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Evaluation of the need for hospital-based pediatric palliative care in a single center

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ABSTRACT

Introduction/Aim: Cancer is one of the leading causes of death for children . Evidence suggests that these children experience substantial suffering from physical and emotional symptoms. Over the past two decades, paediatric palliative care has emerged as an approach that aims to ease suffering for children and their families coping with any life-threatening illness. Our aim is to encourage the expansion of palliative care centers for children with cancer and integration of these into healthcare services to assist clinicians and policy makers in developing services that address these needs.

Material and Method: Our study is a single-center retrospective cohort study. The records of 39 patients who were followed up in the pediatric oncology clinic between 2010-2021 and died were reviewed retrospectively.

Results: The age of diagnosis of patients was the most in the 6-12 range (n=16; 41%) and the least in the adolescent (n=11; 28.2%) age range. The cause of death was related to a disease in 79.5%. Treatment-related deaths were seen in eight patients, four of which were chemotherapy toxicity, two were engraftment failure in autologous hematopoietic stem cell transplantation, and two were post-transplant GVHD. 76.9% of the patients died in the intensive care unit.

Conclusion: In our study, patients with cancer and those who lost their lives were evaluated retrospectively in terms of symptom load, invasive procedures, and psychosocial needs and the need for end-of-life palliative care. Many studies have confirmed that the timely integration of palliative care into routine oncological care has many advantages, such as improvements in physical and psychological symptoms, quality of life and prognosis, as well as reducing costs. In Turkey, palliative treatment is tried to be provided to late stage pediatric cancer patients by pediatric intensive care units and pediatric oncologists. This both increases the workload of physicians and causes intensive care bed occupation. The development and expansion of palliative care on late stage pediatric cancer patients will contribute significantly to the quality of life of both children and their families.

Keywords: Palliative care, children, cancer

INTRODUCTION

Cancer is the leading cause of death for children, especially in high-income countries (1). Despite important medical developments in recent years, approximately 20% of children diagnosed with cancer die (2). Children with cancer in low- and middle-income countries are four times more likely to die from the disease than children in high-income countries (1). It is estimated that 2500-3000 new pediatric cases will be seen in Turkey every year (3).

Palliative care is an approach that improves the quality of life of patients and their families facing a life-threatening disease-related problem through early detection, accurate assessment and treatment of pain and other problems (4). Palliative care is a multidisciplinary approach and is provided by a team that can handle the child's physical symptoms as well as the spiritual and psychosocial needs of children and their family (5). The World Health Organization evaluates cancer patients' access to pain relief and palliative care within global health inequalities and accepts palliative care as a human right (4).

There are limited number of studies on the palliative care needs of pediatric oncology patients in Turkey. In our study, patients with cancer and those who lost their lives were evaluated retrospectively in terms of symptom load, invasive procedures, and psychosocial needs, and the need for end-of-life palliative care. The necessity of end-of-life care, and palliative care units for pediatric cancer patients was discussed.

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MATERIAL AND METHOD

The study was carried out with the permission of Health Sciences University Non-interventional Clinical Researches Ethics Committee (Date: 08.01.2019, Decision No: 18/364). All procedures were carried out in accordance with the ethical rules and the principles of the Declaration of Helsinki.

Our study is a single-center retrospective cohort study. The records of 39 patients who were followed up in the pediatric oncology clinic between 2010-2021 and died were reviewed retrospectively. Patients' age, diagnosis, diagnosis category (leukemia/lymphoma, brain and other solid tumor), admission complaints, psychological support status, length of stay in hospital and intensive care unit, frequency and duration of intensive care hospitalization, invasive procedures, invasive supportive treatments, hematopoietic cell transplantation information, pain treatment and types, cardiopulmonary resuscitation, cause of death, and place of death were recorded. Ethics committee and patient and parents consent were obtained before the study was initiated. Inclusion criteria of the patients were determined as being in the pediatric age group, having received treatment in the oncology clinic, and being the patient who died.

Statistical Analysis

Statistical analyses were performed using SPSS version 15. Normality was checked by Shapiro Wilk and single-sample Kolmogorov Smirnov tests, histogram, and drawing QQ plot and box plot graphs. Data were given as mean, s.deviation, median, minimum, maximum, frequency, and percentage. Variables between two groups were analyzed with the Mann Whitney U test. Nominal variables were evaluated with Chi square test with Yates correction and Fisher's exact probability tests. The level of significance was taken as p<0.05 and bidirectional.

RESULTS

The mean age of the patients was 8.51±4.59 years (1-17), 26 (66.7) were male and 13 (33.3) were female. The most common type of malignancy was solid tumors (n=22, 56.4%), followed by brain tumors with 30.8% (n=12). Five patients (12.8%) had leukemia/lymphoma. The age of diagnosis of patients was the most in the 6-12 range (n=22; 56.4%) and the least in the adolescent (n=11; 28.2%) age range. Demographic data of the patients are shown in **Table 1**. The cause of death was related to a disease in 79.5%. Treatment-related deaths were seen in 8 patients, four of which were chemotherapy toxicity, 2 were engraftment failure in autologous hematopoietic stem cell transplantation, and 2 were post-transplant GVHD. 76.9% of the patients died in the intensive care unit. For the last three months, pain was the most common complaint

Table 1. Sociodemographic characteristics of the patients

	Mean±SD	Range
Age of diagnosis, years	8.51±4.59	1-17
Age of death, year	10.59±4.84	2-18
	n	**%**
Gender		
Male	26	66.7
Female	13	33.3
Age of Diagnosis (years)		
1-5	12	30.8
6-12	16	41
>13	11	28.2
Leukemia/lymphoma (n=5;12.8)		
Hodgkin's Lymphoma	1	2.56
Non-Hodgkin's lymphoma	2	5.13
Leukemia	2	5.13
Glioma (n=12;30.8)		
Anaplastic Astrocytoma	3	7.69
Diffuse Astrocytoma	1	2.56
Glioblastoma	3	7.69
Gliomatosis Cerebri	1	2.56
Medulloblastoma	4	10.25
Solid Tumor (n=22;56.4)		
Adrenocortical Carcinoma/ Rhabdomyosarcoma	1	2.56
Ewing Sarcoma	5	12.82
Hepatocellular Carcinoma	1	2.56
Neuroblastoma	11	28.21
Norofibroma/ Angiosarcoma	3	7.69
Retinoblastoma/ Osteosarcoma	1	2.56
Mix-Germ Cell Tumor	1	2.56
Cause of Death		
Treatment related	8	20.5
Disease related	31	79.5
Place of death		
Service	6	15.4
Intensive care	30	76.9
Home	3	7.7
Patient provided with spiritual care	0	0
Child patient receiving psychological support	22	56.41
Social Service Support	1	

Table 2. General complaints of patients with cancer diagnosis

Application complaint	n	%
Pain	19	48.7
Fatigue	13	33.3
Nausea-vomiting	3	7.7
Dyspnoea	1	2.6
Fever	1	2.6
Paroxysm	1	2.6
Blackout	1	2.6

(n=19; 48.7%). Pain was significantly higher especially in children with solid tumors (n=14; 63.6%) (**Table 2**). There was no statistical difference between the number of symptoms and age groups (p=0.13). It was observed that the number of symptoms was higher in children age groups. Fifteen patients (38.4%) underwent an invasive procedure in end-of-life care. The most common invasive procedure applied to the patients was chest tube and tracheostomy (n=4; 8.52%), while the invasive method was ventilator (n=28; 72.8). Ventilator support was provided to 28 patients (71.8%) and dialysis support was provided to 5 (12.8%). Late stage supportive treatments that the patients received are shown in **Table 3**. A total of 19 patients (48.7%) received pain treatment in their late stages. The most common treatment was Morphine by IV ROA (94.7%). Two of the patients with tracheostomy had brain tumors and two were Graft Versus Host Patient (GVHD) with lung involvement. Two of our patients who had a chest tube had neuroblastoma with a thoracic mass, one had Ewing's sarcoma originating from the ribs and causing compression in the lungs, and one had anaplastic ependymoma who was kept on the ventilator for a long time and developed pneumonia. Approximately one third of the patients (n=11, 28%) underwent HSCT (Hematopoietic Stem Cell Transplantation) at least once. Transplantation was performed after ten patients were in remission after chemotherapy, and one patient was transplanted while in partial remission. Of these patients, 5 had lymphoma/leukemia, 4 had neuroblastoma, and 2 had Ewing sarcoma. 71.8% (n:28) of the patients needed intensive care from the moment they were diagnosed. 95 percent of them were treated in the intensive care unit in the last month. The rate of those who were treated in the intensive care unit three times or more was approximately 15%. The mean duration of stay of the patients in the ICU was determined as 11.67± 3.2 days. Psychiatric support was provided to more than half of the patients (n=22; 56.4%). (**Table 4**) Their complaints before death were respiratory failure in 31 patients, bleeding in 7 patients, and 1 patient died due to liver failure. CPR was performed on every patient died in the hospital, but not on those who died at home.

Table 3. Patients' complaints and psychological support status according to their cancer types

	Application complaint		Psychological assistance	
	n	**%**	**n**	**%**
Leukemia/ lymphoma				
Pain	2	40	2	5.1
Fatigue	3	60		
Brain			7	17.9
Pain	3	25		
Fatigue	3	25		
Dyspnoea	1	8.3		
Nausea- vomiting	2	16.7		
Fever	1	8.3		
Paroxysm	1	8.3		
Blackout	1	8.3		
Solid tumor			15	38.5
Pain	14	63.6		
Fatigue	7	31.8		
Nausea-vomiting	1	4.5		

Table 4. Distribution of supportive treatments applied to patients

	Mean±SD	**Range**
The length of hospital stay, days	109±25	2-357
ICU length of stay, days	11.6±3.2	1-120
	n	**%**
Hospitalization for >3 weeks without clinical improvement		
Yes	22	62.86
No	13	37.14
Invasive procedures applied		
Liver biopsy	1	2.13
Paracentesis	2	4.26
Peritoneal catheter	1	2.13
Thoracentesis	3	6.38
Chest tube	4	8.51
Tracheotomy	4	8.51
Invasive support		
Ventilator	28	71.8
Dialysis	5	12.8
Stem cell transplantation		
Yes	11	28.2
No	28	71.8
Number of transplants		
0	28	71.8
1	8	20.5
2	2	5.1
3	1	2.6
Pain Treatment		
Yes	19	48.7
No	20	51.3
Which pain treatment?		
Morphine	7	36.84
Fentanyl, morphine	5	26.32
Fentanyl,morphine, tramadol	5	26.32
Morphine,tramadol, pethidine	1	5.26
Tramadol, fentanyl	1	5.26
Intensive care need		
Yes	28	71.8
No	11	28.2
Frequency of i ntensive care hospitalization		
1 hospitalization	18	64.29
2 hospitalizations	6	21.43
3 or more hospitalizations	4	14.29
CPR *		
Yes	36	92.3
No	3	7.7

*Three patients died at home. Two families were hesitant about CPR, yet later asked for it

DISCUSSION

Cancer is the leading cause of childhood death in Turkey and 30% of children diagnosed with cancer succumb to their disease. Child mortality from cancer ranks fourth in Turkey after infectious diseases, heart diseases, and accidents (4). Children in the terminal stage have to cope with symptoms such as pain, dyspnea, nausea-vomiting, which will necessitate palliative care in the last stages of their lives (5). Many studies have confirmed that the timely integration of palliative care into routine oncological care has many advantages, such as improvements in physical and psychological symptoms, quality of life and prognosis, as well as reducing costs. Since pediatric palliative clinics have not become widespread in Turkey yet, this service is provided by oncologists. Physicians working in oncology centers in Turkey stated that there is a lack of personnel, training, and physical space for pediatric palliative services, and that they do not feel qualified for this service (6). In order to contribute to the organization of the palliative care needs and scope of pediatric oncology patients, in this study, patients with palliative care needs were evaluated retrospectively.

Some of the late stage cancer patients need invasive procedures such as intensive care treatment, tracheostomy, and thoracic tube. In the study conducted by Corkum et al. (7) on advanced cancer patients , the rate of patients who underwent tracheostomy was found to be 30% (n=62), and the rate of patients who had a thoracic tube inserted was 14% (n=345). In our study, the rate of patients who underwent tracheostomy was 8.51% (n=4), and the rate of patients who had a thoracic tube inserted was 8.51% (n=4). Two of our patients with tracheostomy had brain tumors and two had GVHD with lung involvement. Two of our patients who had a chest tube had neuroblastoma with a thoracic mass, one had Ewing's sarcoma originating from the ribs and causing compression in the lungs, and one had anaplastic ependymoma who was kept on the ventilator for a long time and developed pneumonia. Invasive procedures may be required for masses or infections involving the thoracic region.

Stem cell transplantation, which is performed by applying high-dose chemotherapy and/or radiotherapy and can sometimes cause early and late side effects, is used as a treatment method in children with relapsed or advanced cancer and contributes to the decrease in mortality rates (5,8). One third of the patients had HSCT for at least once in the study. Of these patients, 5 had lymphoma/leukemia, 4 had neuroblastoma, and 2 had Ewing sarcoma. Palliative care, which requires patient-specific care, family support and multidisciplinary teamwork, has an important place in the management of symptoms, which emerge on patients with advanced cancer after performing HSCT, such as pain, dyspnea, nausea-vomiting. Especially in the parents of the patients who underwent HSCT and died, depression, anxiety and deterioration in quality of life were observed more than the parents of those who did not get HSCT treatment (8). Palliative care is extremely important for these families and patients.

Children with cancer included in our study and their families expressed pain as their most common symptom. Wolfe et al. (9) in their study, showed that pain in children with cancer at late stage increased heavily in the last 12-week period of their lives. It has been found that children who receive palliative care support in the last period of life manage pain better than those who do not (10). In our study, approximately half of the patients used morphine and similar opioids. Within the scope of the Pallia-Turk project, which was initiated in Turkey in 2010, it was aimed to increase the availability of opioids and to put the community-based palliative care model into practice (11). The use of opioid analgesics in Turkey has increased over the years, but has not reached the desired level (12). The amount of opioids per individual was 14.6 mg in Turkey in 2010. Considering that the average of the first twenty countries with the highest amount of opioid use is 216.7 mg, this is quite low (13). Access to opioid drugs in Turkey has become much more possible with the increase in adult palliative care. However, there are several barriers in opioid use. In a study conducted in Turkey, the obstacles for the pain treatment of pediatric patients were investigated, and these were determined as the pain was not evaluated regularly and permanently by physicians, the nurses did not fill the pain scales, and the absence of psychosocial support units in hospitals (14). Another study showed that mothers of children cancer patients who were treated at home avoided the use of analgesics because of insufficient education and concerns about side effects (15).

Three fourth of the patient group examined in this study received intensive care treatment. Studies have shown that one out of every three to four children with cancer receives intensive care treatment and the mortality of these patients is four to five times higher than the mortality of patients hospitalized in the pediatric intensive care unit (PICU) for non-cancer reasons (16,17). Pediatric intensive care units, which are limited in number in Turkey, are used by palliative patients (18). In the literature, it has been shown that pediatric oncology patients with early integration into pediatric palliative have lower intensive care unit admission and intervention rates, and have lower costs (19-22). We think that, with the spread of palliative care centers, pediatric intensive care units will be used less and invasive interventions will decrease in late stage patients.

In our study, most of the patients died in the hospital, mostly in the intensive care unit. It was determined that children who died in a hospital environment suffered more and their relatives experienced more depression, anxiety, stress, and a difficult mourning period than those of the children who died outside the hospital (23). It has been shown that the mortality rate of children receiving palliative care in the terminal stage in the intensive care unit and hospital decreases (10). The fact that the majority of patients in our study died in hospitals and intensive care units may be due to the lack of a palliative center in our hospital.

Life-threatening diseases confront individuals with the reality and imminence of death, and spirituality becomes more important to end-of-life patients. Spiritual care has been practiced in a modern setting for over a hundred years in Europe and the United States. The American Society of Clinical Oncology (ASCO) and the American Academy of Hospice and Palliative Medicine defined spiritual care for oncology patients as one of the criteria for quality palliative care (24). The European Association of Palliative Care (EAPC) also prepared guidelines on spiritual care in 2014 (25). However, spiritual care is a newly developing concept in Turkey (26). In our study, there was no record of whether the patients in the terminal stage received spiritual care or not.

In our study, only 12.5% of patient relatives did not want resuscitation (DNR). There are publications showing that pediatric patients who do not receive palliative care are almost eight times more likely to be resuscitated at the time of death than patients who do receive palliative care (10). There is no legal basis for limiting end-of-life support (EOL) in Turkey. There are not enough studies on end-of-life decisions and DNR among pediatricians in Turkey.

Studies have shown that the treatments applied on cancer patients, the side effects of the treatment, the fear of death, the uncertainty about life and treatment cause more emotional and behavioral problems in these children (27,20). Palliative care centers provide psychosocial support for both children and families. As in many hospitals in Turkey, psychosocial services are not a part of routine patient care in the hospital where we conducted the study. In cases in which the patient is thought to be in need, psychological support and social service support can be provided upon the request of the relevant physician. Psychiatric support was provided to more than half of the children in our study. Many studies have confirmed that the timely integration of palliative care into routine oncological care has many advantages, such as improvements in physical and psychological symptoms, quality of life and prognosis, as well as reducing costs.

CONCLUSION

In Turkey, palliative treatment is tried to be provided to late stage pediatric cancer patients by pediatric intensive care units and pediatric oncologists. This both increases the workload of physicians and causes intensive care bed occupation. In Turkey, the development and expansion of palliative care on late stage pediatric cancer patients will contribute significantly to the quality of life of both children and their families.

Our recommendation is to encourage the expansion of palliative care centers for children with cancer and the integration of these into healthcare services.

ETHICAL DECLARATIONS

Ethics Committee Approval: The study was carried out with the permission of Health Sciences University Non-interventional Clinical Researches Ethics Committee (Date: 08.01.2019, Decision No: 18/364).

Informed Consent: Because the study was designed retrospectively, no written informed consent form was obtained from patients.

Referee Evaluation Process: Externally peer-reviewed.

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