



EDITORIAL

Development of palliative care, unstoppable in pediatrics[☆]



Desarrollo de la atención paliativa, imparable en pediatría

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Since the creation of the first paediatric palliative care units in Spain, there have been significant advances. Still, we have a long way to go before palliative care is universal, standardised and truly centred on the child* and the family.

Paediatric palliative care (PPC) refers to the care provided to children with life-threatening or life-limiting conditions, chiefly congenital diseases, diseases secondary to severe neurologic damage or advanced cancer, among others. Palliative care has evolved to a more comprehensive approach and earlier delivery, with provision of care not only in the most advanced stages of disease or at the end of life, but also during stages of disease when the quality of life of the child or the family may be impaired in any of its dimensions—physical, psychological, social or spiritual. If the child dies, the family and immediate circle continues to receive support in the bereavement process.

Organizations like the European Association for Palliative Care or the American Academy of Pediatrics have stated that PPC should be available in any setting, including the home, the hospital and the school. On the other hand, families have described a lack of continuity in care delivery, demanding improved organization and support in the coordination of

hospital- and community-based services. This makes it clear that PPC is not fully integrated as one of the basic services offered by the Spanish public health system.

The advent of the COVID-19 pandemic forced the rushed development of a broader range of telemedicine services, and while their indications are still being calibrated, the evidence suggests that telemedicine may be a key tool for the delivery of specialised care in patients with very complex disease with a low prevalence and geographically dispersed. It is also emerging as a potential backbone in the coordination and integration of care across care levels and settings.

One of the objectives pursued by institutions and professionals is a more accurate assessment of the magnitude of the problem. How many children have life-threatening or life-limiting diseases, and how many of them need specialised palliative care? The number of children that require palliative care in Spain is not known exactly, but it is probably somewhere between the 120 per 10 000 children identified in Zimbabwe and the 20 per 10 000 children reported by some case series in the United Kingdom.¹ In the framework of its National Strategy for Paediatric Palliative Care, the Ministry of Health of Spain, with the collaboration of the Sociedad Española de Cuidados Paliativos Pediátricos (Spanish Society of Paediatric Palliative Care, PEDPAL) and regional departments of health, has made estimations and determined that approximately 25 000 children and their families have palliative care needs in Spain. Studies like the one published by Peláez et al.² in this issue contribute valu-

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able information on the profile of these patients and the characteristics related to the end-of-life process. One of the variables analysed in the study was the place of death of children managed by PPC teams and units. At this time, there is already evidence that most children and their families would rather have the death take place at home.³⁻⁵

The study by Peláez et al. found that more than 40% of children in palliative care had died at home. Dying at home is not just a matter of choice, it requires specific skills and the necessary conditions and resources⁶ to provide specialised care around the clock, and we know that in Spain, fewer than 5 PPC teams can provide this type of care.

There is evidence that the probability of dying at home is higher if the patient has the support of a PPC team.⁴ At present, the place of death for paediatric patients is a well-established quality indicator⁶ in countries with a longer palliative care tradition, and this is an aspect in which it is important to consider the wishes of the child and the family. Wherever the child dies, the child passing in the desired setting, and, perhaps more importantly, having had discussions regarding the desired place of death, may also be indicators worth considering.

Current recommendations establish that, whenever possible, the family home should be the setting where care is provided to the child in the advanced stages of disease, which requires that we make the greatest effort yet in networking for integrated care delivery.

Although dying in the hospital may displace the patient and carries a risk of unnecessary medicalization of end-of-life care, death in a medical setting may still be necessary and in many cases the most appropriate option. In this regard, beyond the possibility of death at home, there is a growing trend toward the adaptation of hospital spaces to make them more suitable, as is the case of the Integrated Paediatric Palliative Care Unit of the Region of Madrid. In addition, centres are being created for the specific purpose of managing chronic complex diseases and providing end-of-life care, such as the Paediatric Intermediate Care Centre of Catalonia, named *La Casa de Sofía*.

Another important challenge is the standardization and uniform application of concepts related to PPC. One key example is the concept of "paediatric palliative sedation", as Noriega et al.⁷ discuss in the article published in this issue of the journal, a subject that has been widely studied in adults but on which there is little consensus in paediatrics.

To take away awareness from an individual is to take away what is most intimately personal, and in paediatrics practice this is most frequently done (due to young age or cognitive impairment) without explicit consent from the child, an intervention that should only be entrusted to teams that are both competent and compassionate. In paediatrics, the challenge resides in upholding appropriate indications for sedation, prescribing it based on the needs of the patient, which must be prioritised over any wishes or suffering of either families or health care professionals.

*Child: we use this term to refer to newborns, infants, children and adolescents of any sex.

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