



EDITORIAL

## The challenge of complex chronicity and palliative care in paediatrics<sup>☆</sup>



### El desafío de la cronicidad compleja y la atención paliativa en pediatría

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At present, we are facing one of the most far-reaching opportunities in paediatrics to improve the care of individuals: newborns, infants, children, adolescents<sup>1</sup> and their families, and even us, health care professionals. The objective of palliative care is to optimise quality of life in individuals suffering a severe and incurable condition that is life-threatening or life-limiting, focusing on the patient and the family through a holistic approach to care in its different dimensions: physical, psychosocial and spiritual.<sup>1</sup> Such care should also be provided in cases where death is likely to occur prior to birth or where it is known that the child has only hours or minutes to live at the time of diagnosis.

Fortunately, in recent decades there has been a decrease in mortality in Spain, although this has been accompanied by an increase in morbidity. The latter often involves a chronic comorbidity, which in some cases we refer to as 'complex' as if to justify the lack of response to actual patient needs, the fragmentation of care and the increased costs of care due to the inefficiency of a system that is too 'hospital-centred'. In fact, the complexity concept represents those cases where the 'whole' is different and more than the sum of its parts and depends on individual variables and the care ability and training of the health team that evaluates them.<sup>2</sup> The palliative care model that used to be reserved for end-of-life care is at the heart of our response to this 'highly complex chronicity' and aims to provide an additional layer of support.

There have been several key moments in the "recent" history of paediatric palliative care in Spain. Starting in 1991 and over the two decades that followed, some units were created that in some cases became fully established and set a reference at the national and international level. Still, there has always been a blatant inequality between geographical areas, some of which often depend on the solidarity of non-profit organisations, since palliative care continues to be perceived as a social and health care luxury as opposed to a fundamental right, which is what it is recognised as at the international level. In Spain, there was a turning point in 2014 with the publication of the National Strategy for Paediatric Palliative Care of the National Health System.<sup>3</sup> Since then, different institutions have launched new initiatives. Soon after, in 2016, the Sociedad Española de Cuidados Paliativos Pediátricos (Spanish Society of Paediatric Palliative Care [PEDPAL]) was created within the broader framework of Asociación Española de Pediatría (Spanish Association of Pediatrics), aiming to provide a multidisciplinary platform from which to promote the development, education, social awareness and ultimately advocacy for the right to palliative care in paediatrics.

The exponential pace of this growth carries the risk of laying a shaky foundation for the future. Before building on, essential concepts need to be formalised: transversal competency, teamwork and networking, the development of appropriate spaces and the transfer of care to the home.

The effective approach to the management of the most complex cases requires all intensive care, neonatology, inpatient care and primary care professionals, among others, to be prepared to address, directly or indirectly, any emerging problems and needs through the implementation

<sup>☆</sup> Please cite this article as: Navarro Vilarrubí S. El desafío de la cronicidad compleja y la atención paliativa en pediatría. An Pediatr (Barc). 2018;88:1-2.

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of protocols and guidelines in every subspecialty. There is increasing evidence that the model of shared decision making in pursuit of the best interest of the child and involving the child and/or family improves their perceived control and satisfaction.<sup>4</sup>

The evidence shows that there is only one way to serve this population, and it is through multidisciplinary teamwork and a well-established network to coordinate not only different levels of care, but also social resources and schools, among others, developing individualised plans in agreement with families and shared by all providers from different fields who are involved in the care of the patient. In this regard, the (no longer 'new') information and communication technologies have been and will continue to be an essential tool to provide a coordinated response from different fields. This could potentially reduce the incidence of hospitalization as well as health care costs.<sup>5</sup>

We ought to ask if our settings (the clinic, the delivery room, the emergency room, the inpatient wards...) are ready for the care of these patients or need to be appropriately fitted, regardless of the relatively low frequency of these cases, perhaps even creating new spaces, such as day centres, social and health care clinics and hospices tailored to this population.

We could also make a similar evaluation of the training of health professionals, and conclude that it does not suffice to match current needs, as is the case with the currently available specialised support. Fortunately, education on the management of medical complexity and palliative care needs is becoming more common in universities, and it should be a mandatory part of the curriculum of the paediatrics specialty in medical and nursing courses. In most instances, a general basic knowledge is sufficient to apply a palliative approach, reserving specialised training for professionals dedicated exclusively to more complex cases.

We have learned and continue to learn from our experience and the evidence available on this type of approach in the adult population, and need further evidence in the field of paediatrics, as this population is in and of itself more complex, so that organisation of paediatric palliative care must involve the development of a specific network focused on this particular group. An increasing number of children with severe and incurable diseases are now reaching adulthood, so that professionals that work in paediatrics as well as professionals that manage these patients once they become adults must be prepared to carry out a seamless transition to adult care.

We must not forget that palliative care inherently involves the continuation of care, even if the patient eventually dies, as well as self-care and mutual care among providers, so that we are able to continue caring for others.

We also need to develop networks for the follow-up and bereavement care of families that have lost a child, and set up self-care programmes.

Research and innovation need to be promoted in order to establish objectives that address the needs of these children and their families in Spain, and above all to set standards regarding the indication for palliative care and the quality indicators that should be used to assess its impact.

The two articles<sup>6,7</sup> published in this issue of the journal demonstrate the strategies that are already being developed to support complex chronic patients and in palliative care in reference units that are well established, and express the conviction that this model of care will experience significant growth in upcoming years. As we can see, its development should be based on teamwork, comprehensive care, continuity of care, networking and the resurgence of home-based care, with the main objective of improving the quality of life of patients and their families. This can only be accomplished through the training of all professionals engaged in the care of this population and the creation of specialised units to serve the needs of large geographical areas.

We now have experience in this field, and with an ever-growing body of evidence, the time has come to implement this approach in each autonomous community of Spain to meet the objectives set in 2014 and fulfil the current and growing need for palliative care.

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