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Research Article / Araştırma Makalesi

Palliative Care Need in Pediatric Intensive Care Unit: Single Center Experience

Pediatrik Yoğun Bakım Ünitesinde Palyatif Bakım İhtiyacı: Tek Merkez Deneyimi

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Abstract: Pediatric palliative medicine is a multidisciplinary approach for finding solutions for end-of-life care of children with life-treathening conditions or conditions which inevitably shorten life. Due to inadequate definition of special palliative care needs and its scope, pediatric palliative care has not been broadly applied in our country or in the world. These patients are cared for in Pediatric Intensive Care Units (PICU) which already have limited bed counts. Patients who receive palliative care have tracheostomies, gastrostomies, central venous catheters, ventriculoperitoneal shunts and such medical procedures done whilst their stay at PICU and this prolongs their stay and probabilty of exposure to multi-drug resistant hospital infections. No research has been done on patients in PICU who are receiving palliative care on pathogens and antibiotic resistance. In this study, we discuss patients in need of palliative care in PICU and data on their duration of care, surgical operations, cultures, antibiotherapies and cost. Patients who stayed in PICU more than 70 days were scanned from medical records retrospectively. Sixteen patients who were included in the study stayed an avarage of 195.4 days in PICU. Three (21.42%) of the patients were inside the PICU all their lives. Seven (50 %) of the patients stayed in the PICU for >25% of their lives. Most of the patients had a diagnosis of neuromuscular disease or were cared for a sequela from a perinatal condition. Half of the patients had a congenital disease or an anomaly. One of the patients had a malignancy and an another one was being care after drowning. Ten (71.24%) patients had tracheostomies, 9 (64.28%) had central venous catethers, 8 (57.14%) had gastrostomies done. Only one patient had no positive cultures while all other patients had many positive cultures for resistant bacteria species and received 11 different types of antibiotics and antifungals. Average cost per patient was 233,552.5 TL. Continued care for these patients in regular PICUs result in increase in nosocomial infections, antibiotic resistance and treatment costs. Establishment of more pediatric palliative care units will alleviate these problems and allow for parents to spend more time with their children. We shared our single center experience of patients in need of palliative care in our PICU. Studies done with a bigger population from multiple centers will define de quality of pediatric palliative care in our country.
Keywords: palliative care, nosocomial infection, antibiotic resistance, cost

Özet: Pediatrik palyatif tıp, hayatı ciddi derecede tehdit eden ve kaçınılmaz şekilde kısaltan durumlara sahip çocukların takibi ve bu çocukların hayat sonu bakımı konusunda birçok soruna çözümler üretmeye çalışan multidisipliner bir yaklaşımdır. Ancak dünyada ve ülkemizde bu hastalara özel palyatif bakım ihtiyaçlarının ve kapsamının düzenlenmesinin yetersiz olması nedeniyle pediyatrik palyatif bakım uygulaması henüz yaygınlaşmamıştır. Bu hastalar ülkemizde pek çok merkezde zaten yetersiz yatak sayısına sahip Çocuk Yoğun Bakım ünitelerinde (ÇYBÜ) takip edilmektedir. Palyatif bakım alan çocuklar bu süreçte trakeostomi, gastrostomi, santral venöz kateter, ventrikülöperitoneal şant gibi tıbbi girişimler geçirmekte; hem hastanede kalış süreleri uzamakta hem de çeşitli antibiyotik dirençli hastane enfeksiyonlarına maruz kalmaktadırlar. Palyatif bakım alan hastaların ÇYBÜ' deki kültürlerinde saptanan patojenler ve antibiyotik direnci hakkında kapsamlı çalışmalar yapılmamıştır. Bu çalışmada ÇYBÜ' nde palyatif bakım gerektiren hastaların tanıları, yoğun bakım takip süreleri, uygulanan cerrahi işlemler, kültür üremeleri, antibiyoterapiler ve maliyet hakkında verilerin değerlendirilmesi ile palyatif bakım ünitesi gerekliliği tartışıldı. Çocuk Yoğun Bakım Ünitesinde 70 günden fazla yatan hastaların tıbbi kayıtları geriye dönük olarak değerlendirildi. Çalışmaya dahil edilen 16 hastanın ortalama yatış süresi 195.4 gündü. Hastaların 3'ü (%21,42) tüm yaşamları boyunca ÇYBÜ'de takip edilmişti. Hastaların 7'si (%50) yaşamlarının %25 veya daha fazlasını ÇYBÜ'de geçirmişti. Hastaların büyük bir kısmında nöromusküler hastalık tanısı mevcuttu veya perinatal dönemde ortaya çıkan durumların sekeli nedeniyle takip edilmekteydi. Hastaların yarısında konjenital bir hastalık veya anomali mevcuttu. Hastaların biri malignite, biri de suda boğulma nedeniyle takip edilmişti. Hastaların 10'una (%71,42) trakeostomi, 9'una (%64,28) santral venöz kateter, 8'ine (%57,14) gastrostomi açıldı. Hastaların sadece 1'inde hiçbir kültürde üreme saptanmamışken geri kalan hastaların takipleri boyunca pek çok kez farklı dönemlerde dirençli suşlar da içeren kültür üremeleri olması üzerine ortalama 11 çeşit antibiyotik ve antifungal tedavi kullanıldı ve ortalama maliyet hasta başına 233.552,5 TL olarak hesaplandı.. Bu hastaların bakım ve takibinin yoğun bakımda devam etmesi hastane enfeksiyonlarının, antibiyotik direncinin ve tedavi giderlerinin artmasına neden olmaktadır. Çocuk palyatif bakım servislerinin açılması ve yaygınlaşması hem bu olumsuzlukların azalmasına hem de çocuğun ebeveynleriyle daha fazla vakit geçirmesine olanak sağlayacaktır. Biz bu çalışmada pediatrik yoğun bakım ünitesinde takip edilen ve palyatif bakım gerektiren hastaların özelliklerini ve deneyimimizi paylaştık. Çok merkezli ve örneklemi daha büyük olan çalışmalarla ülkemizdeki pediatrik palyatif bakımın niteliği daha da iyi belirlenebilecektir.
Anahtar Kelimeler: palyatif bakım, hastane enfeksiyonu, antibiyotik direnci, maliyet

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1. Introduction

Pediatrive palliatic care has been recognized as a new medical specialty in the last two decades. American Academy of Pediatrics has published a report containing goals, guides and suggestions on pediatric palliative and hospice care in 2013 (1). Pediatric palliative medicine works to offer solutions for newborns, children and adolescents on life threatening or inevitable life shortening situations, and end-of-life care (2). Pediatric palliative medicine aims to alleviate physical, psychological, social, spiritual problems, while allowing the family to stay functional in the course of the loss of a family member, also to help the families and health personel make informed decisions and coordinate different specialties (3-6). There has not been proper organization of the minimal requirement of physician, nurse, social worker, religious personal and therapist as the palliative care team (7). It is expected for the children to outlive their parents in the modern world however, genetic, congenital, neuromuscular, respiratory diseases, comorbities of premature birth, cancer and trauma can change the life expectancy drastically. Medical technologies such as tracheostomies, gastrostomies, central venous catheterization, ventriculoperitoneal shunts are frequently used for patients receiving palliative care (8). Previous studies show that patients who received palliative care and died had less medical financial cost compared to those who survived (9). There have been no comprehensive study on blood, urine, respiratory secretion or cerebrospinal fluid cultures of patients in need of palliative care. Effect on antibiotic resistance in such situations should not be forgotten.

2. Method

Stuides on pediatric intensive care unit patients who need palliative care in our country are rare. There is little information on diagnoses, frequently used medical technologies, medical costs, and antibiotherapy of these patients. It is our aim to gain data on how to implement palliative medicine in our country by gathering information on diagnoses, in-patient durations, surgical procedures, cultures, antibiotherapies and cost of patients in need of palliative care in a single center pediatric intensive care unit.

Medical records of patients who stayed in the Eskişehir Osmangazi University Medical Faculty Pediatric Intensive Care Unit for more than 70 days from May 2016 until September 2018 was scanned. These patients were evaluated on diagnoses, in-patientdurations, surgical operations, cultures, antibiotherapies and medical costs. Our study was appoved by Eskişehir Osmangazi University Medical Faculty Clinical Studies Ethical Committee (13.11.2018/12)

3. Results

Eight (50%) of the 16 patients included in our study were males. Mean in-patient duration in pediatric intensive care units was 195.4 days. Five (31.2%) of the patients stayed inside intensive care units whole their lives. Thirteen (81.2%) of the patients were died. Eight (50%) of the patients were in intensive care units for more than 25% of their lives.

Ten (62.5%) of the patients had a neuromuscular disease. Five (31.2%) of the patients were being cared for a sequela from perinatal period. Eight (50%) of the patients had a congenital disease or anomaly. One (6.2%) of the patients were cared for malignancy and another one after drowning (Table 1).

Table 1. Types of Diagnoses

Type of Diagnosis	*n*	*%*
Neuromuscular	10	62.5
Congenital(Myopathy, hydrocephaly, Meningomyelocel)	8	50.0
Perinatal sequela (IVC, NEC, HIE)	5	31.2
Malignancy	1	6.2
Drowning	1	6.2

Ten (62.5%) patients had undergone tracheostomy operations while 10 (62.5%) had a central venous catether. Eight (50.0%) had gastrostomy operations and four of them had undergone Nissen fundoplication along side the gastrostomy operation. Four (25%) patients had ventriculoperitoneal shunts (Table 2).

Table 2. Frequency of surgical operations

Surgical operation	*n*	*%*
Tracheostomy	10	62.5
Central venous catether	10	62.5
Gastrostomy	8	50.0
Nissen fundoplication	4	25.0
Ventriculoperitoneal shunt	4	25.0
Other	5	31.2

Only one of the patients had no positive cultures. Three patients had positive cultures for carbapenemase producing bacteria and all but one patients had positive cultures for wide spectrum beta lactamase producing bacteria. Thirteen (81.2%) patients had positive cultures for Pseudomonas aeruginosa, 11 (68.7%) for Klebsiella pneumoniae, Eleven (68.7%) for Acinetobacter baumannii, 6 (37.5%) for Serratia marcescens and 5 (31.2%) for Stenotrophomonas maltophilia. Three (18.7%) patients had positive cultures for Candida spp (Table 3).

Table 3. Pathogens found in cultures

Pathogen	*n*	*%*
Staphylococcus epidermidis	13	81.2
Pseudomonas aeruginosa	13	81.2
Klebsiella pneumoniae	11	68.7
Acinetobacter baumannii	11	68.7
Staphylococcus haemolyticus	9	56.2
Escherichia coli	6	37.5
Serratia marcescens	6	37.5
Enterobacter cloacae	6	37.5
Stenotrophomonas maltophilia	5	31.2
Staphylococcus aureus	4	25.0
Enterococcus faecalis	4	25.0
Staphylococcus hominis	3	18.7
Klebsiella oxytoca	3	18.7
Achromobacter spp.	2	12.5
Corynebacterium spp.	2	12.5
Serratia plymuthica	2	12.5
Enterobacter faecium	2	12.5
Enterobacter aerogenes	2	12.5
Morganella morganii	1	6.2

Streptococcus sanguinis	1	6.2
Staphylococcus schleiferi	1	6.2
Enterococcus casseliflavus/gallinarum	1	6.2
Pseudomonas putida	1	6.2
Citrobacter koseri	1	6.2
Proteus vulgaris	1	6.2
Pantoea agglomerans	1	6.2
Burkholderia cepacia	1	6.2
Acinetobacter ursingii	1	6.2
Pseudomonas alcaligenes	1	6.2
Candida glabrata	1	6.2
Candida albicans	1	6.2
Candida parapsilosis	1	6.2

A maximum of 19 and a minimum of 3 types of antibiotics and/or antifungals were used in our patients. Eleven types of antimicrobials were used in average per patient. Meropenem and teicoplanin were used for 14 (87.5%), cefotaxime, vancomycin and colistin were used for 12 (75%), amikasin, caspofungin and fluconazole were used for 10 (62.5%) patients (Table 4).

Table 4. Antibiotherapy and antifungal use frequencies

Treat	n	%
Meropenem	14	87.5
Teicoplanin	14	87.5
Cefotaxime	12	75.0
Vancomycin	12	75.0
Colistin	12	75.0
Amikacin	10	62.5
Caspofungin	10	62.5
Fluconazole	10	62.5
Linezolid	9	56.2
Lyposomal Amphotericin B	9	56.2
Cefoperazone-sulbactam	8	50.0
Ertapenem	6	37.5
Piperacillin-Tazobactam	6	37.5
Clarithromycin	6	37.5
Cefepime	5	31.2
Levofloxacin	4	25.0
Metronidazole	3	18.7
Imipenem	3	18.7
Ceftriaxone	3	18.7
Voriconazole	2	12.5
Trimethoprim-Sulphametoxazol	2	12.5
Clindamycin	2	12.5
Ciprofloxacin	2	12.5
Ampicillin-Sulbactam	2	12.5
Azithromycin	1	6.2
Ceftazidime	1	6.2
Ticarcillin	1	6.2
Rifampicin	1	6.2

Sixteen patients who were included in the study stayed an avarage of 195.4 days in PICU. Three (21.42%) of the patients were inside the PICU all their lives. Seven (50%) of the patients stayed in the PICU for >25% of their lives. Average cost per patient was 233,552.5 TL (Table 5).

Table 5. NICU in-patient care durations and medical costs

Patient no	*PICU in-patient days*	*PICU medical cost* (TL)*
1	86	885.985
2	194	114.941
3	119	135.889
4	209	238.757
5	113	90.711
6	120	91.213
7	328	336.134
8	94	134.598
9	303	306.543
10	281	274.798
11	71	76.729
12	131	252.335
13	330	203.944
14	259	188.138
15	225	261.591
16	264	216.570
Mean	195.4	238.055

4. Discussion

Definitions of World Health Organization (10) about pediatric palliative care and the guideline of Royal College of Paediatrics and Child Health (RCPCH) (11) has started to form the basis of international pediatric palliative care. However, a healthcare system formed around this basis has not yet become widespread. Main reason for the inadequate implementation of this care both nationally and internationally is that palliative care needs and scope has not been organized. Patients who would benefit from palliative care are occupying valuable pediatric intensive care unit vacancies. Early identification and categorization of these patients and establishing palliative care units for these patients will alleviate the burden on pediatric intensive care units and allow for emergent and critical care patients to be accepted to the much needed intensive care unit. Continued PICU treatment of these patients results in increased nosocomial infections, antibiotic resistance and treatment costs while decreasing concentration and motivation of PICU personel. Widespread application of pediatric palliative care units would alleviate these problems and also help the children spend more time with their families. Our pediatric intensive care unit is the only PICU that serves our city and neighbouring cities as a tertiary healthcare facility. Many patients with neurometabolic diseases are cared for in our unit and as most of their life is spent in our PICU, our restricted number of beds are occupied with these patients. Discharge or transfer of these patients to other in-patient clinics is delayed due to nosocomial infections and antibiotic resistance. We shared our experience of patients who needs palliative care in a single center PICU. Pediatric palliative care in our country can be shaped with multi-center studies including a bigger population. A beter medical practice both from the patients view and public health view can be achieved with this process.

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