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Food Insecurity Screening and Childhood Cancer Management In India



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Warmest, Anju Morarka & Sripriya Venkiteswaran

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Executive Summary

Nila was 7 years old when she was diagnosed with high-risk Pre-B Cell Acute Lymphoblastic Leukaemia. When her family had to sell the only piece of land they owned to pay back loans, the money left could only get them food for 15-16 days in a month. With her father often away for labour work at different construction sites, her mother worked at roadside tiffin centres. She would wash vessels till evening, only to return home with leftovers from her employer for Nila and her 10-year-old brother. Until her diagnosis, for a part of the month, Nila and her family survived only on that one evening meal. Her family is what we classify as food insecure.

Food insecurity is when one cannot consistently afford access to healthy or adequate food. Being food insecure can often force one to make improper food choices leading to an increased risk of malnutrition and non-communicable diseases such as diabetes, obesity, hypertension and hyperlipidemia. Children and adolescents, both healthy and unwell, are particularly vulnerable to the ill effects of food insecurity.

If food insecurity occurs in the milieu of childhood cancer as we see in the case of Nila, it can negatively impact the entire cancer care process derailing treatment adherence and completion. An article in the journal, Indian Pediatrics, estimates that approximately 76,000 children and adolescents may develop cancer in India every year. Approximately, 40% of children with cancer in India are malnourished at diagnosis. However, it is unknown what percentage of this results from primary acute malnutrition and what percentage is due to the disease itself or a combination of both. This report investigates the correlation between food insecurity and paediatric cancer treatment and explores possible ways to mitigate its ill-effects on patient outcomes.

For example, Cuddles Foundation has supported paediatric cancer patients and their caregivers in public cancer hospitals over the past decade by providing food aid and nutrition counselling through their FoodHeals[™] Programme. An internal socioeconomic study by the organisation found that the majority (70.2%) of beneficiaries belonged to the lower (11.7%) and upper-lower class (58.5%) as categorised by the Kuppuswamy scale. Cuddles also assessed food insecurity amongst its beneficiaries using the Hunger Vital Sign[™] tool, a commonly validated screening tool for adult and paediatric patients. It was found that the majority of beneficiaries (82%) may have been at risk of being food insecure even before cancer diagnosis.

This report concludes by suggesting that food insecurity screening should be mandatory in all paediatric cancer care centre protocols. More importantly, this screening should be conducted at the initial or earliest visit.

This will help connect patients and their caregivers with governmental and non-governmental food assistance programmes. It will also help identify children with pre-existing malnutrition and nutrient deficiencies at the earliest possible stage and match them with necessary nutritional interventions, thereby improving cancer treatment adherence and outcomes for children like Nila.

What is Food Insecurity

According to the Food and Agriculture Organisation, a person is food insecure when they lack the ability to regularly obtain safe, nutritious and sufficient food for an active and healthy life.^[1] Food insecurity can vary in severity, depending on availability, access, utility and stability of food resources:

Availability	refers to the actual or potential physical presence of food, in markets, production and reserves.
Access	addresses whether households and individuals have sufficient physical and economic ability to obtain that food.
Utilisation	refers to whether the intake of sufficient energy and adequate nutrients is maximised.
If factors of availability, access and utilisation are adequately met,	

Stability refers to the situation in which the whole system is stable, ensuring that households are food secure at all times. This dimension also differentiates issues of acute food insecurity (caused by short-term instability) and chronic food insecurity (caused by medium- to long-term instability).

In simple terms, food insecurity is a form of economic struggle that poses challenges for individuals and households to acquire healthy and/or adequate food.^[2]

CASE STUDY

Inadequate access to food

Nila was 7-years-old when she was diagnosed with high risk Pre-B Cell Acute Lymphoblastic Leukaemia. Her family consisted of her construction labourer father, homemaker mother and 10-year-old elder brother. They lived off the land, which just about got them food to last the entire month. However, they had to sell their land to pay back unpaid loans. After the sale, the food they could acquire sufficed only for about 15-16 days in a month. With her father often away for work at different construction sites, her mother took up jobs working at roadside tiffin centres, to provide food for the children. Her mother washed vessels till evening, only to return home with leftovers the owner could provide. Until her diagnosis, for a part of the month, it was only that one evening meal Nila and her family could access.

How Food Insecurity Impacts India

India has experienced remarkable growth in the last few decades with increase in per capita incomes and achieving self-sufficiency in food production.^[3] However, India continues to bear enormous burdens of poverty, food insecurity and malnutrition, ranking 101st out of 116 countries on the 2021 Global Hunger Index Report.^[4] The State of India's Environment Report 2022 underlines that healthy diets remain out of reach for over 70% of the Indian population.^[5]

According to The State of Food Security and Nutrition in the World 2022 report,^[1] India still accounts for nearly a quarter of all undernourished people worldwide although the number of undernourished in India declined from 247.8 million in 2004-06 to 224.3 million in 2019–21. With the prevalence of malnutrition in India well above acceptable levels and large numbers of women and children suffering from micronutrient deficiency disorders, there is a risk of direct and indirect effects on public health. This can negatively impact the nation's productivity and growth. Therefore, it is crucial to allot priority to food and nutrition security to mitigate negative outcomes.

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Safeguards to Address Food Insecurity

To provide food and nutritional security through a life-cycle approach, the Government of India has rolled out numerous initiatives. They passed the National Food Security Act (NFSA) in 2013 and launched the Poshan Abhiyan in 2018 (formerly the National Nutrition Mission) backed by a National Nutrition Strategy. The NFSA takes a rights-based approach to food security, entitling rural and urban populations to receive subsidised food grains under its Targeted Public Distribution System (TPDS)^[11], covering about two-thirds of the people of India.^[11]

Some of the other schemes that target the vulnerable populations of pregnant women, lactating mothers and young children are Take-Home Rations, monetary maternity benefits and the Mid-Day Meals scheme.^{IVI} Ambitious programmes under the Poshan Abhiyan and the NFSA aim to tackle all forms of malnutrition in mission-mode, with a goal to make India malnutrition-free by 2022.^{I6I} The Poshan Abhiyan scheme specifically targets malnourished children up to six years of age by prescribing higher nutritional norms for these children. Despite self-sufficiency in major food commodities and a favourable policy environment for food security action, long-standing issues of fluctuating food prices, high unemployment, and economic inequality stand in the way of deserving families obtaining better nutrition. Large proportions of poor Indian households rely on the informal economy for low, uncertain incomes and do not have secure, universalised access to the government's foodbased safety nets for adequate nutrition, leading to widespread food insecurity.

The technological challenges faced by fair-price shops to process ration cards of other states and high inclusion errors^[7] in the TPDS meant that entitled households were excluded and did not have access to their monthly quota of subsidised food. The COVID-19 pandemic was also a major setback to the positive actions underway and exacerbated the vulnerabilities of already distressed sections of the population. Besides the economic downturn, the extent of India's food insecurity also became painfully evident.

Many informal workers walked on foot to their hometowns during the nationwide lockdown with no access to proper food and nutrition, while coping with the sudden loss of livelihoods. Food provisions under Atma Nirbhar Bharat Abhiyan began to be made available during this time.

The government started rolling out an aspirational programme - One Nation One Ration Card (ONORC) - on a pilot basis in a few select states subsequently in May 2020.^[8] This scheme nationalised beneficiary ration cards by linking them with their aadhaar cards to maximise portability, thereby enabling NFSA beneficiaries to claim their subsidised entitlements from any ePoS (electronic Point of Sale device) enabled fair price shop in the country.^[9] The 'Mera Ration' mobile application was also rolled out to help beneficiaries take advantage of the ONORC scheme, to improve coverage through digitisation and further mitigate pandemic-induced hardships.

However, a study conducted by Dalberg and Omidyar Network India earlier in 2022^[10] pointed out that only 58% of migrant workers were availing of inter-state ration portability. Knowledge of the scheme also appeared to be a challenge with only 48% of all beneficiaries and 74% PDS dealers being aware of inter-state ration portability. Additionally, 12% of households experienced transaction failure.

More recently, the government pushed the ONORC into mission mode and the scheme is said to have reached all 36 states and union territories in June 2022.^[11] Until increased awareness builds among the population and they are able to fully utilise the benefits, a substantial percentage of the population may continue to be food insecure and suffer from its consequences. It has been reported that every year 1.7 million Indians die due to diseases caused by a poor diet.^[12]

The 2022 conflict in Ukraine has further intensified food insecurity around the world by disrupting food supplies.^[13] Shocks like the war in Ukraine are a reminder that food insecurity challenges are not always issues of availability but are also a matter of accessibility and affordability. There are nutritional impacts to these crises that have serious, long-term consequences that need to be addressed.



How Food Insecurity Affects Health

Food is a basic need that helps an individual live a healthy, fulfilling life. Humans need a diet that not only meets the quantity prescribed for health but also meets the daily requirements for energy, macronutrients and micronutrients.

A. Adverse Health Outcomes Due to Food Insecurity

In food secure households, adequate quantity and quality of the diet can protect its members against nutritional deficiencies and can help prevent or delay onset of non-communicable diseases. In food insecure households, the need for other basic human necessities such as housing, medication, transportation and utilities often competes with the need for food. Spending on nutritious and quality foods such as pulses, fruits and fresh vegetables is difficult when budgets are stretched, and households opt for cheaper, less nutritious alternatives leading to gaps in the nutritional quality of the diet.^[14]

CASE STUDY

Adequate food but poor in quality

Manoj is a 5-year-old boy who was diagnosed with Chronic Myelogenous Leukaemia. Manoj and his parents live in one of India's metro cities. His father is a truck driver and his mother was a domestic help. However, during the COVID-19 pandemic his father had to stop working during the first lockdown and his mother lost her job. Although Manoj's father could return to work after six months, unfortunately his mother could not. Manoj started falling sick with fever frequently and his mother stayed home to care for him. Living in a metro city with no income during the lockdown and only one income thereafter, they took loans they are still paying off. Manoj's mother now has to rely on the local grocery store for low-cost supplies, buying third-grade pulses and grains, non-branded oils loosely sold and vegetables that are no longer fresh.

Inadequate nutrition, due to food insecurity, at individual and household levels can impact health outcomes negatively. Insufficient nutrition especially during early life stunts both physical and cognitive development, affects schooling performance and adult productivity.^[15] It can increase the risk of malnutrition and associated diet-related non-communicable diseases later in life, and triggers long-term productivity losses that could extend to future generations.^[16] When food insecurity becomes more severe in households, then both dietary diversity and consumption of nutritious foods tend to worsen.^[17] In such situations malnutrition becomes a serious problem that can significantly contribute to morbidity and mortality, specifically among children under five. In the event of illnesses, children living in food insecure households can face higher hospitalisation rates and longer recoveries.^[18]

B. Food Insecurity Leading to Malnutrition

Food insecurity affects the quantity and quality of diets in different ways, potentially leading to malnourishment. Although malnutrition encompasses both under-nourishment as well as over-nourishment (overweight and obesity), in this report malnourishment is used in reference to undernourishment.

Malnutrition can be acute or chronic in form. Acute malnutrition results from either inadequate energy or protein intake.

Primary acute malnutrition in children is most commonly a result of inadequate food supply caused by economic, social, and environmental factors.

This may lead to wasting, generally characterised by weight loss and low weight to height ratio. Secondary acute malnutrition on the other hand primarily results from the presence of an underlying disease condition which causes abnormal nutrient loss, increased energy expenditure and or decreased food intake.^[19]

Chronic malnutrition is the result of prolonged episodes of sustained undernourishment, which may lead to stunting or low height for age ratio. There are multiple causes of chronic malnutrition and these can be spread over different periods of an individual's lifetime. The effects of chronic malnutrition can be intergenerational by nature.^[20] UNICEF, therefore, calls for attention in the areas of maternal nutrition, infant and young child feeding practices, food insecurity, access to healthcare and disease environments.

Households and individuals that experience food insecurity have diets that lack in quantity and quality foods. Studies from different countries have shown a low intake of vegetables, fruits, and dairy causes nutritional deficiencies which contributes to malnutrition and increases the risk of associated non-communicable diseases.

C. The Food Insecurity and Non-Communicable Disease Connect

In India, there's been a rapid epidemiological transition of disease burden from infectious to noncommunicable diseases (NCDs).^[21] Since 2016, NCDs^[V] contribute to over 60% of the India's disease burden, with conditions like cardiovascular diseases, certain cancers, chronic respiratory diseases, and diabetes on the rise every year.^[22]

Unhealthy diets and poor nutrition are among the top risk factors for diet-related non-communicable diseases, such as diabetes, depression, hypertension, hyperlipidemia, and sleep disorders.^[23] Although morbidity and mortality from NCDs most often occurs in adulthood, exposure to risk factors such as poor nutrition begins in early life. There is a growing body of evidence that indicates that food insecurity leads to adverse health outcomes. This can lead to increases in out-ofpocket healthcare costs, reductions in productivity, and slower growth.

The same study suggests that the close interplay between food insecurity and chronic disease perpetuates a cycle of poverty and ill-health.^[24]

Food Insecurity and Cancer

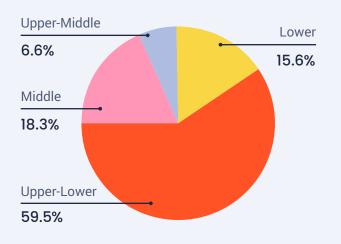
Cancer accounts for 8.3% of the total burden of NCDs in India.^[25] An Indian Council of Medical Research (ICMR) report estimates a 12% increase in cancer cases in the country by 2025.^[26]

With respect to childhood cancers, a study in the journal, Indian Pediatrics, estimates that approximately 76,000 children and adolescents (age 0-19) may develop cancers every year.^[27]

With healthy diets out of reach for over 70% of Indians, the risks of food insecurity and resultant malnutrition are serious. In this context, it becomes important to ascertain potential levels of food insecurity among patients of childhood cancer in order to address their nutrition needs better.

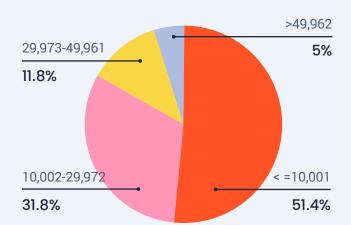
In the absence of evidence examining food insecurity among paediatric cancer patients within India, we turn to studies conducted in the US for context. Population-based studies have suggested a link between food insecurity and adult cancer risk. It has been seen that individuals living in food-insecure households are at higher risk of cancer compared to food secure households.^[28] Some proposed mechanisms for this association are poor socio-economic status leading to unhealthy living conditions and exposure to environmental carcinogens. The deleterious effects of these can be exacerbated by unhealthy dietary choices due to food insecurity.^[29]

Food insecurity often occurs in the context of socioeconomic disadvantage. Therefore, it becomes crucial to assess socioeconomic status among patients of childhood cancer. Cuddles Foundation conducted an internal study in 2021 to evaluate the socio-economic status of patient caregivers. This study, using the Kuppuswamy scale,^[VI] covered a total of 1,105 beneficiaries across 34 partner hospitals. 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 beneficiaries and presented in the pie-charts below.



SOCIOECONOMIC STATUS OF CUDDLES FOUNDATION BENEFICIARIES

MONTHLY INCOME OF CUDDLES FOUNDATION BENEFICIARIES (INDIAN RUPEES)



The results from the internal study indicated that the majority (70.2%) of Cuddles Foundation beneficiaries belonged to the lower (11.7%) and upper-lower class (58.5%). With regards to monthly income, 51.4% of beneficiaries earned equal or less than INR 10,001 per month, 31.8% earned between INR 10,002 - 29,972, and 11.8% earned between INR 29,973- 49,961.

These distressing results prompted us to further investigate the prevalence of food insecurity among Cuddles Foundation's beneficiaries.

Food insecurity was assessed using the validated Hunger Vital Sign™ tool, the results of which are presented later in the report.

Why Addressing Food Insecurity is Vital in Childhood Cancer in India

It is well-established that malnutrition is a by-product of food insecurity. This is of particular importance in paediatric cancer. Food inadequacy precipitated by food insecurity can worsen the malnutrition accompanying paediatric cancers affecting treatment outcomes.

Malnutrition in paediatric cancers is very common especially in lower middle income countries like India. The Indian Journal of Cancer estimates that 40% of children with cancer are already malnourished at the time of diagnosis.^[30] Cancer therapy can further impact a child's nutritional status.

The causes of malnutrition accompanying cancer and its treatment can be multifactorial and dynamic in nature. Complex metabolic disturbances, changes in the inflammatory and hormonal system and side-effects of treatment trigger alterations in the body. These effects are very often exacerbated by poor appetite, vomiting and nausea that hinder adequate food intake and further compromise the nutritional status.

Additionally, in India, the logistical challenges of receiving appropriate treatment can add or place stress on the family budget. Sometimes, families from the rural parts of India need to move along with their children to cities to access medical care. This increases out-of-pocket expenditures and in some cases leads to loss of income, which are further compounded by costs of the additional nutritional needs of the patient. The emotional struggle to cope with cancer diagnosis and treatment alongside financial risks and burdens of travel, nutritious foods, and income loss, may lead to the abandonment of treatment altogether.^[31]

The World Health Organisation underscores that poor nutritional status in children with cancer increases the risks of infection, treatment-related toxicities and may be associated with increased rates of treatment abandonment.^[32]

Currently, it is unknown what percentage of malnourishment in paediatric cancer results from primary acute malnutrition and what percentage is due to the disease itself or a combination of both. Therefore, it becomes crucial to address malnutrition by remediating food insecurity in children with cancers from lower socioeconomic households. CASE STUDY

Accessibility to food

11-year-old Kusum lives with her father and grandmother. She was recently moved to Mumbai for treatment after being diagnosed with common Acute Lymphoblastic Leukaemia. In their village about 150 kms from Mumbai, Kusum's father works as a cab driver which means he has to go away on work trips, often for five to six days at a stretch. During this time, Kusum stays under the care of her aged grandmother. Her grandmother has arthritis and can barely walk. The only proper food Kusum gets is the mid-day meal at school. On the days her grandmother can move around, she helps her grandmother cook.

Role of Cuddles Foundation in Addressing Malnutrition in Paediatric Cancer

From 2013 onwards, Cuddles Foundation has formally partnered with most Indian government hospitals and leading charity cancer treatment centres to bridge the nutrition gap in Indian childhood cancer care. Starting its journey with counselling and nutrition supplement distribution efforts at Tata Memorial Hospital, Cuddles Foundation's role has evolved over the years to address different aspects of food insecurity affecting patients and their caregivers.

THE FOODHEALS[™] PROGRAMME HAS EXPANDED TO INCLUDE THE FOLLOWING INITIATIVES:



Hot Meals

To keep patients away from unsafe street food, the programme enables access to freshly prepared, nutritious, and hygienic hot meals to help children with cancer get the right amount of carbs, protein, and fat, through long waiting hours during hospital visits.



In-Meals

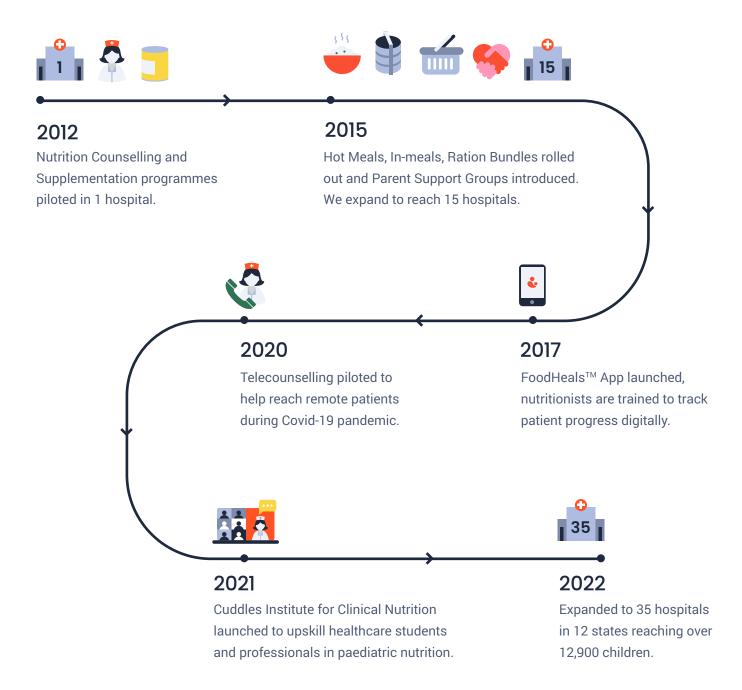
To ensure availability and quality of nutrition, healthy supplements like eggs, bananas, dry fruits, ghee, milkshakes, peanut *chikki* and *lassi* are provided to admitted children, children undergoing treatment in the out-patient department, or those visiting for follow-ups.



Ration Bundles

Monthly ration bundles helps provide food security to a family of four while fulfilling 100% of the daily caloric requirement of a child. Each bundle contains cereals, pulses, millets, nuts, oilseeds, ghee, oil, spices, condiments and basic personal hygiene products.

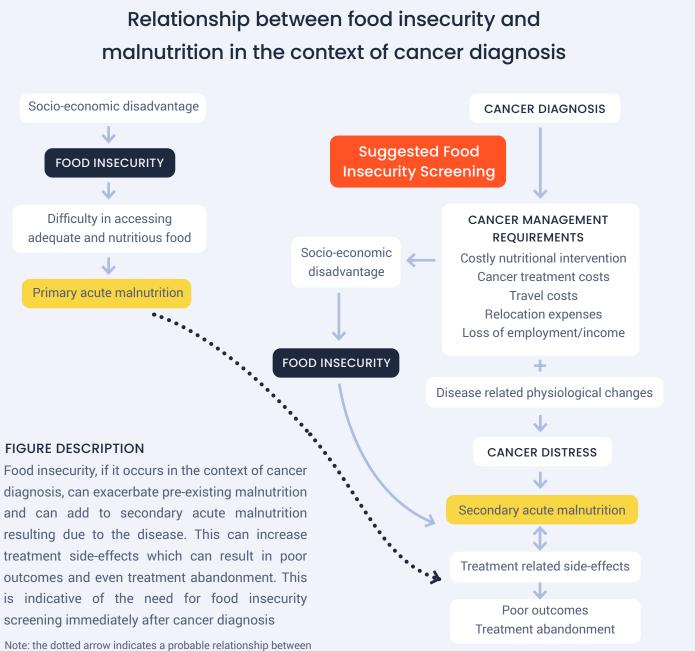
Addressing Food Insecurity: Historical Timeline of Cuddles' FoodHeals™ Programme



Cuddles Foundation also deploys specially-trained paediatric cancer nutritionists in hospitals across India. They provide free nutrition counselling and support to underprivileged children undergoing cancer treatment using evidence-driven childhood cancer care protocols. The nutritionists are aided by the FoodHeals[™] App that is a first-of-its-kind tool performing automated calculations of nutritional status, body mass index and calorie deficiency among other indicators. Additionally, the nutritionists conduct support groups for caregivers providing nutrition education that enables them to better manage their children's treatment. Caregivers are also taught how to utilise the food-aid provided by Cuddles in a way that helps maximise the nutritional benefits for their children.

Food Insecurity Screening During Cancer Treatment: A Need of the Hour

It is important to assess food insecurity in cancer patients as it can be a significant driver of cancer distress, which can lead to treatment non-adherence, greater difficulty in decision-making and poorer quality of life.^[33] If the level of food insecurity is readily identified in patients with cancer, then patients can be connected with food and nutrition resources^[34] that can help increase patient food security and address deficits in nutritional needs.



primary acute malnutrition and treatment-related side effects.

Given the robust association connecting food insecurity with poor health outcomes, organisations such as the American Academy of Pediatrics and the American Diabetes Association have advocated for the regular screening of patients for food insecurity in clinical settings. The American Cancer Society has also called for the need to make food insecurity assessments a necessary tool in the treatment of cancer.^[35] This is important because response to cancer treatment is dependent upon nutritional 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. To assess food insecurity, some of the tools available are The U.S. Household Food Security Survey Module (18 questions) and The Food Insecurity Experience Scale (8 questions). Cuddles Foundation assessed food insecurity using the Hunger Vital Sign[™] tool (2 questions) which are the first two questions of the US Household Food Security Survey Module. This is the most commonly used screening tool in the US and has been validated for both adult and paediatric patients.

Hunger Vital Sign™

The Hunger Vital Sign[™] tool helps identify households as being at risk for food insecurity.^[36] 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:

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

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

In June 2022, Cuddles Foundation administered the Hunger Vital Sign[™] tool to those beneficiaries who had 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 29 partner hospitals and garnered 339 responses.

The results from the survey indicated that a large proportion of the beneficiaries were food insecure the year before they started receiving the monthly ration bundles from Cuddles Foundation.

RESULTS

77%

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

74%

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

82%

of beneficiaries were deemed at risk for food insecurity before they were initiated into the FoodHeals™ programme. A further qualitative exploration on how the beneficiaries procured food or resources to procure food, indicated that they either sold their livestock; sought help from relatives or friends; took up multiple jobs and worked often without a break; purchased low-cost and low-quality pantry staples; or just had one meal a day. Some of the respondents also shared that the adult portion of the food was given to the children with the result that adults would miss their meal.

Suggestions For Practice

Within the context of childhood cancer care, it is important to bridge the nutrition gap in treatment for improved outcomes. Children may suffer from primary or secondary acute malnutrition at the time of diagnosis or may develop it as they proceed with exacting cancer treatments.

Constant monitoring and correction of nutritional deficiencies and status at diagnosis, at the start of and throughout treatment could minimise the side effects of treatment, improve survival, and reduce the risk of nutritional morbidity. A key step to ensure effectiveness of treatment would be to identify the socioeconomic status and level of food insecurity among patients in order to understand the extent of nutritional support required. Cancer care centres should ideally incorporate food insecurity screening during the patient's initial visit. To determine cancer care requirements during treatment, paediatric cancer units already deploy various assessments to cover socio-economic, demographic and nutritional backgrounds of patients. This background screening can be augmented to include simple questionnaire-based validated surveys and scales to measure food insecurity of the patients.

Employing such screening tools help to identify food insecure households and thus allow for provision of holistic care to children with cancer with the ultimate goal of better tolerance to treatment and treatment outcomes.^[37]

When cancer care centres identify patients who are from food insecure households, they can recommend or offer the following as required:

- Identify children with urgent pre-existing nutrition needs and recommend to the relevant department for further robust screening and immediate intervention.
- Educate caregivers on the complex relationship of food insecurity, malnutrition and treatment outcomes.
- Refer caregivers to local or nongovernmental organisations that provide food-aid.
- Connect them to existing national governmental food assistance programmes such as the ONORC.

Conclusion

Food insecurity is a human developmental challenge that has an immense impact on health outcomes of people. Although this aspect has not been specifically studied in the context of children with cancer in India, pre-existing food insecurity and resulting malnutrition may compromise the odds of survival as they are more prone to risks of infection and treatment-related toxicities. Food insecurity screening can help determine the duration of malnourishment in a child and can help understand the nutritional situation and dietary practices of the family. Therefore, to ensure recovery and survival, it is important to assess the nutritional status of patients and their caregiver's ability to provide nutritional support throughout treatment.

The use of food insecurity screening at the earliest or initial visit is the first step towards providing critical nutrition assistance, holistic patient care and ensuring improved treatment outcomes in children with cancer.

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