

Assessing the need for home-based end-of-life palliative care in pediatric cancer care



Anukriti Srivastava¹, Nita Radhakrishnan², Archit Pandharipande³, Zeenat Brar⁴, Shrutika Verma⁵, Eby P Baby⁶

¹Senior Social Worker, ²Associate Professor, ³Assistant Professor, ⁴Social Worker, ^{5,6}IAP Fellow, Department of Pediatric Hematology Oncology, Post Graduate Institute of Child Health, Noida, Uttar Pradesh, India

Submission: 10-11-2023

Revision: 29-12-2023

Publication: 01-02-2024

ABSTRACT

Background: Palliative care is underrepresented in our community at large. End-of-life care is offered mainly in palliative care hospices or hospitals worldwide. As access to such a facility is often sparse, and since many of them are located far away from home, most families wish to go home if a curative treatment option does not exist. **Aims and Objectives:** The study was done to analyze the preferences for the location of end-of-life care for families of children with cancer. We analyze the reasons for the same and offer suggestions for improving this situation. **Materials and Methods:** Parents of 77 children who died following a diagnosis of childhood cancer between 2019 and 2023, either due to progressive or refractory disease or due to toxic death, were interviewed to understand their choice of location for end-of-life care. The interview was done telephonically or face to face. **Results:** 41 out of 77 deaths were anticipated, and out of these, we observed that only 3 (7.3%) opted for a formal palliative care center. Fifteen families (36%) opted for end-of-life treatment in the hospital, and 23 families (56%) went home despite having no support at home for palliation. The decision is taken considering the practical needs of the rest of the family, although it is more difficult to implement. The reasons behind the decision are analyzed here. **Conclusion:** We recommend that integrated home-based palliation for end-of-life care in children be developed instead of hospice support. Hospices that take care of adults may be used with children where required. A multidisciplinary team that can support the needs of families and can visit them at home needs to be developed around centers managing children with cancer.

Key words: Childhood cancer; Palliation; End-of-life care

INTRODUCTION

Palliative care is emerging as a vital pillar in the management of children with life-threatening diseases such as cancer. India, with its burgeoning 1.4 billion population, has a huge burden of children with cancer. Many of them are not diagnosed, and some abandon treatment due to the fear or stigma associated with it. Even for those who are diagnosed and receive treatment, the challenges remain many. Palliative care is underrepresented in our community at large. It is often misunderstood that palliative care equates to terminal or end-of-life care. Also, awareness that pain relief needs to be addressed separately is often limited. To add to the challenges, there are no trained

or palliation-oriented nurses, doctors, or allied staff in the team, and often no provision for home- or hospital-based palliation.¹ In the 2 most populous states of North India, i.e., Uttar Pradesh and New Delhi, which cater to 253.6 million and 32 million people, respectively, there is only 1 government hospital and 1-2 non-governmental organizations providing palliative care services. Most end-of-life care is offered mainly in palliative care centers or hospitals in India. As access to such a facility is often sparse, and since many of them are located far away from home, most families wish to go home if a curative treatment option does not exist. Home-based palliative care provides the basic needs of palliation within the comfort of the patient's home.²

Access this article online

Website:

<http://nepjol.info/index.php/AJMS>

DOI: 10.3126/ajms.v15i2.59876

E-ISSN: 2091-0576

P-ISSN: 2467-9100

Copyright (c) 2024 Asian Journal of Medical Sciences



This work is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License.

Address for Correspondence:

Dr. Nita Radhakrishnan, Associate Professor, Department of Pediatric Hematology Oncology, Post Graduate Institute of Child Health, Noida, Uttar Pradesh, India. **Mobile:** +91-9999041524. **E-mail:** nitaradhakrishnan@yahoo.com

Aims and objectives

In this paper, we describe the preferences for the location of end-of-life care for families of children with cancer. We further analyze the reasons for the same and offer suggestions for improving this, which we have incorporated into our care.

MATERIALS AND METHODS

The institute is an autonomous state-run government facility in Uttar Pradesh, India. Our institute has been a referral center for children with blood diseases and cancer since 2017.

Inclusion criteria

All children who died following a diagnosis of cancer between January 2019 and March 2023 (50 months) were included in this analysis.

Exclusion criteria

Children who were registered with a diagnosis of cancer but did not continue treatment or abandoned treatment midway were excluded from the study.

Study design and protocol

This was a cross-sectional survey of parents or guardians of children who died following a diagnosis of cancer at our center. On diagnosis of cancer, children are registered and initiated on treatment with the inclusion of input from all concerned departments. The services provided inside the hospital from a pain and palliative care standpoint were procedural sedation for all, dedicated nursing, daily visits by a counselor for psychosocial concerns, heavily subsidized free treatment support, a pain and palliative outpatient clinic thrice a week, and travel support. Since patients hail from poor socioeconomic strata, financial support for treatment and the provision of accommodation for family members were important tools to prevent abandonment. We analyzed the choice of location of the end-of-life by families of children between 0 and 18 years who died following a diagnosis of cancer between January 2019 and March 2023. Death from both the progression of disease or toxicity (infection or treatment-related) was included. Infection-related deaths were classified as neutropenic deaths and infections during the non-neutropenic period that were not related to underlying treatment. The hospital records (inpatient and outpatient) were examined, and families were interviewed to understand the reasons for the decision. For children reaching end-of-life or refractory disease, there were three options.

Option 1 was to continue treatment inside the hospital, which often parents requested but had to be turned down frequently since it was better for the child not to

be under active treatment. Option 2 was to recommend institutional palliative care at a center that was run by a non-governmental organization for childhood cancer care, CanKids, which was situated around 16 kilometers away from the hospital. This center provided 24 × 7 support from a doctor and nurse, provision for opioids, and psychosocial support for children and their families. Option 3 was to go home if the family did not wish to use the earlier options. They were asked to report to the hospital weekly to the palliative care outpatient and 24 × 7 to the emergency if the child was sick and could not be managed at home. They were also provided essential medicines, including pain relief in the form of paracetamol or morphine, as required. The social aspects that guided the decision making, were analyzed.

Ethics approval

Ethical approval was received for this study from the Institutional Ethics Committee (2022-06-IM-19, dated July 01, 2022).

Statistical analysis

Data were collected in paper proforma and digitalized in Microsoft Excel format. Descriptive statistics were applied as required. Since this is a qualitative work, the responses of patients were also recorded as part of the analysis.

RESULTS

During this period of 50 months, 420 children between 0 and 18 years old were diagnosed and registered for treatment of cancer. 95% of patients belonged to lower or upper lower socioeconomic status as per the Kuppaswamy classification. These patients belonged to districts of Uttar Pradesh as well as to the surrounding states of Delhi, Uttarakhand, Bihar, Madhya Pradesh, etc. 77 children fulfilled the inclusion criteria of death following a diagnosis of childhood cancer. The male: female ratio was 1.3:1. The median age of this cohort was 7 years (0.4–18 years). 32 deaths occurred while the child was being treated with a curative intent (either toxic deaths or infection-related deaths).

Four children died at home due to unexpected causes. In the rest of the patients (n=41), where end-of-life was anticipated, families were counseled for relapse or progressive disease, and options for palliative care were provided. The options of a formal palliative care center versus continuing in the hospital as an inpatient versus continuing shared care with outpatient-based palliation were all financially equivalent options for the families, as the stay of the child and family, food, and treatment were being supported.

In this analysis, we observed that only 3 of these families (7.3%) opted for a formal palliative care center (option 1). Fifteen families (36%) opted for end-of-life treatment in the hospital (option 2), and 23 patient families (56%) went home (option 3). Although formal palliative care options were not available near home, most families still wished to be at home during the final days. They were provided pain medicines with the option to return to the hospital when needed. The families who opted for option 1 included those of a child with Ewing sarcoma with recurrence, stage IV osteosarcoma, and a child with refractory leukemia. In all these cases, the family preferred to be in a residential palliative unit under the care of formal specialists, during the last few days of life. Families who went home were interviewed to understand the reasons why they opted to be at home. They expressed that it is *“easier to take home while sick than after death,”* as traveling with a dead boy would require special vehicles such as hearse van or ambulance, which are costlier and more difficult to arrange, and more documentation so that they could avail of public transport if they were traveling with a sick child, even though critically ill. They also felt that *“if there is no option of cure, then why stay in a hospital or hospice?”* and *“waste caretaker time if there is no survival expected.”* There were many families who usually express difficulty staying in another city for treatment of cancer, as it impacts their livelihoods and the survival of other family members who are dependent on them. When the option of a cure is limited, many express their wish to go back to their regular lives and resume work since the changes of salvaging this child are miniscule. The other reason to take the child home was to meet siblings, extended family, and friends and to keep the child comfortable at home. Although they expressed fear of being unaware of how to handle symptoms that may arise during end-of-life care, they still wished to be home and requested that we *“help them by admitting them back to the hospital and administering treatment if the child’s condition progressed.”*

DISCUSSION

The World Health Organization defines pediatric palliative care as the total care of a child’s body, mind, and spirit, and it also involves giving support to the family. The purpose of this would be to provide the best quality of life for the child when being treated either with curative or palliative care.³ There are different patient care models that have been tested globally to provide pediatric palliative care. One is institutional care, where children stay in hospitals or hospices where their medical and palliative needs are taken care of. The other is home-based palliation or integrated home-based care programs that provide for the needs of the child from the comfort of home. Both programs need

professional investment with expertise and organizational skills, which are often not available in many countries or regions.

Children with life-threatening or life-limiting diseases where death is an expectation for which the family prepares themselves require both palliative care for the days to weeks prior to death as well as support for terminal care where the event is as pain-free as possible. Since the understanding of these, as separate entities often does not exist, there is a lack of support for both, especially for the palliative part of it, thus leaving parents to fend for themselves during this period. The management of pain and other symptoms like breathlessness or inability to feed is very inadequate in a home setting, thus leaving the child suffering during the last days. When it comes to children as patients who need palliative care, the issues related to planning and implementation are compounded by their specific emotional needs, the novelty of many issues, the psychosocial needs of siblings and caretakers, as well as ethical and legal considerations in decision making.⁴ In this context, our study assesses an important aspect of end-of-life care, viz., the choice of the location of care during the final few days.

Home unarguably provides the best area for managing children for comfort care during the end-of-life. It is culturally acceptable and satisfies the emotional and affective needs of families going through this ordeal of having to see a child pass away. However, home care needs planning and implementation, which goes beyond regular medical care and entails a support structure that is customized for the family. In pediatric cancer care, end-of-life care is offered mainly in palliative care centers or hospitals. However, unlike in adult care, especially geriatric care, the provision of free-standing hospices is not popular as an option for children. Parents of children going through terminal care and clinicians prefer home for end-of-life care and death for children with cancer.⁵

Hospital- or hospice-based palliation is easier for medical institutions to offer as it can be built around an existing infrastructure. It also offers the comfort of a “known” treatment setting, trust in hospital personnel, and does not upset the functioning of the home, where death can have a negative impact on other family members, especially siblings.^{6,7} However, in our study, we show that even when a facility for palliative care centers is available, many families opt to return home despite anxieties surrounding how the child can be managed at home. We show that even when financial planning for the sick child was taken out of the equation, a formal palliative care setting was opted for by <10%. This decision is often an economic

and pragmatic one rather than an emotional one. The risk of having to manage the terminal care of children at home alone without any help from a medical institution can be terrifying for families. Despite this, the decision is taken as it is more practical considering the needs of the rest of the family.

Hence, we strongly recommend integrated home-based palliation for end-of-life care in children. A regular visit from the medical team, the provision of medicines at home, psychosocial counseling for families to prepare them for the eventuality, and advise on how to manage documentation and rites at the end of life can help families get through this agonizing period of life. The essentials after death, such as the pronouncement of death, death certificate, aids for travel to perform last rites, etc., are also aspects that need to be considered while offering home-based palliation.⁷ Parents should not be burdened with the logistics of providing end-of-life care while going through this emotionally taxing period.

Limitations of the study

The limitation of the study is that it's a retrospective work. A prospective study will give deeper insights.

CONCLUSION

Palliative care should be engaged early in the treatment of childhood cancer and should not restrict itself to end-of-life care. Home-based palliation with active support from the medical team to cater to the child and family's wishes and medical needs is needed. Hospital- or hospice-based palliation, although helpful in adult settings, is not preferred in the case of children.

ACKNOWLEDGMENT

The authors take the privilege to thank the Government of India, state governments and NGOs involved in the care of these patients.

REFERENCES

1. Benini F, Orzalesi M, de Santi A, Congedi S, Lazzarin P, Pellegatta F, et al. Barriers to the development of pediatric palliative care in Italy. *Ann Ist Super Sanita*. 2016;52(4):558-564. https://doi.org/10.4415/ANN_16_04_16
2. Roberts B, Robertson M, Ojukwu EI and Wu DS. Home based palliative care: Known benefits and future directions. *Curr Geriatr Rep*. 2021;10(4):141-147. <https://doi.org/10.1007/s13670-021-00372-8>
3. Muckaden M, Dighe M, Balaji P, Dhiliwal S, Tilve P, Jadhav S, et al. Paediatric palliative care: Theory to practice. *Indian J Palliat Care*. 2011;17(Suppl):S52-S60. <https://doi.org/10.4103/0973-1075.76244>
4. De Noriega Í, García-Salido A, Martino R and Herrero B. Palliative home-based care to pediatric cancer patients: Characteristics and healthcare delivered. *Support Care Cancer*. 2022;30(1):59-67. <https://doi.org/10.1007/s00520-021-06412-5>
5. Kassam A, Skiadaresis J, Alexander S and Wolfe J. Parent and clinician preferences for location of end-of-life care: Home, hospital or freestanding hospice? *Pediatr Blood Cancer*. 2014;61(5):859-864. <https://doi.org/10.1002/pbc.24872>
6. Noyes M, Herbert A, Moloney S, Irving H and Bradford N. Location of end-of-life care of children with cancer: A systematic review of parent experiences. *Pediatr Blood Cancer*. 2022;69(6):e29621. <https://doi.org/10.1002/pbc.29621>
7. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics*. 2013;132(5):966-972. <https://doi.org/10.1542/peds.2013-2731>

Authors Contribution:

All contributed to study design, conduct of survey and preparation of manuscript.

Work attributed to:

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

Orcid ID:

Dr. Nita Radhakrishnan - <https://orcid.org/0000-0002-7941-5641>

Source of Support: Nil, **Conflicts of Interest:** None declared.