

Expected Death in Pediatrics. The End of Life

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In general, in our culture and society little is said about death. What we hope and usually project is that the end of life will come in an advanced age, in old age, peacefully, having achieved the illusions we have, without pending “things”, in a sweet and serene way.

We, normally imagine a life projection that goes through birth, development, growth, with the possibility of loving, of being loved, of becoming adults, of maturing and aging until death comes.

But death in pediatric age is a reality. Children are dying, too. There are children living with a life-limiting disease, which we know will die before reaching adulthood, some in very early childhood, and some even before they are born, in prenatal times. Advances in medicine and technology have made survival longer in some cases, and they are children living with a chronic, complex and life-limiting disease that is highly fragile.

The study of the specialty of paediatrics is focused on a very vital phase of life, the phase of the birth, growth and development of the individual, and surely this makes it even more difficult to talk about death.

Paediatric palliative care is one of the fundamental pillars for accompanying the disease and the end of life in these children, seeking to offer the best possible quality of life and also a good death for the child and their family.

The definition of paediatric palliative care constructed by PEDPAL (Spanish Society of Paediatric Palliative Care) based on the WHO definition is as follows: “It is a form of specialized care offered by multiple professionals for those children and their families facing serious and chronic illnesses that are seriously life-threatening. It consists of the active and total assistance of the body, mind and spirit of the child. It focuses on the prevention and relief of symptoms, pain, stress, as well as on supporting the psychological, spiritual and social aspects of the patient and their family. Paediatric palliative care guarantees respect for their dignity and the right to their autonomy, through continuous and individualised care”.

Paediatric palliative care is a right recognised by the WHO.

In Spain in 2014, one of the key documents in its development appeared, the framework document for care criteria.

In Catalonia, the beginning and trajectory of paediatric palliative care is relatively recent, although there are teams that have existed for more years.

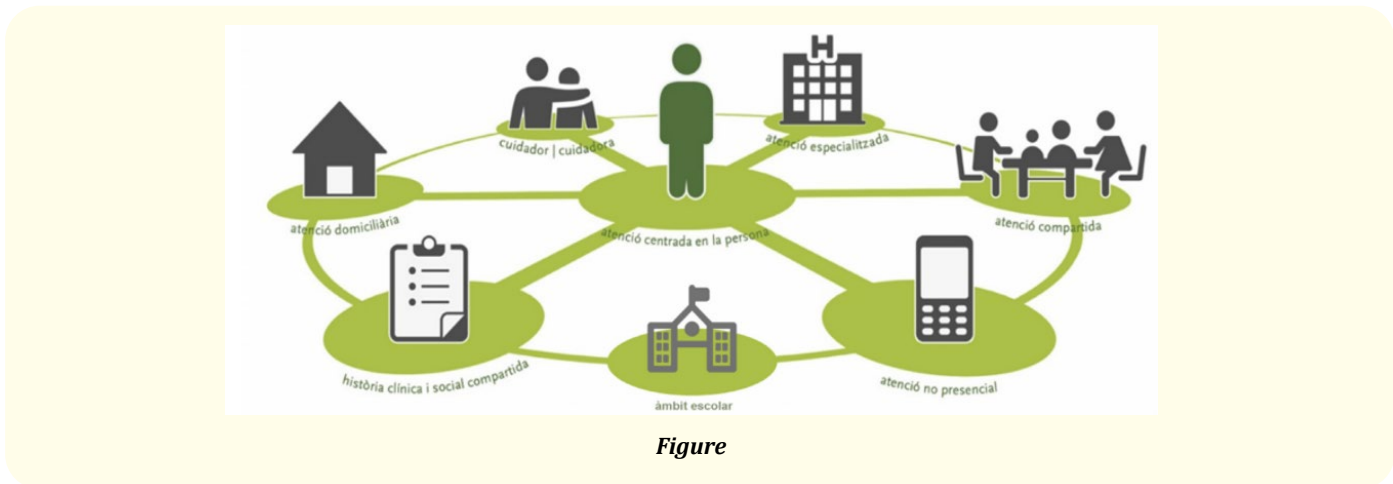
The Health Plan 2016-2020 includes the development of paediatric palliative care in Catalonia.

The PEDPAL (Society of Paediatric Palliative Care) was created in 2016.

At the same time, the Working Group of the Catalan Society of Paediatrics for Palliative Care and Chronicity (2015) was formed. This group promotes, promotes and works on the care model, and on how to work in a network in the territory, and evolves in the form of the Spanish Comprehensive Paediatric Palliative Care Network (XAPPI), a document that appears at the end of 2020.

In October 2021, the First XAPPI Conference was held and disseminations was made about this network. It presented the developed equipment and those are under development, too.

The paediatric palliative care model proposed in XAPPI tries to focus on the person, in this case the child and their family and the professionals who care for them. It seeks to provide comprehensive care, collecting needs in a multidimensional way (physical, psychological, social and spiritual). It must be teamwork and multidisciplinary, which coordinates care between the different levels of care. We try to promote home care, which is where the child usually prefers to be, trying to dehospitalize him as much as possible. We also work in the child's environment, not only with the family but also with the school or centers of early stimulation. It tries to draw up a comprehensive individualized and shared care plan (PIIC) that serves as a guide for all professionals who can care for it and that is updated according to the evolution and changes that occur.



Figure

The target population of this care model are children with complex chronic disease and advanced disease (PCCP, MACAP), definitions that are currently being worked on by XAPPI and the Palliative Care and Chronicity Working Group of the SCP, with the intention of improving the identification and registration of tax children to receive it. while homogenizing this attention in the Catalan territory.

In the same sense, work is being done to adapt some scales (NECPAL, HEXCOM-RED) to identify, define and classify complexity in pediatrics, in an attempt to plan the best care strategy in each case according to the resources and resolution capacity of each level of care.

When death is expected, it is important to know and be aware of this reality, identify the end-of-life situation, so that we know how to recognize it, to anticipate and accompany it in the best way.

Death is part of life, and it is a natural process, which as health professionals we must know how to accompany, trying to guarantee the maximum possible comfort, not medicalizing more than necessary.

In the process of dying there is a decrease in the level of consciousness, with a tendency to fall asleep or comatose state, cognitive worsening, changes in skin coloration, temperature, rejection of food and fluid intake, alteration in behavior (agitation, anxiety may appear), rejection of social contact, decreased speech, decreased diuresis or anuria, Change in pattern of constants, pauses of apneapuntos, sneezes, bradycardia and signs of multi-organ dysfunction may appear.

Without forgetting the pain it represents, it is necessary to shed more light on the process of dying, with more knowledge of what is happening, trying to have good symptomatic control, and focusing on their comfort, of the child and the family, respecting their wishes.

As paediatric palliative care teams, it is important to identify this process, which is not always easy, but also during the disease it is important to detect turning points, the irreversibility situation, and develop multidisciplinary care plans (in this sense, work is being done on the PIIC 3.0 tool, which will include a more specific paediatric part). It is necessary to have sufficient conversations with all the professionals and the family about decision-making and the most appropriate diagnostic and therapeutic measures in each case. Also, it is important to think about what is the best for the child, about what he needs, individually, trying to allow natural death and not medicalize it when it is not necessary, focusing on symptomatic control and comfort. They are children for whom there is no curative treatment but we can always alleviate. Palliative sedation arises in the face of refractory symptoms and in the phase of agony.

Decision making is a process of collaboration between professionals with an agreement with the child-family. It is important that we collect the wishes and values of the child and family, taking into account the bioethical principles (beneficence, non-maleficence, justice, autonomy), so the relationship of trust with child and family is essential.

Throughout this process it is important to respect the times, accompany the process, use presence, take care of communication, anticipate events, attend to the family, provide coordinated attention, allow farewell, care for grief, which often begins before the death of the child and is also part of palliative care.

In the end, what we do is try to humanize and personalize the process as much as possible, which is why home care is essential, which allows us to have a more accurate vision of how the child and the family are and what they need.

Our mission in this accompaniment is well expressed in the phrase of Maya Angelou: "People will forget what you said, what you did, but they will never forget how you made them feel" [1-10].

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