Sedation at the end of life in patients treated by Paediatric Palliative Care Teams. Multicentre observational study

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Trowbridge A, Walter JK, McConathey E, et al. Modes of Death Within a Children's Hospital. Pediatrics. 2018;142(4):e20174182. Cohen J,Deliens L (2012) Apublic health perspective on end of life care. Oxford university press, Oxford.

### **Palliative sedation**

Resort measurements which are used at the end of life to relieve refractory distress.



Administration of sedative medications



Induce a state of decreased or absent awareness



The goal is the relief of suffering to terminally ill patients



N.I. Cherny, on behalf of the ESMO Guidelines Working Group. ESMO Clinical Practice Guidelines for the management of refractory symptoms at the end of life and the use of palliative sedation. Ann Oncol [Internet]. 25 (2014).

Sedation is used in paediatrics palliative care in several settings:

- ) Transient sedation for noxious procedures
- () Sedation used in end of life weaning from ventilator support
- **3)** Sedation in the management of refractory symptoms at the end

of life

- **4)**. Emergency sedation
  - ) Respite sedation
  - ) · Sedation for psychological or existential suffering



European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliative Medicine. 2009; 23(7), 581–593.





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## Patients and Methods







Multicentre, ambispective, descriptive and analytical study

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Multicentre, ambispective, descriptive and analytical study January 1 → December 31





Every patient who was managed by de paediatric palliative care team and died under their care

Review of health records







Hospital (Year of creation)	Number of patients treated by Paediatric Palliative Care team 2019 N	Number of deceased patients treated by the Paediatric Palliative Care team in 2019 N	Mortality rate 2019 (%)	Number of patients included in the study N(%)
Hospital San Juan de Dios de Barcelona (1992)	321	59	18,3%	42 (25,6%)
Hospital Universitario Infantil Niño Jesús de Madrid (2008)	127	40	31,4%	40 (24,4%)
Hospital Regional Universitario de Málaga (1999)	59	17	28,8%	17 (10,4%)
Hospital Universitario Virgen del Rocío de Sevilla (2016)	63	16	25,3%	16 (9,8%)
Hospital Universitario Son Espases de Mallorca (2013)	79	9	11,3%	9 (5,5%)
Hospital Universitario Virgen de las Nieves de Granada (2018)	50	8	16%	8 (4,9%)
Hospital Universitario de Cruces de Bilbao (2012)	52	6	11,5%	6 (3,7%)
Hospital Universitario Miguel Servet de Zaragoza (2017)	87	6	6,8%	6 (3,7%)
Hospital Clínico Universitario Virgen de la Arrixaca de Murcia (2009)	35	5	14,2%	5 (3,0%)
Hospital Universitario Torrecárdenas de Almería (2014)	34	5	14,7%	5 (3,0%)
Hospital Universitario Parc Taulí de Sabadell (2016)	50	3	6%	3 (1,8%)
Complejo Virgen de la Salud de Toledo (2015)	58	7	12%	3 (1,8%)
Hospital General Universitario de Alicante (2008)	96	3	3,1%	3 (1,8%)
Hospital Universitario Nuestra Señora de Candelaria de Tenerife (2018)	35	1	2,8%	1 (0,6%)
	1164 —	→ 185 1	3.1% (IQR 6.3)	164





The main diagnoses in patients receiving PPC are **neurological diseases and genetic or congenital disorders** (cancer being the underlying disease in only 20% of the treated children)

Oncological	79 (48,2%)
Neurological or neuromuscular	39 (23,8%)
Metabolic	15 (9,1%)
Prematurity and neonatal	14 (8,5%)
Congenital or genetic defects	12 (7,3%)
Others	5 (3,1%)



Nolte-Buchholtz S, Zernikow B, Wager J. Pediatric patientsreceiving specialized palliative home care according toGerman law: A prospective multicenter cohort study. Chil-dren [Internet]. 2018;5 [citado 4 Ene 2021]. Disponible en:https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6028915/.













### Place of death 100 [VALOR] 90 (57.9%) 80 70 6

60 50

40 30

20

10 0

Hospital



Home

	Achieve preferences	No achieve preferences
Talk preferences	119 (95.2%)	6 (4.8%)



#### Talk about preferences



# Data analysis





## Results: analysis



Paediatric palliative teams with more than 5 years of experience sedate less



Z = 5.6; p 0.018

Children who die in the hospital are often more sedated than those who



# Results: analysis



Verbalizing preferences regarding the place of death decreases the probability of sedation



Z = 4.4; p 0.036



Families where it had not been verbalized it is sedation in end of life was more frequent

		Agony situation	Refractary symtomps
Verbalizing preferences	No	16 (72.7%)	6 (27.3%)
tal	Yes	24 (42.2%)	28 (53.8%)



We established incidence, indication, refractory symptoms and drugs related to

sedation at the end of life.

Sedation is less likely to take place in the home, which may indicate less

invasiveness at the end of life in this setting.

Our study innovates by considering the age of every PPCT and anticipating the

place of death with the patient's families with the need for sedation.

The results clearly highlight the need to count on highly trained professionals to



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