



ORIGINAL ARTICLE

Retrospective study of children referred from paediatric intensive care to palliative care: Why and for what[☆]



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Death

Abstract

Introduction: The creation of paediatric palliative care units (PPCU) could optimise the management of children with palliative focus after admission to a paediatric intensive care unit (PICU). This study describes the clinical and epidemiological characteristics of children referred from PICU to the PPCU of the Autonomous Community of Madrid (CAM). The overall treatment, relapses, re-admissions, and deaths, if occurred, are described.

Patients and method: A retrospective review was performed using the medical records from children transferred from the CAM paediatric intensive care units to the paediatric palliative care unit (1 March 2008–31 January 2015).

Results: A total of 41 patients were included (26 male/15 female) with a median age of 33 months (range 1–228). In the follow by the PPCU follow-up, the main approaches were respiratory (invasive ventilation with tracheostomy tube 8/41), nutritional (gastrostomy in 20/41), and pharmacological (anti-epileptics in 29/41 and 34/41 on antibiotic treatment). Hospital re-admission was required by 11/41 patients, with no re-admissions to PICU. Of the 13/41 patients who died, 9/13 were at home, with all of them accompanied by the primary caregivers and family, and only 1/9 with the presence of the home team.

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PALABRAS CLAVE

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Atención domiciliaria;
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Gastrostomía;
Fallecimiento

Conclusions: The palliative approach at home is feasible in children, and the integration of PPCU could optimise the comprehensive care of previously critically ill children. It is necessary to achieve an optimal domiciliary care, and not just because of patient death. More observational, multicentre and prospective studies are needed to confirm these findings.

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Estudio retrospectivo de pacientes derivados de cuidados intensivos pediátricos a cuidados paliativos: por qué y para qué

Resumen

Introducción: La creación de Unidades de Cuidados Paliativos Pediátricos (UCPP) podría optimizar el manejo de niños que tras ingreso en la unidad de cuidados intensivos pediátricos (UCIP) requieren enfoque paliativo. Este trabajo describe las características clínico-epidemiológicas de pacientes derivados por este hecho a la UCPP de la Comunidad Autónoma de Madrid (CAM). Se detallan el tratamiento global requerido, las reagudizaciones, los ingresos hospitalarios y las condiciones del fallecimiento, si se produjo.

Pacientes y método: Estudio retrospectivo mediante revisión de historias clínicas de pacientes derivados desde las diferentes UCIP de la CAM a la UCPP (1 de marzo del 2008-31 de enero del 2015).

Resultados: Se incluye a 41 pacientes (26 varones/15 mujeres, mediana de edad de 33 meses, rango de 1-228). En seguimiento por la UCPP son los abordajes principales el respiratorio (ventilación invasiva con traqueostomía 8/41), nutricional (20/41 gastrostomía) y farmacológico (29/41 anticomiciales y 34/41 antibioterapia). El tiempo de seguimiento fue de 232 días (rango 1-1.164). Requieren ingreso hospitalario 11/41, sin reingresos en UCIP. Fallecen 13/41 pacientes de los cuales 9/13 lo hacen en domicilio, todos acompañados por los cuidadores principales y solo en 1/9 con presencia del equipo domiciliario.

Conclusiones: El enfoque paliativo domiciliario de niños con ingreso en intensivos y dependientes de tecnología es posible. Se requiere hospitalización domiciliaria que no deriva en todos los casos en el fallecimiento del paciente. La integración de UCPP podría así optimizar el cuidado integral de pacientes previamente críticos, siendo necesarios trabajos observacionales, prospectivos y multicéntricos para confirmar esto.

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Introduction

New therapeutic approaches and technological advances have succeeded in reducing mortality in paediatric intensive care units (PICUs). This decline in mortality does not entail a full recovery to the state prior to admission in every case.^{1,2} The associated morbidity and potential dependency of children on technologies that temporarily or permanently replace a vital function may shorten life expectancy by years without the expectation of death in the short-term. This fact may influence the approach to management in the PICU, increase the use of health care resources and sometimes hinder the discharge home of the patient.³⁻⁵

The goal of intensive care treatment needs to be adjusted in this group of patients. It should no longer be to *cure*, but to tailor treatment to the needs of the patient and uphold the patient's right to individualised care (*what does the patient need at this moment?*).^{6,7} Taking into account the emerging needs of the patient sometimes leads to the

initiation of a *palliative approach* that requires the collaboration of paediatric palliative care units (PPCUs).⁸ These units could adapt the management of these children, facilitating discharge from hospital and their followup at home until they improve or die.⁹⁻¹¹ Furthermore, this approach optimises and reduces the use of health care and financial resources.

Thus, paediatric palliative care involves the active and comprehensive care of the body, mind and spirit of the child, and includes services to the family. It aims to improve the quality of care and of life in paediatric patients with terminal or fatal illness and their families through a holistic approach, upholding their right to dignity and autonomy with the delivery of continuous and individualised care.

This article describes the epidemiological and clinical characteristics of patients referred after a stay in one of the PICUs of the Autonomous Community of Madrid to the regional PPCU based in the Hospital Infantil Universitario Niño Jesús. The primary objective of the study was to

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