



Enhancing Logistic Support During Chemotherapy to Nonlocal Children with Cancer and Their Families through Home Away from Home Program

Vasudeva Bhat K.¹ Archana Melavarige Venkatagiri¹ Vinay Munikoty Venkatesh¹ Ashwini S.¹
Girish Nair² Ankeet Dave² Krithika Shantanu Rao³ Naveen Salins³ Sharath Kumar Rao⁴

¹ Division of Pediatric Hematology and Oncology, Manipal Comprehensive Cancer Care Centre, Kasturba Medical College, Manipal, Manipal Academy of Higher Education, Manipal, Karnataka, India

² Access Life Assistance Foundation, Mumbai, India

³ Department of Palliative Medicine and Supportive care, Manipal Comprehensive Cancer Care Centre, Kasturba Medical College, Manipal, Manipal Academy of Higher Education, Manipal, Karnataka, India

⁴ Department of Orthopaedics, Kasturba Medical College, Manipal, Manipal Academy of Higher Education, Manipal, Karnataka, India

Address for correspondence Vasudeva Bhat K, Associate Professor, Division of Pediatric Hematology and Oncology, Manipal Comprehensive Cancer Care Centre, Kasturba Medical College, Manipal 576104, Manipal Academy of Higher Education, India (e-mail: vasudev.bhat@manipal.edu).

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Abstract

Childhood cancers have excellent outcomes in terms of cure rates and survival if they are diagnosed early and treated appropriately. However, there is a huge disparity in outcomes between high- and low-middle income country(ies) due to out-of-pocket expenditure, therapy abandonment, and severe infections. To bridge these gaps in outcomes, a partnership between a private medical institute and a nongovernmental organization was fostered to develop a long-stay facility for children with cancer and their families while receiving disease-directed therapies. This report aims to expound the story of development of the “Home Away from Home” program and its transformative potential and societal impact.

Keywords

- ▶ logistics
- ▶ low-middle income country
- ▶ pediatric oncology

Background

In the setting of childhood cancers, a disparity in treatment and survival outcomes is noted among high-income countries (HICs) and low-middle-income countries (LMICs), with an 80% and upward long-term survival in HICs and 30 to 40% in LMICs.^{1–3} Treatment refusal and abandonment often contribute to this disparity, along with delayed presentation, severe infections, and poor nutrition.^{4,5} Out-of-pocket spending, high cost of cancer therapies, and nonaffordability often lead to decisions surrounding treatment refusal and abandonment.^{4,6} Direct costs corresponding to their cancer therapy are often supported by government or private insurance or bridged through external funding.⁴ However, during prolonged cancer therapy, indirect costs toward logistics

such as housing, food, and travel, especially for families nonlocal to the cancer center, can be daunting, often leading to treatment abandonment.^{4,5} A Home Away from Home program was an initiative to mitigate this treatment abandonment by enhancing logistic support during chemotherapy for children with cancer and their families.

An audit of our childhood cancer services showed that 5% of the treatment abandonment among nonlocal families was due to indirect costs associated with treatment logistics.⁷ Despite receiving adequate financial help toward cancer-directed therapies, the mounting indirect costs hindered their continuation in the cancer center. Most children with treatment interruptions or abandonment had cancers that had excellent potential for cure. Furthermore, families

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Table 1 Timelines for the development of the home away from home

Process	March 2021	April 2021	September 2021	October 2021	November 2021	March 2022	April 2022
Initial communication and Zoom discussion							
Discussion with hospital and university administration							
Visit by the NGO and identification of premise							
Preparation and signing of the memorandum of understanding							
Starting of the renovation work							
Completion of the renovation work							
Operational start of the center							

continuing treatment also experienced significant distress related to financial toxicity. The expenses were mainly due to rentals, food, local travel, and child needs. These children's rental accommodations were small units, often unclean, and unsuitable for a child's stay. It was seldom a homelike environment and deprived the child of education and entertainment. Besides, we as a service endeavor that no child should be denied cancer treatment due to lack of funds. Thus, we explored the possibility of creating a system to mitigate these concerns.

Conceptualization, Collaboration, and Co-Creation

A nongovernmental organization (NGO), Access Life Assistance Foundation (AL),⁸ was approached to replicate the respite and long-stay models that they had built in Indian cities like Pune and Mumbai to support children with cancer. AL is a nonprofit organization that started in 2014. It provides accommodation with hygienic and quality living environment for the children with cancer and their parents with no cost to them. A memorandum of understanding was signed between two partnering organizations. Both partnering organizations agreed to share costs involved in setting up the center and maintaining it. AL did a feasibility assessment

and visited the premises to understand the local needs. Subsequently, they offered to support the capital and operational costs of the new center at Manipal, India. Over the next few weeks, an area closer to the pediatric oncology clinical services was identified to minimize transport costs. The timelines are provided in **Table 1**.

The center is built over 9,000 ft² and the facility is wheelchair accessible. It is Wi-Fi enabled and has a security surveillance system. The amenities at the center and their description are provided in **Table 2**.

Operations

Every family that moves into the center is provided with a kit that enables them to sustain their stay at the center. The kits include utensils like plates, spoons, steel tumblers, pressure cookers, and other steel utensils essential for cooking, and hygiene kits that include soap, hand sanitizer, nail clippers, hot flask, medicine box, dental hygiene kit, comb, and spirometer.

All patients seeking admission at the center are assessed by the hospital medical social worker to determine their eligibility based on the strict assessment criteria. The assessment criteria include parameters like socioeconomic status along with details like possession of land, vehicles, etc., distance from

Table 2 Amenities within the center

Sl no.	Room description	Approximate area available (ft ²)	Main function
1	Recreational area	800	Indoor recreational activity
2	Kitchen area	88	Cooking
3	Dining area	120	Meal time
4	Counseling room	110	Psychosocial counselling
5	Center coordinators room	110	For the center coordinator to stay
6	Office area	110	For administrative work
7	Family units	480 (40 × 12 units)	For families to sleep
8	Washrooms and toilets	400	Washrooms
9	Outdoor play area	2,800	Recreation and games
10	Outdoor garden	2,800	Kitchen garden and relaxation

the cancer center, and availability of a unit to stay. The social worker will liaise with the center manager to complete the admission process and allotments of the family units based on availability. The allotment of unit is on a first come first served basis and patients who need the facility after the facility is full is waitlisted and allotted as per the waitlist. Furthermore, the children and families are able to access an array of support services at the center, which include hygienic accommodation, psychosocial support, vocational training, nonformal education, and recreational activities.

The center coordinator ensures that the families have a pleasant stay and receive all the care needed, oversees the efficient management of the center, and handles the documentation, case studies, and interactions with funders. The operations manager, human resource department, finance, and administrative team from the head office at Mumbai, India offer technical and logistic support remotely and through periodic visits to the center.

Evaluation of the Impact of the Center

Various key performance indicators are assessed annually to understand the impact of the center. Few of the indicators include the following:

- Reduction in treatment abandonment rate.
- Reduction in out-of-pocket expenditure in those staying at the center versus those staying outside the center.
- Reduction in mortality during intensive therapy in those staying at the center versus those staying outside the center.
- Quality-of-life studies for children and caregivers.

Reduction in treatment abandonment rate has been the vital key performance indicator. In a retrospective audit, the treatment abandonment rate in the division was 4.5%, which had reduced to 0 when looked at 8 months after the intervention.⁷ Twenty-eight children and 56 caregivers benefitted within a span of 8 months of initiation of the Home Away from Home program.

Conclusion

Although in India there are some "Home Away from Home" centers set up alongside tertiary cancer care centers treating children with cancer, it was always with a public health institute partnering with an NGO. It is the first project where an NGO has engaged with a private medical institute for developing a pediatric oncology respite and long-stay facility. Furthermore, this project resonates with the theme of international childhood cancer day 2022, where better survival is achievable through your hands. In this project, multiple hands worked synchronously and collaboratively for the benefit of children with cancer and their caregivers. Creating facilities like these helps in capacity-building in comprehensive pediatric cancer cares that complements the treatment with a safe, secure, nourishing, and positive environment. It endeavors to enhance the cure rate and survival rate by reducing costs, minimizing treatment abandonment, improving compliance,

and limiting infections. We hope to develop this as an emancipatory transformative model that could be scalable and replicable and provide a platform to create funding opportunities for childhood cancer.

Author Contributions

Vasudeva Bhat K., Naveen S. Salins, and Sharath Kumar Rao conceptualized the center and the manuscript. Ankeet Dave and Girish Nair did the planning of the center and contributed to the manuscript. Archana M.V., Krithika Shantanu Rao, and Vinay M.V. drafted the manuscript with provision of intellectual content.

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The budget for the facility is divided into the capital budget and operational budget. The capital budget was achieved through corporate social responsibility of multinational companies, local foundations, philanthropic support, and individual donors. The operational budget for the center was managed by an alumnus of the Manipal Academy of Higher Education for a duration of 5 years.

Competing Interests

None declared.

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