MedCrave
Step into the World of Research

Journal of Pediatrics & Neonatal Care

Case series

Open Access

CrossMark

Patients with palliative needs in a tertiary hospital emergency department in 2021 - retrospective chart review

Abstract

Introduction: Children with complex chronic diseases and life-limiting conditions require a differentiated and adapted medical approach. OBJECTIVES: Characterise the affluence and management of children, followed by an in-hospital pediatric palliative care support team, who presented to a tertiary hospital pediatric emergency department in 2021.

Methods: A one-year retrospective analysis of emergency episodes was performed by consulting medical records. Episodes were categorized, data were recorded anonymously, and descriptive statistical analysis was carried out.

Results: Of the 58 pediatric patients monitored by the team, 66% resorted to the emergency department in 2021, leading to 85 admissions (average: two per patient; 82% classified as urgent, very urgent, or immediate). The most frequent admission reasons were respiratory symptoms. Hospitalization was required in 45%: 3 patients transferred from another hospital in the pediatric intensive care unit, 32 to the pediatric ward, and the remaining in the observation service. Blood tests, cultures and imaging tests were performed in 45%, 48% and 46% respectively, and antibiotics instituted in 44%. Twenty-three children (61%) admitted to the emergency department had an orally discussed advanced care plan. No patients died in the emergency department or the intensive care unit. One died at home with support from the team and three in the ward.

Discussion: The reduced emergency department visits per patient and the frequent hospitalization needed when recurring reflects the effectiveness of a differentiated multidisciplinary team, domiciliary care and caregiver training. Establishing an advanced care plan and an emergency approach protocol is fundamental for individualized care delivery.

Keywords: advanced care planning, continuity of patient care, emergency department, palliative care, pediatrics

Volume 14 Issue 1 - 2024

Joana Magalhães Vasconcelos,[1] António Gama da Silva,[1] Diana Isabel Ferreira Pereira,[1] Inês Cristina Francisco Viegas,[2] Catarina Salgado,[1] Joana Malveiro Castelhanito Lourenço Coelho,[1] Emília Fradique,[1] Erica Torres,[1] Maria João Rodrigues Palaré[1]

[1]Department of Pediatrics, Centro Hospitalar Lisboa Norte (CHLN), Portugal

[2]Department of Pediatrics, Centro Hospitalar Universitário de Lisboa Central, Portugal

Correspondence: Joana Magalhães e Vasconcelos, Department of Pediatrics, Centro Hospitalar Lisboa Norte (CHLN), Av. Prof. Egas Moniz MB, 1649-028 Lisboa, Portugal, Tel 00351915319016, Email joanavasconcelos@gmail.com

Received: January 17, 2024 | **Published:** March 29, 2024

Abbreviations: ACP, advanced care plan; CCD, complex chronic diseases; INPPCST, in-hospital pediatric palliative care support team; PED, pediatric emergency department; PICU, pediatric intensive care unit; PPC, pediatric palliative care

Introduction

The World Health Organization defines palliative care as "the prevention and relief of suffering of adult and pediatric patients and their families facing the problems associated with a life-threatening illness."[1]

Children with complex chronic diseases (CCD) and life-limiting conditions accompanied by pediatric palliative care (PPC) teams may be divided into the following care categories: I - Potentially fatal but curable diseases; II - Diseases that cause premature death but may have prolonged survival if treated; III - Progressive diseases with no possible cure; IV - Non-progressive irreversible conditions that increase morbidity and the probability of premature death.[2] Recently, a fifth group has been proposed: V - Unborn children with major health problems who may not live through birth and infants who may survive for only a few days.[3] They may receive home care with the help of medical home visits enhancing their quality of life. Still, in case of chronic disease exacerbation or due to intercurrences, children may be forced to resort to the pediatric emergency department (PED).[4] The sudden and unforeseen nature of the acute illness in these children can make the emergency approach difficult, often leading to the need for hospitalization and, not rarely, to over-treatment. As such, accurate clinical information and an updated advanced care plan (ACP) to implement in the face of acute illness should be available and healthcare professionals should be prepared to deal with these circumstances.[5]

Advanced care planning has thus become one of the main concerns of the PPC team, resulting from a multidisciplinary discussion process, recording care goals and the pros and cons of diagnostic and therapeutic attitudes. Furthermore, a document that summarizes the due care and facilitates communication between the child's family and the medical team is written, enabling the patient approach, which can be changed and readjusted according to the disease course and the child's condition.[2,6]

This study aims to report the affluence and characteristics of PPC patients followed by tertiary care, pediatric university-affiliated in-hospital PPC support team (IHPPCST), who presented to this tertiary hospital PED in 2021 and to expose some details about these patients' PED episodes and approach.

Our hospital does not have a pediatric oncology department. Therefore, this IHPPCST rarely follows children with the oncological disease, and paediatric neurology is the subspecialty that most refers patients to the team.

Material and methods

This is a one-year retrospective medical record review from January 1 to December 31, 2021. The population was all patients aged 0 to 18, followed by an IHPPCST support team, who presented to a PED in 2021.

Initially, a list of all patients followed by the IHPPCST until March 2022 was provided and patients 0-18 years old were selected. The patient's medical records were then consulted to obtain information about their admission to the urgency/emergency room. Afterward, patient information and their PED visits characteristics were collected and recorded anonymously by the study's primary investigator and 20% of the PED visits were independently examined by a second researcher to ensure the validity of the data extraction and inter-rater reliability. Data were recorded into a standardized data collection tool and stored in a password-protected file assuring data confidentiality, only accessible to the research team.

The sample description was performed based on the following parameters: age, multidisciplinary follow-up, category of palliative needs,[2,3] date of referral to the palliative team and the existence of an ACP. The emergency episode was characterized by the PED admission schedule, the category assigned by the Manchester triage system, the reason for recurrence, the diagnostic tests performed, the approach achieved, the need for hospitalization, and mortality. It was considered missing if there was a lack of information in the medical chart about one variable being evaluated.

Data were entered into an Excel spreadsheet. Data analysis and presentation were performed using Excel® tools in the form of descriptive statistics, for patients' and PED visits characterization.

Ethical considerations: Patient consent was granted as this is a retrospective observational study with the consultation of patient data already in clinical files. All data sets are anonymous.

Results

There were 31 289 admissions to the hospital's PED in 2021 (daily average n=86 admissions). Fifty-eight patients aged 0–18 years old were followed by the IHPPCST during the year 2021. Of the previously mentioned, 38 patients (66%) resorted to the PED at least once during the study period, leading to 85 admissions to the PED and a median of 2 PED visits per patient (range 1-6). Table 1 presents the patients' characteristics. The time of recurrence to the PED was variable, with three peaks at ten AM, two PM and seven PM.

Table 1 Characterisation of the patients followed by the in-hospital paediatric palliative care support team (IHPPCST) who resorted to the pediatric emergency department during the study period (2021)

Patient number, N	**38**	**Age at the PED recurrence in years, mean and median**	Mean: 5,59
Male, n (%)	21(55%)		Median: 3,75
Paediatric emergency department recurrence (admissions), n	85	**PED visits per patient, median [range]**	2 [1-6]
Baseline diagnosis, n (%)		**Palliative care category (3),** n (%)	
Neurology	25 (66%)	Group I	10 (26%)
Cardiology	3 (8%)	Group II	6 (16%)
Pneumology	3 (8%)	Group III	7 (18%)
Genetic syndrome	2 (5%)	Group IV	15 (40%)
Metabolic disorder	2 (5%)	**Referral to the IHPPCST (Year),** n (%)	
Oncology	2 (5%)	2018	1 (3%)
Gastroenterology	1 (3%)	2019	6 (16%)
Mortality, n (%)	4 (11%)	2020	12 (32%)
In-hospital	3[a]	2021	18 (47%)
After discharge	1	2022	1 (3%)

[a] < 72hours after admission to the paediatric emergency department: 1; >72hours after admission to the paediatric emergency department: 2

Table 2 exposes relevant aspects of the 85 PED visits. Most admissions (82%, n=70) were classified as urgent, very urgent, or immediate. Frequent admission reasons were respiratory complaints (56%, n=48) like cough and dyspnea. Consequently, blood tests and imaging tests, mainly chest X-rays, were performed on more than 40%. Antibiotics were instituted in 44% (n=37) and respiratory support was provided in 42% (n=36), namely secretions aspiration in half of them. It is also worth noting that although the device (catheter, nasogastric tube, or percutaneous endoscopic gastrostomy) malfunction was mentioned in 12% (n=10), its replacement or cleaning was only needed in 6. Of the total recurrences to the PED, 55% (n=47) resulted in discharge. The remaining 45% (n=38) led to admission for transient surveillance in the PED observation service (n=23) or to a pediatric ward (n=32). Three of them were transferred from another hospital requiring hospitalization in the pediatric intensive care unit (PICU) and had no established diagnosis then. No patients died in the PED or the PICU. Three patients died in a hospital ward, one less than 72 hours and two more than 72 hours after admission to the PED. The fourth patient died after discharge at home with support from the IHPPCST.

Thirty patients (79%) were referred to the IHPPCST between 2020 and 2021. Calculating the distance from the referral to the palliative care team to the day of emergency recurrence, we found that referral before PED recurrence had a mean of 10 months and median of 8 months which means that the IHPPCST followed most patients who went to the emergency room for less than one year. Ten patients went to the PED and were referred to the palliative team afterward, following observation or during hospitalization in the ward. The first IHPPCST evaluation after the recurrence to the pediatric emergency department had a mean and median of one month.

Of the 38 patients who went to the PED, 61% (n=23) had an orally discussed ACP at the PED admission, and 32% (n= 12) already had a written one.

Citation: Vasconcelos JM, da Silva AG, Pereira DIF, et al. Patients with palliative needs in a tertiary hospital emergency department in 2021 - retrospective chart review. *J Pediatr Neonatal Care.* 2024;14(1):66–69. DOI: 10.15406/jpnc.2024.14.00543

Table 2 Pediatric emergency department (PED) visits characteristics

Admission number, n (%)	**85**		
Manchester Triage Category, n (%)		**PED work-up**, n (%)	
Immediate	2 (2%)	Cultures [e]	41 (48%)
Very Urgent	41 (48%)	Imaging Tests [f]	39 (46%)
Urgent	27 (32%)	Blood tests [g]	38 (45%)
Standard	6 (7%)	Respiratory virus detection	22 (26%)
Non-urgent	1 (1%)	Urinary sediment	10 (12%)
Elective	8 (9%)	**Approach/Medicines administered,** n (%)	
PED recurrence reason, n (%)		Antibiotic	37 (44%)
Respiratory symptoms [a]	48 (56%)	Respiratory support [h]	36 (42%)
Fever	29 (34%)	Other medicines [i]	26 (31%)
Gastrointestinal symptoms [b]	23 (27%)	Device [d] (re)placement /cleaning	6 (7%)
Neurological symptoms [c]	18 (21%)	Fluid therapy	4 (5%)
Device [d] problems	10 (12%)	**Multidisciplinary support,** n (%)	
Pain	5 (6%)	Paediatric surgery	12 (14%)
Asthenia or fatigue	3 (4%)	Neurology	7 (8%)
Cardiorespiratory arrest	1 (1%)	Cardiology	6 (7%)
Inpatient admission, n (%)	38 (45%)	Pneumology	3 (4%)
Paediatric ward, n	32	Palliative care team	2 (2%)
Observation service, n	23	Orthopaedics	2 (2%)
Paediatric intensive care unit, n	3	Paediatric intensive care unit	2 (2%)

[a]Cough, cyanosis, dyspnea, hypoxemia, respiratory secretions increase, respiratory distress signs, rhinorrhea, thoracic pain and other respiratory complaints; [b] Decreased intake/ eating disorder, vomiting, weight loss, other gastrointestinal complaints; [c] Altered state of consciousness, irritability, seizure, other neurological complaints; [d] Catheter, nasogastric tube and percutaneous endoscopic gastrostomy; [e]Blood, respiratory secretions and urine culture; [f] Computed tomography scan, echocardiogram, echography, electrocardiogram and radiography; [g] Blood count, biochemistry and blood gas test; [h] Aspiration of secretions, bronchodilation, nasal irrigation, non-invasive ventilation, and oxygen therapy; [i] Antiemetics, antiepileptics, antifungals anti-inflammatories, antipyretics, corticosteroids and opioids

Discussion

To our knowledge, there is only one similar article[5] exposing PPC PED consults. In this review, only one-third of the PPC team population resorted to the emergency department, a significantly smaller amount compared to 66% of our sample. On the other hand, the median of visits by each patient was the same as ours, which can be considered a reduced number, considering the population.[5,6]

Like in our study, most visits to the PED were classified as urgent or emergent, highlighting the complexity of these patients and the management carried out by the palliative care teams, which try to obviate more straightforward issues from the need to recur to these services. As a result, from multidisciplinary support and home care, caretakers are empowered to deal with less urgent complaints, capable and comfortable with caring for these patients at home /in institutions and aware of the signs and symptoms that should motivate going to a PED.

It became evident that respiratory exacerbations and increased secretions (or difficulty in managing them) have often taken these patients' caretakers to the hospital. Curiously, despite the frequent neurological baseline diagnosis, also reported in other case series by,[7,8] admissions were rarely due to seizures, which may point to an excellent therapeutic adjustment and the fact that caregivers know how to approach the episodes. As for the tests requested, most were simple tests, such as blood tests and chest radiography. Accordingly, the most frequent approaches were antibiotics, oxygen therapy, secretions aspiration and bronchodilation. Despite these patients' complexity and multidisciplinary management needs, specialized support was only requested in the minority; the most frequent being pediatric surgery and the palliative care team was only asked twice. However, almost half of the recurrences to the PED ended up admitting these children for surveillance in the emergency department or hospital ward, which can be considered significant and is similar to the results obtained in the series mentioned above.[5] From the three patients admitted to the PICU, two were electively transferred from other hospitals and were therefore not yet followed by the IHPPCST, and the third, who's primary diagnosis had been made less than a month ago, was only referred to the palliative care team after the PICU admission.

It is essential to highlight that although three patients died in-hospital, no patient died in the PED nor the pediatric intensive care unit, having been provided a private room in the pediatric ward for the family to live the moment with comfort and support. The mortality rate during hospitalization was higher in Gaucher's review,[5] with about 40% of patients dying and 19% passing in the first 72 hours post-admission. However, we must consider that the population in this study was different from ours, with most of the patients having an oncological diagnosis (40%). In contrast, our hospital does not have a pediatric oncology department being neurological diseases the most frequent diagnosis.

It is also worth noting that Gaucher et al.[5] reported more patients with an ACP (84%), of which 65% were available at the time of PED consultation, compared to the 32% in our study. They mentioned that on multivariable logistic regression, discussions about goals of care were associated with having a signed advanced care directive, which emphasizes the importance of developing ACP. An interesting finding was that acutely ill patients were already thought to be in the end phase of their lives and were more likely to have an advanced care plan. It was helpful in interprofessional communication and fulfilling

the goals designed for each child. There has been a growing concern by our IHPPCST to develop ACPs as families feel prepared, which was confirmed by the fact that 61% of patients had a discussed ACP. The discrepancy between the orally discussed and written plans arises from the time needed to speak to the family, caretakers, and clinical team members, to develop the best plan possible, considering everyone's opinion. Our IHPPCST is working on the written ACPs, which, when consented to, will be available in the patient's file for consultation. In addition, the palliative and emergency team has developed an emergency approach protocol to guide professionals in making decisions in the PED. These aspects, as well as good communication with parents and other specialized teams and adequate hospital infrastructure, will contribute to a better and more straightforward approach to these patients.

Due to the high complexity of these patients, it is essential to emphasize the need for the total availability of the IHPPCST at any time and day to help with decisions and guide these patients' approaches. An effort has been made to respond quickly to the referrals, as seen by the short time (one month) between the recurrence to the PED and the first IHPPCST evaluation afterward. In addition, future studies should evaluate the impact of having home care, ACP, and emergency protocols on PED recurrence so that institutions and health professionals have evidence of the steps to be followed to reduce the burden of the emergency department and ensure these patients' safety and comfort.

Conclusion

The reduced emergency department visits per patient and the frequent hospitalization needed when recurring reflects the effectiveness of a differentiated multidisciplinary team, domiciliary care, and caregiver training. Establishing an advanced care plan and an emergency approach protocol is fundamental for individualized care delivery. Future research should evaluate the impact of having home care, advanced care plans, and emergency protocols on paediatric emergency department recurrence so that institutions and health professionals have evidence of the steps to be followed to reduce the burden of the emergency department and ensure these patients' safety and comfort.

What is already known:

1. Children accompanied by pediatric palliative care teams' approach in the emergency department may be difficult and often leads to hospitalization.
2. The existence of an updated advanced care plan helps to approach an acute situation.
3. Pediatric palliative care teams should empower caretakers to deal with the most frequent complaints avoiding going to the emergency department for less urgent complaints and being aware of the signs and symptoms that should prompt urgent medical observation.

What is added:

1. Children with palliative needs went to the emergency department mainly for respiratory reasons – dyspnea and cough were the most frequent symptoms.
2. The number of emergency visits in 1 year was approximately two per patient, which reflects the effectiveness of a differentiated multidisciplinary team, domiciliary care and caregiver training.
3. Only 32% of children with palliative needs had a written advanced care plan, which is crucial to effective management and avoiding therapeutic futility.
4. Future research should evaluate the impact of having home care, advanced care plans, and emergency protocols on pediatric emergency department recurrence so that institutions and health professionals have evidence of the steps to be followed to reduce the burden of the emergency department and ensure these patients' safety and comfort.

Acknowledgments

None.

Funding

None.

Conflicts of interest

The authors declare that there are no conflicts of interest.

References

1. WHO. *Integrating palliative care and symptom relief into paediatrics*: a WHO guide for health care planners, implementers and managers. Geneva: World Health Organization. Licence: CC BY-NC-SA 3.0 IGO. 2018.
2. Grupo de Trabalho de *Cuidados Paliativos Pediátricos*. Relatório do Grupo de Trabalho do Gabinete do Secretário de Estado Adjunto do Ministro da Saúde (despachos 8286-A/2014 e 8956/2014). 2014.
3. Benini F, Papadatou D, Bernada M, et al. International standards for pediatric palliative care: from IMPaCCT to GO-PPaCS. *J Pain Symptom Manage*. 2022;63(5):e529–e543.
4. Linebarger JS, Johnson V, Boss RD, et al. Guidance for pediatric End-of-Life care. *Pediatrics*. 2022;149(5):e2022057011.
5. Gaucher N, Humbert N, Gauvin F. What do we know about pediatric palliative care patients consulting to the pediatric emergency department? *Pediatr Emerg Care*. 2021;37(7):e396–e400.
6. Walsh-Kelly CM, Lang KR, Chevako J, et al. Advance directives in a pediatric emergency department. *Pediatrics*. 1999;103(4):826–830.
7. Widger K, Davies D, Drouin DJ, et al. Pediatric patients receiving palliative care in Canada: results of a multicenter review. *Arch Pediatr Adolesc Med*. 2007;161(6):597–602.
8. Thrane SE, Maurer SH, Cohen SM, et al. Pediatric palliative care: a five-year retrospective chart review study. *J Palliat Med*. 2017;20(10):1104–1111.