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REVIEW

Summary of article - Moving on from a "good death": Child- and family-centred end-of-life care in paediatric critical care

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Integrative palliative medicine and end-of-life care studies have been advancing and gaining increasing importance in recent years. The definition of a "good death" has long been limited to the absence of pain or suffering during the process. This article[1] critically and succinctly addresses end-of-life care practiced in pediatric intensive care units (PICUs) and the definition of a "good death" from the perspective not only of healthcare professionals and researchers, but primarily of the patient and their family.

Death is an individual experience, both for the patient and their family, and varies according to each individual's personal, social, and educational background, as well as their own religious and cultural beliefs. In this regard, the article recognizes the importance of the ICU environment as a crucial factor in the appropriateness of the dying process, which includes mutual trust between the family and the healthcare team, satisfactory communication and accessible information, meeting the individual needs of the child and family, and the compassion of healthcare professionals in the face of the situation.

The article clarifies the limitations of this topic: physicians and researchers generally advocate a good death when it occurs after the failure of a proposed therapy, for example, to bring comfort to the healthcare team. In other words, the narrative of a dignified death often serves the needs of physicians more than those of the family itself, which often cannot view a child's death as a good thing. Faced with such a complex process, the healthcare team must embrace a patient- and family-centered

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approach before, during, and after death, providing not only medical and pharmacological care, but also emotional and social care, encompassing the cultural and spiritual context to ensure the most dignified death experience possible for all involved. Furthermore, family members are not limited to the father and mother, but also siblings, grandparents, and those considered "extended family," and healthcare professionals must understand the need to accommodate, for example, everyone's presence in this process (Figure 1). The dying process is complex and, unfortunately, frequent in intensive care settings, and the experience of a child's successful death is a challenge still far from being mastered. The authors emphasize the need for the healthcare team and the family to work together in this painful process, which also includes the physician's grief over their inability to heal. The presence of adequate physical space in the PICU to promote reflective practices and support for family members is essential in this shift in perspective, and organizational and institutional support for the PICU multidisciplinary team and the family is crucial.

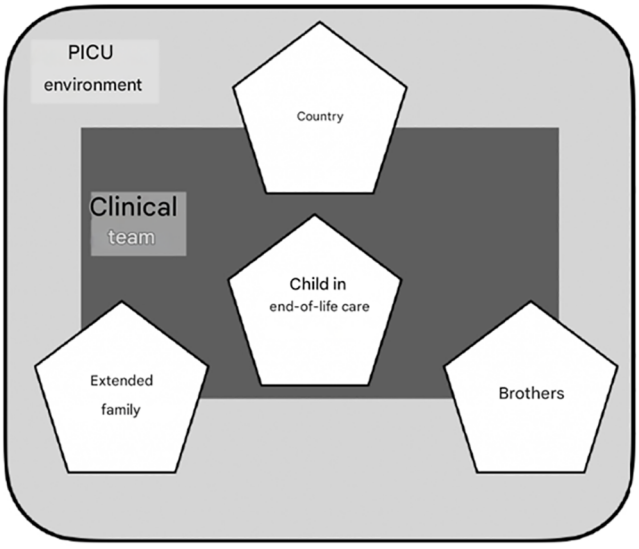


Figure 1. Child- and family-centered end-of-life care in the PICU (Figure adapted from the original article). *PICU - Pediatric Intensive Care Unit.

In conclusion, the authors emphasize that many challenges remain in this field, requiring further research to enhance patient and family understanding of this scenario, both individually and collectively, including specific characteristics such as culture and religion. All of this is important in our attempt to move closer to the ideal of granting a dignified death for all involved, remembering that in the case of a child's death, it is always difficult to consider it "good," but perhaps less painful.

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