



## Revista Brasileira de Hematologia e Hemoterapia Brazilian Journal of Hematology and Hemotherapy

www.rbhh.org



### Original article

# Palliative care in pediatric hematological oncology patients: experience of a tertiary hospital



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#### ARTICLE INFO

##### Article history:

Received 21 January 2013

Accepted 25 June 2014

Available online 18 September 2014

##### Keywords:

Palliative care

Neoplasms

Death

#### ABSTRACT

**Objective:** To evaluate the approach to palliative care for hematological oncology patients in the pediatric ward of a tertiary hospital.

**Methods:** This was a retrospective, descriptive study of 29 hematological oncology patients who died between 2009 and 2011. Data regarding the approach and prevalence of pain, prevalence of other symptoms, multidisciplinary team participation, communication between staff and family and limited invasive therapy were collected from the medical records.

**Results:** Twenty-seven (93.1%) patients displayed disease progression unresponsive to curative treatment. The median age at death was ten years old. Pain was the most prevalent symptom with all patients who reported pain receiving analgesic medications. The majority took weak (55.2%) and/or strong (65.5%) opioids. The patients were followed by pediatricians and a pediatric hematologist/oncologist. Participation of other professionals was also documented: 86.2% were followed by social services and 69% by psychologists, among others. There were explicit descriptions of limitation of invasive therapy in the medical records of 26 patients who died with disease progression. All these decisions were shared with the families.

**Conclusion:** Although the hospital where this study was conducted does not have a specialized team in pediatric palliative care, it meets all the requirements for developing a specific program. The importance of approaching pain and other prevalent symptoms in children with cancer involving a comprehensive multidisciplinary team is evident. Discussions were had with most of the families on limiting invasive therapy, but no record of a well-defined and coordinated treatment plan for palliative care was found.

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<http://dx.doi.org/10.1016/j.bjhh.2014.09.003>

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## Introduction

Palliative care in pediatrics is, according to the World Health Organization, active and total care delivered to a child in relation to his or her body, mind and soul, with support provided to the whole family. The focus of this approach is early identification and treatment of pain and other symptoms with a view to providing patients and their families with the best quality of life possible.<sup>1</sup>

There are currently many children in need of palliative care<sup>2</sup> including patients with neoplasms. Every year, 200,000 children and adolescents are diagnosed with cancer around the world. In Brazil, the mortality rate of children and adolescents aged between one and 19 due to cancer was 8% in 2005 making this the second leading cause of death and the first leading cause of death by disease in this population. Global initiatives to provide care for these children are, therefore, necessary and urgent.<sup>3,4</sup>

This study aimed to evaluate the approach of palliative care in hematological oncology patients who progressed to death in the pediatric ward of a tertiary hospital.

It is important to state that palliative care should be introduced at the time of diagnosis. However, as curative measures decrease, palliative care becomes an absolute necessity<sup>5</sup> and for this reason, the study sample was composed of patients who died.

## Methods

This was a retrospective, descriptive Study that included all under 18-year-old patients diagnosed with hematological oncology diseases who died in the pediatric ward of the Hospital das Clínicas at Universidade Federal de Minas Gerais (HC-UFGM) between 2009 and 2011.

Patients with other diseases who also needed palliative care and progressed to death were excluded as were patients with hematological oncology diseases who died in their homes, emergency services, intensive care units or in other hospitals.

Data were collected through analysis of the medical records. These data refer to the hospitalization during which the patients died.

The assessed data relate to the main items that constitute good assistance in palliative care: approach to pain, prevalence of pain and other symptoms, involvement of a multidisciplinary team, communication between medical staff and family/patient on the case and disease progression, the family's desire to go home, patient follow-up by the home care service and limitation of invasive therapy.

The study was approved by the hospital's Research Ethics Committee, which waived informed consent.

## Results

Between 2009 and 2011, 44 deaths were recorded in the pediatric ward of the HC-UFGM. Of those, 29 (66%) were patients with hematological oncology diseases, who were included in the study.

Of the 29 patients that died, the median ages at the time of diagnosis and death were six and ten years, respectively. Forty-five per cent had hematological diseases (aplastic anemia or leukemia) and 55% had solid tumors. Twenty-seven (93.1%) displayed disease progression unresponsive to curative treatment. Of these, three patients received chemotherapy as a palliative measure and only one received chemotherapy with curative prospects, even with disease progression and limited invasive therapy.

Ten patients (34.4%) displayed neurological sequelae, with varying degrees of cognitive deficit. Six patients were tracheostomized (all with neurological sequelae: #4, #9, #12, #16, #18, #24), thirteen had been using an enteral tube and one had a gastrostomy.

The median duration of hospitalization was 40 days. Eight patients (27.5%) were admitted into the intensive care unit at least once during hospitalization.

Data regarding the characterization of the sample are shown in [Tables 1 and 2](#).

The median number of symptoms displayed per patient was four. The main symptoms and their prevalences are listed in [Table 3](#). Pain was the most prevalent symptom, reported by almost 80% of the patients.

All patients reporting pain took analgesic medications: 48.3% took common analgesics but the majority took weak and/or strong opioids (55.2 and 65.5%, respectively). Three patients were followed up in the pain clinic. There were no records of scales or non-pharmacological measures to control pain being used.

All patients were followed up by general pediatric residents fully supervised by preceptors on the hospital's clinical staff. All patients were assisted by pediatric hematologists or oncologists as required by their underlying diseases. The

**Table 1 – Characteristics of the 29 hematological oncology patients who progressed to death.**

| Characteristics                                      |         |
|--|---------|
| Gender (male:female)                                 | 18:11   |
| Age at time of diagnosis (years)                     |         |
| Median   | 6       |
| Variation  | 1–16    |
| Interquartile range (25–75%)                         | 2.5–9.5 |
| Age at time of death (years)                         |         |
| Median   | 10      |
| Variation  | 1–17    |
| Interquartile range (25–75%)                         | 4.5–13  |
| Symptoms reported throughout Hospitalization (n°)    |         |
| Median   | 4       |
| Variation  | 0–8     |
| Interquartile range (25–75%)                         | 3–6     |
| Interval between diagnosis of and death (years)      |         |
| Median   | 1.1     |
| Variation  | 0.1–10  |
| Interquartile range (25–75%)                         | 0.7–3.8 |
| Duration of hospitalization when patient died (days) |         |
| Median   | 40      |
| Variation  | 3–246   |
| Interquartile range (25–75%)                         | 10–66   |

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