 76,000 children and adolescents may develop cancer in India every year.^[2]

Although it is challenging to prevent and diagnose childhood cancer, generic medicine and therapy, including chemotherapy and radiation, if provided at the right time, can cure most childhood cancers. Yet, in low and middle-income countries like India, only an estimated 15-45% of children are cured of cancer as compared to more than 80% in high-income countries.^[3]

The world is taking notice of this disparity, and to address this vast difference, the WHO, along with other collaborators, has launched the Global Initiative for Childhood Cancer (GICC), which aims to achieve a 60% survival rate for childhood cancer patients across the world by the year 2030. To work towards this target set by GICC-WHO, more data surrounding childhood cancer is required.

The GICC-WHO initiative recognises the importance of nutrition in childhood cancer cure and calls for capacity building in areas of nutrition assessment, support and nutrition education in order to address malnutrition in children with cancers.

Cuddles Foundation has been working to bridge the nutrition gap by counselling and providing nutrition aid to children with cancer. Last year, they covered 36 government and charitable hospitals in India through their FoodHeals™ Centres. As part of the programme, each centre collects demographic, anthropometric, socioeconomic, nutrition (including food insecurity) and disease-related patient data through the Cuddles' FoodHeals™ App.

The aim of this report is to share findings from the last financial year ('22-'23), which will contribute to a comprehensive understanding of the current state of childhood cancer in India. The findings from the analysis of over 7,600+* Cuddles Foundation beneficiaries shed light on various aspects, such as the demographic statistics of childhood cancer patients, their nutrition status during the initial visit, socioeconomic backgrounds, and the risk of food insecurity. These valuable insights can serve as foundational points for further research endeavours in the field of childhood cancer and nutrition.

► Childhood Cancer Scenario In India

400,000

children are estimated to develop cancer every year worldwide.^[3]

~90%

of these children are from low- and middle-income countries like India.^[4]



~76,000

adolescents (age 0-19 years) may develop cancer every year in India.

49%

is the estimate of undiagnosed cancers in children in India and South Asia.^[5] An even smaller proportion of children initiate and complete treatment.^[6]

“



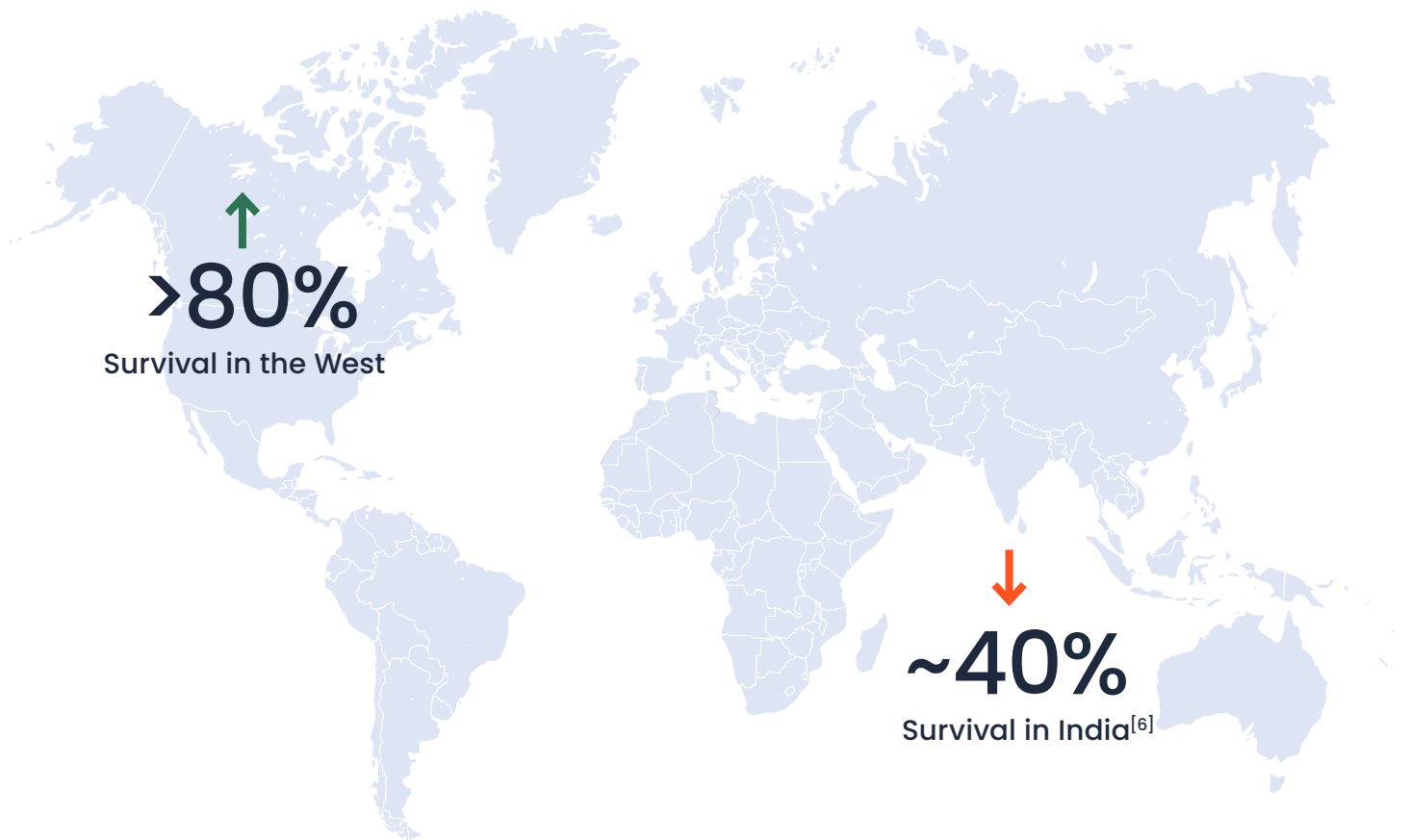
“The challenge of undiagnosed pediatric cancer in India is multi-faceted. Limited access to primary care, lack of awareness, and delayed diagnosis all contribute to this issue. Consequently, the true magnitude of cases remains underestimated, possibly doubling the actual burden. A collective effort is needed to rectify this and ensure timely detection.”

DR SANGEETA MUDALIAR

Full time Consultant and HOD,

Department of Hematology-Oncology, B J Wadia Hospital, Mumbai

► Challenges to Cancer Cure



“Too many children have their lives cut short by cancer, and survival rates in poor countries are scandalously lower than those in wealthy countries.”

DR TEDROS ADHANOM GHEBREYESUS
WHO Director-General

REASONS FOR THE DISPARITY OF SURVIVAL RATES^[7]

Delayed presentation as a result of
inadequate prevention measures
and inefficient detection processes

Poor treatment capacities and
lack of access to care

Limited public awareness

Treatment abandonment

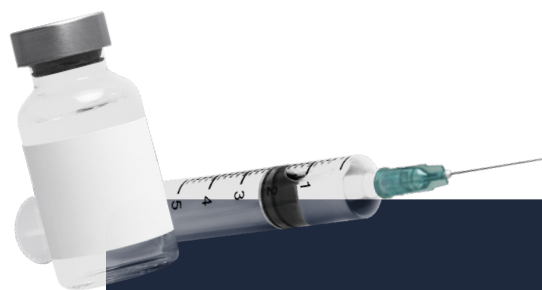
► Treatment Abandonment: A Significant Obstacle

The family faced the agonising choice of abandoning treatment when Reshma developed a rare fungal infection called mucormycosis on the palate after undergoing the initial cycles of chemotherapy. This was particularly a challenging time as they feared that the condition might spread despite surgery. The fear of the condition spreading, combined with a lack of proper nutrition counselling and understanding of treatment options, added to their emotional burden during this trying period.

30%

Treatment abandonment rate in low and middle-income countries.^[7]

In resource-poor settings, treatment abandonment is acknowledged as a primary factor contributing to treatment failure and death among children with cancer.^[8]



REASONS FOR TREATMENT ABANDONMENT^[7]

Financial difficulties

Treatment toxicity due to malnutrition and others^[3]

Long travel times for access to care

Caregiver's belief that cancer is incurable / preference for alternative therapies



Section B:

Demographic Insights

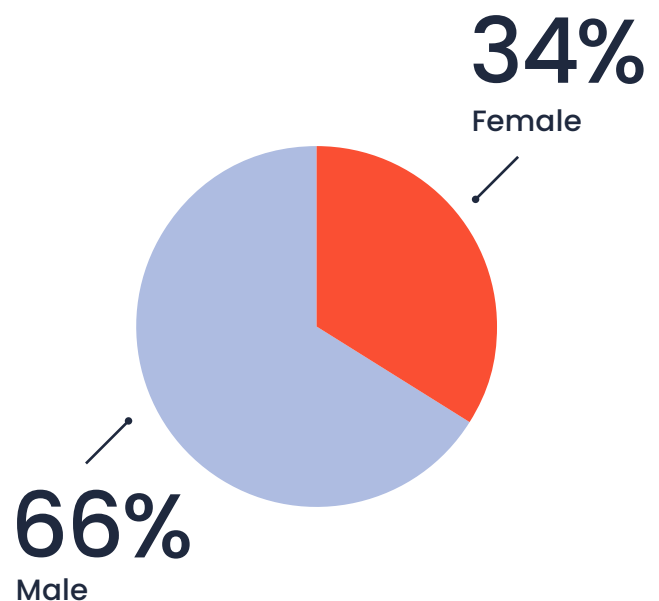
In this comprehensive section, we offer an analysis derived from more than 7,600+ beneficiaries supported by the Cuddles Foundation. This study encompasses 35 government and charitable hospitals across India.

► Gender Distribution

The gender distribution has remained unchanged for the past three years, aligning with the ratio of cancer diagnoses among boys and girls in India, which stands at 1.58.^[9]

This implies that for every five boys diagnosed with cancer, only three girls are diagnosed.

This disparity in gender indicates a potential bias in the access to and continuity of cancer treatment for girls in India.



► Age Distribution

The most affected age group comprises children under 5 years old, followed by those aged 10 and older, while children aged 5 to 10 years comprises the least affected group.

Median age - 7 years
Average age - 8 years



37.38%
< 5 years



30.21%
5 - 10 years



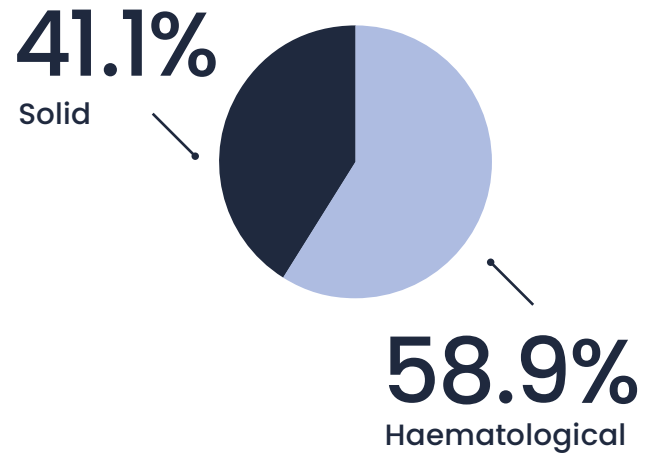
32.41%
10+ years

▶ Childhood Cancer types across India

Childhood cancer types refer to the various forms of cancers that specifically affect children. They often differ significantly from adult cancers in their nature, development, and treatment requirements.

They are broadly categorised as Solid and Haematological (Liquid) Cancers. Solid cancers refer to those that form solid tumours, such as brain tumours, neuroblastomas, Wilms tumours, rhabdomyosarcomas, and osteosarcomas. Cancers of the lymphatic system, or lymphomas are also considered solid tumours. Haematological, or liquid cancers, refer to cancers that affect the blood and bone marrow like leukaemias.

SOLID VS HAEMATOLOGICAL (PERCENTAGE)



Haematological cancers accounted for 58.9% of the total cases.

Solid cancers accounted for 41.1% of the total cases.



“Annually, we provide treatment for approximately 70 to 80 new paediatric cancer cases. The prevalent forms include blood cancer, neuroblastoma, as well as tumours affecting the brain, liver, kidneys, muscles, and bones. A significant portion of our patients hail from socially and economically disadvantaged backgrounds, inevitably confronting a multitude of nutritional insufficiencies. These deficiencies are prone to exacerbation due to both the presence of cancer and its accompanying therapies. Additionally, the families’ challenges are compounded by the fact that prioritising nutrition often takes a back seat.”

DR VIBHA BAFNA

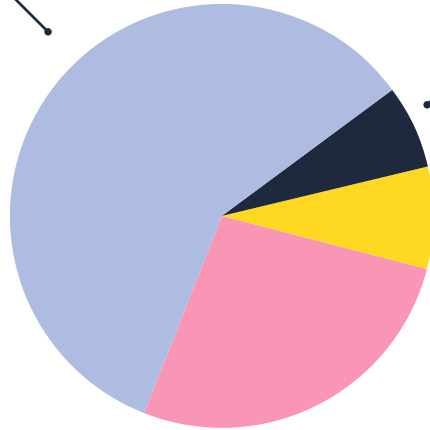
Professor at Dept. of Paediatric Oncology,

Dr B Borooah Cancer Institute, Guwahati, Assam

TOTAL DISTRIBUTION OF DIFFERENT TYPES OF CANCERS AS PERCENTAGES IN THE GIVEN POPULATION

58.92%

Leukaemias
are cancers of the blood and bone marrow and are the most prevalent type of childhood cancer.



6.63%

Lymphomas
are cancers that affect the lymphatic system.

26.75%

All Other Solids

includes all other types of solid tumours not mentioned above. These may include tumours in various organs and tissues, such as kidney tumours (Wilms tumour), muscle and bone tumours (sarcomas), retinoblastoma (eye cancer), and other rare types.

7.70%

Brain and Central Nervous System (CNS) Tumours

are cancers that originate in the brain or the tissues of the central nervous system.

It is important to note that the distribution of childhood cancer types may vary in different populations and regions.

DISTRIBUTION OF HAEMATOLOGICAL CANCERS

Haematological Cancers	%
B-cell Acute Lymphoblastic Leukaemia (ALL)	34.07%
ALL	25.19%
Pre BALL	13.00%
Acute Myelogenous Leukaemia (AML)	10.94%
T-cell ALL	10.39%
Chronic Myelogenous Leukaemia	2.24%
Langerhans Cell Histiocytosis (LCH)	1.84%
Acute Promyelocytic Leukaemia (AMPL)	1.51%
Pro B-cell ALL (Early Pro B- cell ALL), Pro T-cell ALL, Mature Pre B-cell ALL (Burkitt's Leukaemia, Autoimmune Lymphoproliferative Syndrome, Myelofibrosis)	Remaining <1%

Of the haematological cancers, B-cell ALL was the most prevalent (34.07%), followed by ALL (25.19%) and Pre BALL (13.00%).

DISTRIBUTION OF SOLID CANCERS

Solid Cancers	%
Hodgkin's Disease	16.14%
Retinoblastoma	11.41%
The Ewing's Sarcoma Family of Tumours	11.19%
Neuroblastoma	10.42%
Osteosarcoma	10.17%
Wilms' Tumour	8.52%
Rhabdomyosarcoma	6.29%
Brain Tumours	5.78%
Non-Hodgkin's Lymphoma	5.75%
Germ Cell Tumours	5.37%
Burkitts Lymphoma	3.62%
Primitive neuroectodermal Tumours (PNETs)	2.54%
Hepatoblastoma	2.41%
Renal Cell Carcinoma, Mesoblastic Nephroma, Non-metastatic Left Axillary Synovial Sarcoma, Nasopharynx Carcinoma	Remaining <1%

Of the solid cancers, Hodgkin's Disease (16.14%) was the most prevalent, followed by Retinoblastoma (11.41%) and The Ewing's Sarcoma Family of Tumours (11.19%)

Reshma's infection severely impacted her nutritional status, leading her to become severely thin. The surgery to treat mucormycosis had the potential to further worsen her nutritional condition, as it involved the removal of the upper palate, rendering her unable to eat orally post-surgery. These treatment modalities had the potential to further worsen the nutritional status.

Section C: Nutrition Status of Children with Cancer in India

To combat malnutrition in children, the government has launched a range of strategic initiatives.

Some of the initiatives include:

- The Integrated Child Development Services (ICDS) program, operating through Anganwadi centers nationwide. ICDS delivers essential nutrition, healthcare, and early education services to children, especially those from vulnerable backgrounds.
- The National Nutrition Mission (POSHAN Abhiyaan) that celebrates National Nutrition Week and Poshan Mah in the month of September, takes a holistic approach, targeting pregnant women, lactating mothers, children and adolescents.
- The Mid-Day Meal Scheme ensures that millions of students in government and government-aided schools receive nutritious meals, promoting both nutrition and school attendance.
- The National Health Mission (NHM) prioritizes maternal and child health, offering programs like Janani Suraksha Yojana and Rashtriya Bal Swasthya Karyakram (RBSK). RBSK works toward identifying and intervening to prevent diseases, defects at birth, nutritional deficiencies, and developmental delays.

▶ Malnutrition in childhood cancer

Malnutrition in paediatric cancers is very common, especially in lower and middle-income countries like India.

The CureAll Framework: WHO Global Initiative for Childhood Cancer underscores that poor nutrition status in children with cancer:^[3]

- Increases the risks of infection
- Increases treatment-related toxicities
- Associated with increased rates of treatment abandonment



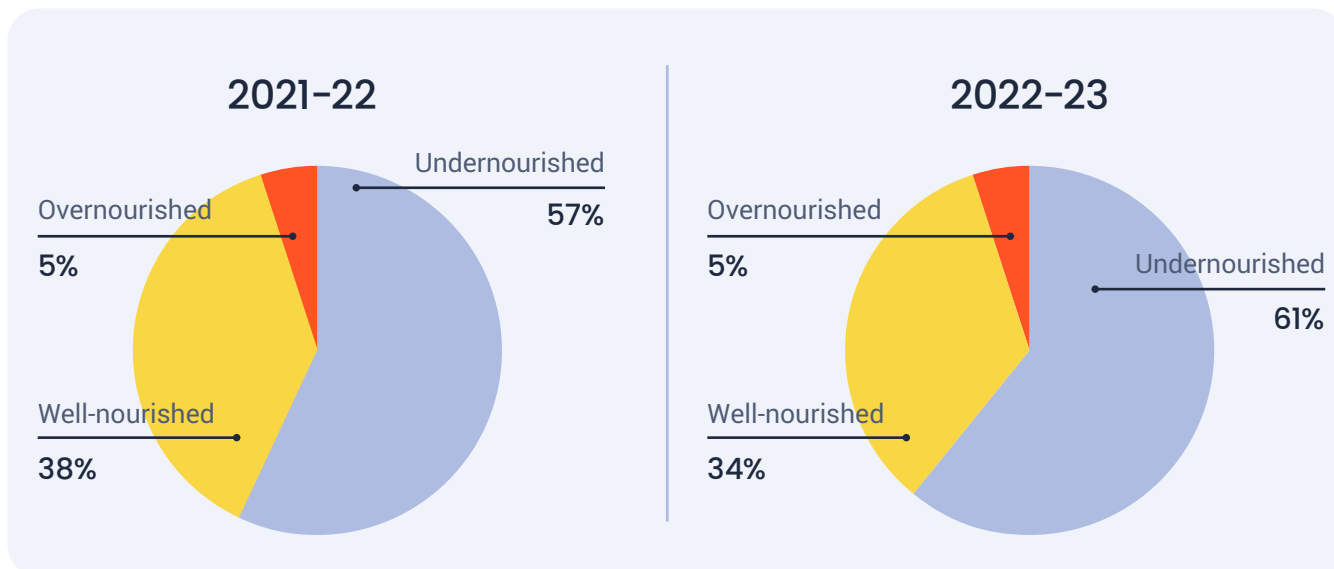
~40%

of children with cancer are already malnourished at the time of diagnosis.^[10]

Cancer therapy can further impact a child's nutrition status leading to poor recovery rates and even loss of life.

► Nutrition status at initial visit

COMPARISON OF NUTRITION STATUS* OF PATIENTS AT INITIAL VISIT WITH CUDDLES FOUNDATION



The data from the past financial year '22-'23 indicates that more patients were undernourished at their initial visit with Cuddles Foundation compared to the previous year. Additionally, there was also a decrease in the percentage of well-nourished patients.

► Nutrition status by cancer type

The following table presents data on nutrition status of patients at initial visit stratified according to cancer type.

NUTRITION STATUS AT INITIAL VISIT BY CANCER TYPE

Nutrition Status	Total Cases	Solid Cases	Liquid Cases
Undernourished	61%	67%	56%
Well nourished	34%	30%	38%
Overnourished	5%	3%	6%

The table above indicates that solid cases have a higher percentage of undernourished beneficiaries compared to haematological cases. Additionally, the percentage of well-nourished patients for solid cases is lower than the haematological cases. Haematological cases have a higher percentage of overnourished beneficiaries.

The CureAll Framework: WHO Global Initiative for Childhood Cancer recommendations for nutrition for paediatric oncology patients:^[3]

- At diagnosis, a trained nutritionist should assess the nutrition status of the patient
- The documentation and tracking of patients' nutrition status are required to help address undernourishment
- Nutrition education should be utilised to help decrease malnutrition

In order to prevent Reshma's nutrition status from becoming worse, tube feeding was required to provide her with essential nutrition. Gradually introducing liquids and semi-solids that were easy to swallow once she was comfortable became crucial for her well-being. Maintaining proper nutrition through a custom nutrition plan played a vital role in the maintenance of nutrition status and her recovery.



“A child on chemotherapy needs active nutrition support which includes assessment by a nutritionist, planning of diet as per the child’s condition, regular nutrition monitoring, educating the parents and constant encouragement for proper hygienic and a balanced diet. This would indeed help in treatment tolerance and mitigate complications leading to a high success rate.”

DR VEERENDRA PATIL

Senior consultant Paediatric Hematology Oncology and BMT physician
Basavatarakam Indo-American Cancer Hospital and Research Institute, Hyderabad

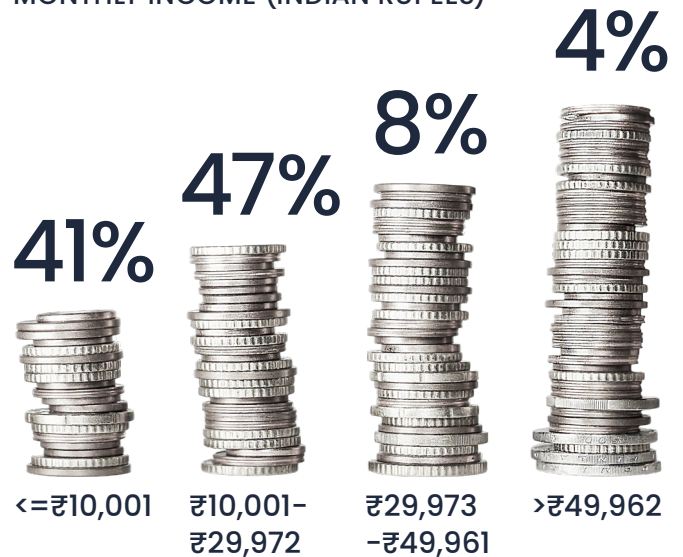
► Nutrition status by socio-economic strata

Malnutrition can often occur in the context of socioeconomic disadvantage. Therefore, it becomes crucial to assess the socioeconomic status (SES) among patients with childhood cancer. Cuddles Foundation conducted an internal study in June 2023 to evaluate the socioeconomic status of patient caregivers.

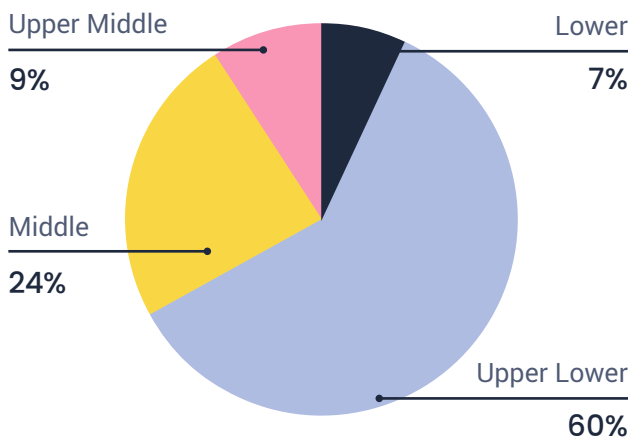
This study, using the Kuppuswamy scale, covered a total of 3,044 beneficiaries across 36 partner hospitals.^[13] The scale examined three parameters: total household income of all earning members, education level and occupation of the head of household. The data collected was self-reported by the caregivers and presented below.

The data indicates from the figure above that the highest proportion (47%) of families earns a monthly income ranging from Rs 10,001 to Rs 29,972. Followed by 41% of families who earn less than Rs 10,000 per month.

MONTHLY INCOME (INDIAN RUPEES)



SOCIOECONOMIC STATUS



The majority of these families fall into the lower and upper lower socioeconomic groups.

The nutrition status at the time of SES data collection was then correlated to their SES. The nutrition status was determined using MUAC or BMI for age indices and beneficiaries were then categorised as undernourished, well-nourished, or overnourished.

NUTRITION STATUS STRATIFIED BY SOCIOECONOMIC STATUS

Socioeconomic Status	Nutrition Status		
	Undernourished	Well-Nourished	Overnourished
Lower	55.70%	39.60%	4.70%
Upper Lower	53.59%	40.19%	6.22%
Middle	47.58%	45.07%	7.35%
Upper Middle	41.55%	47.83%	10.63%

Our findings indicate that beneficiaries belonging to the lower socioeconomic status (SES) group exhibited the highest proportion of undernourished individuals (55%), followed by the upper-lower class (53%), middle class (47%), and upper-middle class (41%).

Conversely, as anticipated, the upper-middle class demonstrated the highest percentage of well-nourished individuals (47%) in comparison to the other classes, especially the lower class (39%). Furthermore, the upper-middle class showed the highest percentage of overnourishment (10%) when compared to all the other classes, notably the lower class (4%).

Despite facing financial struggles, Reshma's family decided to take a chance on her treatment, partly since it did not require significant financial expenditure from their end. However, access to healthy and nutritious food became a concern. Reshma's family which comprised 6 members depended solely on the income of their father who was a rickshaw driver. Before Reshma fell sick they had managed to avoid food insecurity by using his daily earnings to buy food regularly. However, this became a challenge as they had to move to a new city for Reshma's medical treatment and were already burdened with a loan. To cope, they would buy one plate of food and share it among three family members, with the parents often sacrificing their meals to ensure the children were fed, exacerbating their food insecurity.

Section D: Food Insecurity in the Context of Childhood Cancer Management

Food insecurity is a form of economic struggle that poses challenges for individuals and households to acquire healthy and/or adequate food.^[14]

The American Cancer Society has called for the need to make food insecurity assessments a necessary tool in the treatment of cancer.^[15]

This is important because response to cancer treatment is dependent upon nutrition status and assessing levels of food insecurity in patients and caregivers (specifically the economically disadvantaged) could determine the trajectory of care as well as recovery.



“Almost 70% of the paediatric patients coming to Tata Memorial Hospital are from a lower socio-economic status. Further to this, almost 60% of the children are malnourished at presentation. It is important to note here that food insecurity exacerbates the difficulties faced by these paediatric patients, as many of them struggle to access consistent and nutritious meals. This compounds their malnutrition status and makes their cancer treatment more challenging.

Nutritional therapy is the fourth and equally important component of multidisciplinary treatment of childhood cancer like Surgery, Chemotherapy and Radiation therapy. Provision of a holistic nutrition support allows the timely and optimal delivery of other three treatment modalities and improved chances of cure by 20-25% in children with cancer in low-middle income countries like India.”

SHALINI JATIA

Officer-In-Charge (OIC), ImPaCCT Foundation

Pediatric Oncology, Tata Memorial Centre, Mumbai

▶ Hunger Vital Sign™

The Hunger Vital Sign™ tool helps identify households as being at risk for food insecurity.^[16] A household is deemed food insecure if their answer to either one or both of the survey's statements is 'often true' or 'sometimes true', as opposed to 'never true'.

The statements in the survey are:

1. "Within the past 12 months we worried whether our food would run out before we got money to buy more."

In June 2023, Cuddles Foundation administered the Hunger Vital Sign™ tool to those patients' families who had previously received ration bundles. We evaluated whether they were at risk for food insecurity before they started to receive the monthly ration bundles. The survey was conducted across 36 partner hospitals and garnered 1,150 responses.

2. "Within the past 12 months the food we bought just didn't last and we didn't have money to get more."

Results



68%

of respondents worried that they would run out of money to buy food before the end of the month.



58%

of respondents actually ran out of food and did not have the means to buy more food.

Overall:

70%

of respondents were deemed at risk for food insecurity before they were initiated into the FoodHeals™ programme.

A key step to ensure the effectiveness of treatment would be to identify the socioeconomic status and level of food insecurity among patients in order to understand the extent of nutrition support required.

Cancer care centres should ideally incorporate food insecurity screening during the patient's initial visit.

Employing such screening tools helps to identify food-insecure households and thus allows for the provision of holistic care to children with cancer with the ultimate goal of better tolerance to treatment and treatment outcomes.^[14]

A Way Forward: Towards Better Childhood Cancer Care

This report presents conclusions drawn from an evaluation of data from over 7,600+ childhood cancer patients, providing valuable insights into the current status of childhood cancer in India.

Challenges and Recommendations:

To combat childhood cancer effectively in India, a comprehensive approach is essential. The following key actions are recommended:

- ★ Strengthening Cancer Registries:** Improving the coverage and accuracy of cancer registries, particularly for childhood cancer cases, is crucial. Enhanced data collection will offer a more precise understanding of the burden of childhood cancer and its geographical distribution.
- ★ Awareness and Early Detection** Launching public awareness campaigns on childhood cancer symptoms and early detection can lead to quicker diagnoses and improved treatment outcomes. Healthcare professionals, particularly in the rural and semi-rural parts of the country, should receive training to recognise potential signs of childhood cancer for timely referrals.
- ★ Access to Quality Healthcare** Ensuring equitable access to high-quality healthcare services, including cancer treatments and medications, is vital to improving childhood cancer survival rates. Efforts to reduce financial barriers and enhance healthcare infrastructure in urban and rural areas are essential.
- ★ Nutrition Support** Strengthening collaboration between healthcare providers and organisations like Cuddles Foundation can address malnutrition in childhood cancer patients at the earliest or initial visit. Promoting further research and initiatives on nutrition assessment, support, and education will enhance overall care and treatment outcomes.
- ★ Research and Innovation** Continued research into childhood cancer, including causes, risk factors, and innovative treatment approaches, is crucial. Such efforts will lead to improved therapeutic options and ultimately enhance survival rates for paediatric patients.

Effective collaboration among governments, healthcare providers, non-profit organisations, and communities is essential in the fight against childhood cancer in India.

By prioritising comprehensive data collection, early detection, improved healthcare access, and nutrition support, we can work towards achieving the Global Initiative for Childhood Cancer (GICC) and World Health Organization (WHO) target of a 60% survival rate for childhood cancer patients worldwide by 2030. This collective effort ensures a brighter and healthier future for children battling cancer in India and beyond.



Geographic Locations of Operation Pan India

STATES	NUMBER OF HOSPITALS
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West Bengal	2
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Assam	3
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Delhi	2
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Uttar Pradesh	3
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Rajasthan	1
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Jammu & Kashmir	2
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Karnataka	5
-----------	---

Telangana	3
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Kerala	1
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Maharashtra	8
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Chhattisgarh	2
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Tamil Nadu	2
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Andra Pradesh	2
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About Cuddles Foundation



Established in 2013, Cuddles Foundation has been working with government and charity cancer hospitals, enabling them with trained paediatric oncology nutritionists and food aid so that more children may win the battle against cancer. Cuddles Foundation has spread its footprint in 13 states, partnered with 40 hospitals and 50+ nutritionists, and received the National Award for Child Welfare, 2015-16. Their vision is to give every child fighting cancer in India a chance at a cure.

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Cuddles Foundation
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