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



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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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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.¹

There are currently many children in need of palliative care² 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.^{3,4}

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 necessity⁵ 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

Table 2 – Diagnosis, neurological sequelae and use of chemotherapy at the time of death.

Patient #	Diagnosis	Use of chemotherapy at the time of death	Neurological sequelae
3, 7, 21	Aplastic anemia	Does not apply	No
12, 16, 18	Anaplastic astrocytoma	No	Yes
9	Adrenocortical carcinoma	No	Yes
11	Adrenal gland carcinoma	No explicit report found	Yes
4	Chordoma	No	Yes
10	Anaplastic ependymoma	No explicit report found	Yes
5	Glioma	No	Yes
20	Glioblastoma	No	No
8	Hepatoblastoma	No	No
14, 15, 17, 22	ALL	No	No
25	ALL	Curative	No
13, 28	ALL	Palliative	No
2, 19	Acute myeloid leukemia	Curative	No
23	Myeloid leukemia	Palliative	No
24	Medulloblastoma	No	Yes
26	Neuroblastoma	No	No
27	Neurofibroma	No	No
29	Osteosarcoma	No explicit report found	No
6	Brain stem tumor	No explicit report found	Yes

ALL: acute lymphocytic leukemia.

Table 3 – Prevalence of the symptoms displayed during the hospitalization in which the patient died.

Symptom	n	%
Pain	23	79.3
Dyspnea	20	69.0
Nausea/vomiting	18	62.1
Constipation	15	51.7
Depressed mood	13	44.8
Hyporexia	10	34.5
Anxiety	7	24.1
Sleep changes	4	13.8
Weakness	3	10.3
Irritability	3	10.3

involvement of other medical staff is shown in Table 4. Of the patients followed up by the psychiatry department, all were prescribed psychiatric medications (antidepressants and anxiolytics) and only one was not simultaneously followed up by the psychology department. The psychology approach,

Table 4 – Number of patients who received care from the different professionals in the multidisciplinary team during the hospitalization in which the patient died.

Professional	n	%
Pediatric resident/preceptor	29	100.0
Staff nurses	29	100.0
Social worker	25	86.2
Pediatric oncologist	16	55.0
Pediatric hematologist	13	45.0
Psychologist	20	69.0
Nutritionist	16	55.0
Physical therapist	11	37.9
Occupational therapist	8	27.6
Psychiatrist	5	17.2
Pain clinic	3	10.3
Religious support	1	3.5

in its turn, was considered for both family members and patients.

There were reports of explicit communication between the medical team and the family on the evolution of the case and its seriousness, proposed treatment and/or other issues, including limitations of invasive therapy when indicated in 96.5% (28/29) of the medical records. The medical record of one patient, who died with disease complications, contained no reports of communication between the team and his family. There were no reports of explicit communication between the staff and patients in only three cases, who were aged 14, 15 and 17 years at the time of death (#1, #7 and #27).

Four records described the family's desire to take the patient home. All the patients had been undergoing limited invasive therapy. Four patients were followed up by the home care team, but their medical records reported no desire of the family to return home. Of these four patients, the families of two were visited after death by the home care team. According to their records, 25 of the 29 children (92.5%) were accompanied by a family member at the time of death, mostly (8/25 cases) only by the mother although in four cases it was only the father. The father and mother were together in only two cases. In the other cases, the companion was another family member or could not be identified.

Two patients progressed to death with complications secondary to treatment (#2 and #19), and the other 27 (93.1%) died due to disease progression. Among those, there were explicit descriptions by the medical team in their records of limitation of invasive therapy in 26 cases (96.3%). Of these, limitations of invasive therapy started before the last hospitalization in ten patients (38.4%). In all 26 cases, the decision was shared with the families. Only one child, who had not undergone limitation of invasive therapy, died of disease progression. In this case, despite the medical staff having asserted that the patient was not undergoing curative therapy, the parents denied the unfavorable progression of the disease and did not accept to limit therapies. This patient, like the other two who died with

complications secondary to treatment, were the only ones who received cardiopulmonary resuscitation prior to death. Three patients, who had been tracheostomized, died on mechanical ventilation, but none of them received cardiopulmonary resuscitation.

Despite the limitation of invasive therapy having been described explicitly in the medical records of 26 children, these limits were only properly described in 16 (61.5%) patients; that is, in 38.5% the treating physician did not clearly explain which therapy should or should not be delivered to the patient, but used vague terms such as “comfort measures”, “palliative care” and “limitation of therapeutic efforts”.

Discussion

Currently, around 80% of children and adolescents diagnosed with cancer can be cured. In spite of the high rates of cure, cancer-related morbidity and mortality is still significant.^{3,4} Hence, dealing with this new patient profile is a challenge.⁶

Impeccable control of pain and other symptoms is the main strategy in the palliative approach.² In patients with cancer, pain is an important factor of disease-related suffering.⁵ As in most studies, pain was the most prevalent symptom in this sample.^{7,10}

Assessment of pain should be directed due to the child's age and development.² Whenever possible, the child's own report should be esteemed and considered the gold standard.¹¹ It is recommended to use scales to assess the intensity of pain, as well as to monitor the progression of treatment.¹ However, these instruments were not used in the ward where the study was conducted.

Lack of adequate control of pain is at the core of the deficiencies observed in palliative care in developing countries as the availability and consumption of opioids, considered wide indicators of cancer-related pain relief, are still restricted.^{3,12} However, it was observed in this study that the majority of patients who reported pain were prescribed opioids.

Non-pharmacological measures were not described in the medical records. Such measures are part of the integral management of pain and show synergistic effects to drug treatment.^{13,14}

Not only physical symptoms were identified in this study. Psychological symptoms, such as depression and sleep disorders, were also found. These symptoms are described in the literature as an important cause of suffering for children with cancer and they are often not addressed by doctors.^{2,8,10}

As a way of recognizing the complexity of care needed by patients with life-threatening diseases, the involvement of a multidisciplinary team is a prerequisite to deliver quality assistance.¹⁵ It was found in this case study that a significant number of patients were assisted by a multidisciplinary team, but the study design did not allow an evaluation of whether this follow-up was effective. It was not possible to evaluate whether there was interaction with the team, which is essential in multidisciplinary conditions, only by examining the medical records. The optimal functioning of this team requires training, communication and the setting of roles and responsibilities of each member.¹⁵

The service provider where this study was conducted has no specialists in pediatric palliative care, but palliative interventions should not be limited to specialists.¹¹ General pediatricians and pediatricians from different fields should be able to handle palliative care issues.⁶

The two patients who died with treatment-related complications were included in this study since palliative care ought to be initiated at the time of diagnosis.⁶ Moreover, only four of the patients who died with disease progression were receiving chemotherapy when they died. In three of these cases, chemotherapy was employed as a palliative measure. Researchers from different countries have shown that children who receive end-of-life chemotherapy display a higher number of symptoms than children who do not, with greater likelihood of inadequate control of pain.^{8-10,16} Nevertheless, the choice of palliative or curative chemotherapy and suspension of chemotherapy is a difficult decision for both the medical team and the family.¹⁷ This difficulty may cause medical staff to be reluctant to disclose an unfavorable prognosis to patients and their parents.¹⁶

In most of the cases included in this study, there was evidence of communication between teams and families. Three records also reported that there was direct communication with the patients, all of whom were adolescents. However, these patients did not take part in the decision to limit therapy, only their parents did. Studies emphasize that doctors and parents ought to talk to sick children about their feelings and anxieties. Avoiding this sort of communication overlooks the fact that most of the time they are aware of their situation.⁶

The medical records of four families clearly reported the desire to take their children home; all of them were aware that the disease was progressing. Only by examining the records, it is impossible to know whether other families had the same desire. The place of death is an important indicator of end-of-life quality of care.¹⁸ Dying at home, whenever possible, is preferred by the majority of families of cancer patients.¹⁹⁻²¹ In this study, there were reports of after death home care visits to only two children, who had been followed up by the institution's home care program. After death care during mourning is also an important intervention in palliative care and produces a positive impact on families.

Decisions on limitation of futile therapy should be shared with patients and families,²² exactly as happened in this study. In the one case in which there was a divergence between the team and the family in spite of progression of the disease, the patient continued to receive invasive interventions, such as cardiopulmonary resuscitation.

Tonelli et al. evaluated the care profile to pediatric patients who progressed to death in the same hospital as the current research. Participation of parents in discussions was observed in only 20.8% of the cases.²³ This fact differs from the results obtained in this study, which found that discussions were had with the parents of all children with disease progression. Some hypotheses can be suggested to explain this difference. In the study by Tonelli et al., the deaths of all pediatric patients at the hospital were evaluated, including patients with different diseases and in different units, such as in the intensive care unit and operating rooms.²³

Another factor that might have facilitated discussing these issues with the families is that most patients in this

sample already had a bond with the medical team, which can be seen by the interval between the diagnosis of the underlying disease and death.²⁴

It should also be stressed that in recent years medical practice has undergone a cultural change: the paternalistic approach has been replaced by an approach that recognizes the role and importance of the family and the patient.²⁵

One of the possible factors that accounts for this paradigm shift is the current Brazilian Code of Medical Ethics, which stresses the duty of doctors to “provide palliative care for patients with incurable and terminal diseases without undertaking useless therapeutic actions and always taking into consideration the patient’s manifested wish or, should it prove impossible, the wish of his/her legal representative”.²⁶

Limiting invasive therapy means excluding futile interventions, which do not help to control the disease and do not improve the patient’s quality of life.²² Such limitations should be individualized.^{6,22} The six tracheostomized patients of the study can be regarded as examples of this. All of them underwent limitation of invasive therapy and three died without mechanical ventilatory support. For this reason, it is important that the physician records what should or should not be done, after having an appropriate conversation with the family, rather than using vague terms such as “comfort measures”. It should be noted that some terms were used inappropriately. Frequently some doctors, when evaluating medical records, considered the term “palliative care measures” to be similar to “limitation of futile therapy”.

These findings reinforce the impression that there still are health workers who consider palliative care to be end-of-life care.²² Some years ago, palliative and curative care were considered mutually exclusive approaches, and palliative care was only initiated after all curative possibilities had been exhausted. Currently, they are complementary forms of treatment and palliative care should be implemented at the diagnoses of life-threatening diseases. Early integration of these approaches facilitates discussion of sensitive issues between medical staff and families,^{27,28} in addition to improving the quality of life of patients.²⁹

The limitations of this study are mainly related to the relatively small number of cases and the lack of data on the deaths that took place at home or in other wards. However, medical records with clear and comprehensible descriptions were available. This is probably due to the fact that this is a teaching hospital.

The results of this study show that the hospital where this work was carried out, despite not having a team specialized in pediatric palliative care, meets most of the requirements for implementing a specific program.⁶ In developing countries such as Brazil, there are still countless difficulties to follow-up children with cancer. Delays in diagnoses and limited resources are some of the obstacles found. Yet, such facts should not hinder the development of pediatric palliative care programs, which should be given priority in tertiary hospitals.^{3,11}

The importance of managing pain and other symptoms appropriately is evident. For this approach to be truly effective, involvement of workers from different areas, with real integration among them, is imperative. Other tools can also benefit this approach, such as the use of scales.

Despite the involvement of several health workers caring for the patients included in the study and the discussions with most of them about limiting invasive therapy, the medical records did not include descriptions of a well-thought-out treatment plan. This plan consists of discussing with patients and families in advance about what kind of assistance will be delivered. It should not address only medical aspects, but also social issues such as what and who is important to the child and his or her family. This planning should be reassessed as required by changes in the clinical status.⁶

Training communication skills, developing the ability to interact with other workers, learning to cope with the difficulties intrinsic to the process of death are among the items that should be improved.²⁷ In this way, great quality assistance will be delivered to patients throughout the process of disease regardless of whether the final outcome is cure or death.

Conflicts of interest

The authors declare no conflicts of interest.

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