



Original Article

# Choice of Place of the Death of Children with Cancer during End-of-Life Care – Parent’s Perspectives in a Developing Country

Latha Sneha<sup>1</sup>, Swathi Narasimhan<sup>2</sup>, Julius Xavier Scott<sup>1</sup>, S. Shuba<sup>3</sup>, P. S. Rajakumar<sup>3</sup>, Anitha Rani<sup>4</sup>

<sup>1</sup>Departments of 1Pediatric Hematology and Oncology and <sup>2</sup>Pediatrics, <sup>3</sup>Department of Pediatrics, Pediatric Intensive Care Unit, <sup>4</sup>Department of Community Medicine, Sri Ramachandra Institute of Higher Education and Research, Chennai, Tamil Nadu, India.

## ABSTRACT

**Objectives:** The place of a child’s death is an indicator of the quality of paediatric palliative and end-of-life care. This study aimed to identify the choices of parents about the place of death of their children with cancer and to evaluate whether they had any regrets about their choices retrospectively.

**Material and Methods:** All children who were treated in our centre for the past 9 years with palliative intent treatment to improve their quality of life were included in this study. For the children whose place of death was the hospital, data were collected from the case records. For the children who passed away at home, a telephone call was made to the families, informing them of the study, allowing time for there to be any clarifications. A verbal consent was requested for the study. Data were collected through the telephone conversation.

**Results:** Out of the 59 children who died during the study period from 2012 to 2021, 31 children (52.5%) died in hospital settings. Eighteen (58.1%) families who had opted hospital as the place of death had regretted their choices. Families who chose home as a place of death were upset about inadequate pain management. The majority of the families had desired home care services for adequate symptom control and to keep the child comfortable in a familiar environment.

**Conclusion:** Most children with life-limiting conditions continue to die in the hospital setting in developing countries due to a lack of dedicated palliative care services and home care. Most of the families retrospectively, regretted their choices of place of death. Most of the families, however, would prefer home as the place of death, if there was better end-of-life care support for symptom control at home. Specific policies institutional and nationwide need to be formulated to provide guidance to the professionals on the discussion of goals of care and place of care, with a supporting network to ensure its provision.

**Keywords:** Cancer children, End-of-life care, Choice of place of death, Families regret

## INTRODUCTION

Supporting the family and caring for a child at the end of life is an emotional task, requiring a comprehensive and integrative care approach and a skilled multidisciplinary healthcare team including dedicated paediatric palliative care specialists.<sup>[1]</sup>

There has been tremendous work in the field of paediatric palliative care in the last decade and dedicated units were started in Kerala, Delhi, Goa, Chennai, Mumbai, and Hyderabad. However, the development has been patchy and is mainly concentrated in the towns and cities. Quality at the end of life has indicators that ensure the provision of a good death for the child. Place of death is one of the indicators

of the quality of end-of-life care provided by the healthcare system.

Providing dedicated paediatric palliative care provides this quality, but sadly has multiple impediments in a developing country like India. There is a lack of curriculum content, specific to paediatric palliative care at all levels of medical curriculum including paramedical courses that leads to a lack of sensitization of the professionals in accepting its immense benefits when integrated into the care of the terminally ill child and family. The awareness and knowledge about palliative care services are very poor among community practitioners as well. The absence of accessible dedicated paediatric palliative care services, hospice care, and home

\*Corresponding author: Latha Sneha, MD, MRCPCH (UK), IAP PHO Fellowship in Pediatric Hemato Oncology, Professor, Department of Pediatric Hematology and Oncology, Sri Ramachandra Institute of Higher Education and Research, Chennai, Tamil Nadu, India. drmslatha@yahoo.com

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care services in a developing country like India brings uncertainty to decision-making at the end of life. Hence, families believe that the hospital is the only place to provide relief for their child's suffering. As a result of the strict hospital administration policies and intensive care settings, the families suffer emotionally and psychologically, isolating their child in an unfamiliar environment of the paediatric intensive care unit (PICU), drained financially due to the high costs of PICU care, leaving behind unforgettable painful memories for their whole life after their children's death. Introduction to a new palliative care team during end-of-life care, where available, fosters reluctance from the parents to accept the new healthcare team. This clearly emphasises the need to integrate a palliative care team right from the time of diagnosis, who would be supporting the family emotionally and psychologically throughout the illness and will help in the transition from curative to palliative intended care. This study aimed to identify the choices of parents about the place of death of their children with cancer, reasons for the choices, and regrets if any of the choices were made.

## MATERIAL AND METHODS

All children with incurable cancer, who were on palliative intent treatment, focusing on symptom management and comfort care, being managed at our paediatric oncology centre, and who died during 2012–2021 were included in this retrospective study. Ours is a tertiary care paediatric haematology and oncology centre managing children and adolescents aged up to 18 years and has annually 100–125 newly diagnosed cancer cases. There are no dedicated in-house paediatric palliative care services available. The institutional ethics committee's approval was obtained. Relevant data were collected from the case records for those who died in the hospital or until they were cared for in the hospital and for children who died at home, details were obtained from families through telephonic interviews with appropriate consent. The initial call was made to the parents to introduce the concept of the study and to grasp their interest in participating in the study. If they were willing, they were given a week to call the primary investigator and to give their oral consent before starting the study. After the interview, the parents were contacted a week later to assess whether they needed any additional emotional support. If they did, psychologist support was provided.

### Statistical analysis

Data collected were analysed using the SPSS software version 20. Background variables and other categorical variables were described as percentages. Association between categorical variables tested for significance by Chi-square test.  $P < 0.05$  was considered statistically significant.

## RESULTS

The study period was from 2012 to 2021. A total of 59 children declared to be on palliative care had died during the study

period. Demographic details of the children are provided in [Table 1]. Only two of the families had utilised the dedicated palliative care services and 1 family opted for hospice care available in the city outside our hospital. Twenty-four (40%) families desired to have shared care with the paediatrician at their native place but only 10.2% of them could achieve shared care as paediatricians and family practitioners in their native place were not comfortable managing a child at the end-of-life care. A total of 45 families (76%) preferred home care visits by any medical team member. Thirty-one children (52.6%) died in hospital settings. Among the 31 who died in hospitals, 26 (83.8%) of them died in the PICU

**Table 1:** Demographic details of children on end-of-life care.

Variable	n	%
Diagnosis		
Acute leukaemia	25	42.4
Solid tumour	34	57.6
Gender		
Male	38	64.4
Female	21	35.6
Disease status		
Relapsed	36	61.0
Refractory/progressive disease	23	39.0
Permanent residence		
Urban	33	56.0
Rural	26	44.0
Age at the time of death (in years)		
<1	1	3.2
1–3	5	16.1
4–10	15	48.4
11–15	6	19.4
>15	4	12.9
Major symptoms noted during the terminal period		
Pain	27	45.8
Vomiting	3	5.1
Bleeding	3	5.1
Respiratory distress	7	11.9
Seizures	4	6.7
Decreased activity/poor feeding/lethargy	10	16.9
Altered sensorium	2	3.4
Fever	3	5.1
Duration of hospital stay before death		
<2 h	3	9.7
2–6 h	8	25.8
<24 h	5	16.1
24–48 h	3	9.7
>72 h	7	22.6
>1 week	5	16.1
Preferred place of death		
Hospital	31	52.5
Home	28	47.5
Children intubated at the time of death	12	38.7
Families who retrospectively regretted about place of death		
Hospital n (31)	18	58.1
Home n (28)	12	42.8

**Table 2:** Factors associated with choosing place of death.

	<i>n</i>	%
Hospital <i>n</i> (31)		
Feeling secure being under a doctor's care	13	42
Feeling contented that they fought till the end for their child	17	54.8
Symptom management would be better at the hospital	1	3.2
Home <i>n</i> (28)		
The child was scared and reluctant to come to the hospital	14	50
Parents were distressed to see their child suffering due to repeated tests and IV access issues	7	25
The child would be more comfortable at home with family members	7	25

**Table 3:** Factors associated with regret over place of death.

	<i>n</i>	%
Hospital <i>n</i> (18)		
Hospital policies – restricted time spent with child, separated from child while in ICU	4	22
Frequent blood sampling, difficult IV access issues	10	55.6
The child was very scared, upset, and angry in the hospital and would have been comfortable at home with family members	4	22
Home <i>n</i> (12)		
Inadequate symptom management	8	66.8
Feeling guilty due to neighbours and relatives' criticism	2	16.6
Hoped that the child would have lived for some time if managed in a hospital	2	16.6

ICU: Intensive care unit

and 5 in the ward. Among the 26 children who died in the PICU, 12 (46.1%) of them were ventilated. Pain was the major concern in 45.8% and 16.9% had decreased activity/poor feeding as reported by families during their end-of-life care. Five families (16.1%) had stayed for more than 1 week in the hospital before the death of the child. Only 13.6% of families had agreed to no aggressive/intensive resuscitation measures, in the past 72 h of death. Fourteen of the 28 families (50%) who chose home as the place of death had quoted that the child was reluctant and afraid to come to the hospital, 54.8% of families who chose hospital as the place of death had suggested that providing terminal care in hospital, provided them mental relief since they were feeling unsupported at home due to lack of home care. Among 59 families, 30 (50.8%) regretted the choice of the place of death [Table 2]. The regret was more common among the families with hospital deaths than home deaths. The major regret among hospital deaths (55.5%) was regarding the hospital

administrative issues, painful procedures- blood sampling, and repeated IV access issues during the terminal period of life. Among home deaths, the major regret was about the inadequate symptom management (66.8%) and non-availability of home care services (89.7%) [Table 3]. None of the families who were part of the study expressed any emotional distress or requested emotional support.

## DISCUSSION

Families experience an unimaginable painful life event while facing the death of their child which affects them for the whole of their life. The support provided throughout the terminal care and during bereavement has been found to have a positive impact on the long-term grieving outcomes of these parents.<sup>[2]</sup> A report from 36 studies about parental perspectives on their child's palliative or end-of-life care has identified deficiencies across all themes – with insufficient communication, lack of respect, and lack of emotional support.<sup>[3]</sup>

The six domains of paediatric palliative care are the support of the family unit, communication, shared decision-making, relief of pain and other symptoms, continuity of care, and bereavement support are usually not supported adequately in most developing countries where still the focus is only on curative intent treatments.<sup>[4]</sup>

Place of death has been used as a measure of the quality of palliative or end-of-life care in developed countries.<sup>[5]</sup> However, in developing countries, paediatric palliative care services are available only in very few centres and the delivery of dedicated paediatric palliative care services with professional holistic end-of-life care is completely lacking even in major Medical College hospitals in major cities. Fear of anticipated poor symptom control at home especially at the end of life, due to lack of home care services, forces families to prefer treating their child in the hospital. A study by Gibson-Smith *et al.* assessing the trends in place of death for children with life-limiting conditions in England from 2003 to 2017 has quoted that 73% of deaths occurred in hospitals, 6% in hospices, and 16% at home.<sup>[5]</sup>

Kaye *et al.* reported that more than 1/3 of paediatric palliative oncology patients die in hospitals and 50% of them are in intensive care settings.<sup>[6]</sup> Although our study quotes 47.5% of home deaths, which is much higher than other studies, the possible cause could be due to travel restrictions and non-availability of general hospital services during the COVID-19 pandemic. During the COVID-19 lockdown period from November 2019 to November 2020, among the 19 children who died, 13 (68%) died in their homes.

Kaye *et al.* in a study in St. Jude Children's Research Hospital reported that the children who received adequate palliative care never died in hospitals and the late introduction of palliative care, occurring <30 days before death is a factor contributing to deaths in PICU. In turn, hospice involvement

and making advance care plans led to lower death rates in the PICU.<sup>[7]</sup> In our study as well, the three families who utilised the services of available generalist palliative care services, chose home as the place of death, with no regret.

The major symptoms warranting a hospital admission in our study were pain (45.8%), decreased activity/poor feeding (16.9%), and respiratory distress (11.9%). Yanai *et al.* in their study among paediatric cancer patients in Japan between 2004 and 2011 reported primary disease (Haematological vs. solid tumour), disease status (complete remission or incomplete remission) central nervous system (CNS) or non-CNS tumour, and preference of families as the factors influencing the place of death.<sup>[8]</sup> As per his study, home death was observed among all the children with solid tumours. Brain tumours have always been found to be less associated with home deaths as symptoms such as refractory vomiting and seizures are difficult to be managed at home. We could not find any association between the choice of place of death and age of the child, primary diagnosis, and disease status at the time of end-of-life care, the socio-economic status of the families, and whether they were in urban or rural areas. The only factor that was of statistical significance in deciding the place of death as per our study was the major symptoms noted during the terminal period ( $P < 0.04$ ).

In a study by Das *et al.* about parents' acceptance and regret about end-of-life care for children with malignancies, among the 26 children who were on end-of-life care, 18 families (69%) chose home and 8 (31%) chose hospital as a place of death. The families that chose hospital-based terminal care quoted – the lack of availability of medical facilities near their home, relative's pressure, the need to attend to other children at home, and fear of the persistence of symptoms as the reasons for the choices. Among the 18 families that chose a home, 7 (38.8%) regretted their decisions with regard to uncontrolled pain, non-availability of medical help at home, and absence of social support or family at terminal time. Among 8 families that chose the hospital, 5 (62.5%) regretted their choice due to uncontrolled pain, the child's fears about the hospital environment, the child's unfulfilled desire to be at home, the restrictive environment, and lack of privacy. The families who opted for PICU care regretted their decision as ventilation and sedation caused their separation from the child during the terminal care. The regret was more among the families that chose the hospital as a place of terminal care.<sup>[9]</sup>

In our study, 30 families (50.8%) had regretted their choices of place of death. The strict hospital policies regarding the bedside presence of parents with the child in the PICU and multiple invasive tests and medications during the terminal period were the major contributing factors to regretting the hospital as the place of death. For those who died at home, though the families were upset that the symptom management was inadequate and expressed guilt about it,

they were comfortable knowing that they had made the right choice when considering the child's fear of procedural pain, especially IV access and invasive tests. Highly intensive but futile life-sustaining treatments toward the end of life are petrifying for the parents. Accepting death as the inescapable end in light of the advanced disease shifts the focus of care to supportive and symptomatic care alone. Although families had initially agreed to continue only comfort care and symptom control management, this decision was reversed requesting implementation of measures to sustain the life of the child, when the end was near. This burdens the child as well as the families in a heartrending situation, filled with unforgettable misery, ultimately leading to families regretting their decisions. Although the provision of end-of-life care in the PICU is not warranted to deliver optimal palliative care, as per most of the hospital policies, the acutely declining child is no longer managed in the ward and is shifted to the PICU for further care. Cost-effective and goal-centric care should be developed for children with serious life-limiting illnesses. The need to modify the hospital administrative policies for the children on terminal care, such as – lifting restrictions regarding family visiting as well as the time of visitation allowing them to have time with the dying child, was reinforced by Johnston *et al.*<sup>[10]</sup> The majority of the families had wished for dedicated home-based palliative care services, which would have provided adequate pain relief and symptom control for the child. Having this service provision would have made the child more comfortable at home, and surrounded by family members, thereby reducing the child's anxiety and fear. This would also facilitate improved support for the parents and other siblings. Regret regarding Home as a choice for place of death has been mainly attributed to the unavailability of community-based end-of-life care support and non-existent home care facilities in our study. This is as found in most of the developing countries.

Advanced care planning by the primary healthcare team will help the parents understand what is futile and what is required to improve the quality of life and quality of death, thereby reducing the distressing experiences of unwarranted interventions and promoting acceptance of natural death.<sup>[11]</sup> The development of a dedicated paediatric palliative care program with a full-fledged home care services to provide holistic end-of-life care with adequate symptom relief, facilitating a good death is the absolute need of the hour.

## CONCLUSION

Most children with incurable advanced cancer continue to die in the hospital setting in developing countries. In our study, most of the families retrospectively regretted their choices of the place of death – be it the hospital or the home. Specific policies need to be formulated to provide better end-of-life care support for symptom control at home. The need for paediatric palliative care national policies, provision of

the facility at the community level, and availability of medical help at home for dying children is the utmost essential services required in developing countries.

### Ethical approval

The author(s) declare that they have taken the ethical approval from IRB/IEC.

### Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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### Conflicts of interest

There are no conflicts of interest.

### Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)- assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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