

Is it possible to provide palliative care to pediatric patients with neurological diseases?

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Key message

- Patients with neurological diseases often require external mechanical support to maintain mechanical ventilation or supply.
- Little has been done to help the families of affected children make difficult decisions that carry significant physical and psychological consequences.
- The establishment of a department that provides pediatric palliative care for neurological patients should be considered.

According to the International Cancer Protocol for Diagnosis and Treatment, palliative care is usually initiated at the end of life. However, clear end-of-life expectations for patients with severe neurological disease are lacking. Patients with neurological diseases often require external mechanical support to maintain mechanical ventilation or mechanical supply.¹⁾ Thus, while palliative care in the oncology field is “pain-centered,” that in the neurology field primarily involves the use of appropriate mechanical assistance.²⁾ Palliative care requires the participation of doctors and specially trained professionals, including psychologists, psychotherapists, palliative doctors, nutritionists, and physical therapists. Despite significant advances in the identification and treatment of neurological disorders, little has been done to help the families of these children make difficult decisions that carry significant physical and psychological consequences. Moreover, there is a shortage of palliative care specialists, especially for children with neurological disorders. Realistically, pediatric palliative care is available for only a very short period of time. It is also limited to isolated patient groups. Assistance is also provided to these individuals, usually in a hospital and often in an intensive care unit. Family-centered care in neonatal and pediatric intensive care units should improve palliative care support for the child-family system; moreover, coordinators and the rest of the care team should work closely to design

tailored early care programs for infants. Palliative care for patients with neonatal and pediatric neurological disorders is a complex and growing topic of interest to medical practitioners. This paper examines the teaching methods used to deliver palliative care in this field.^{3,4)} In the absence of common established procedures, pediatric palliative care is now handled by health care professionals working in pediatrics or by physicians providing adult palliative care. The establishment of a simple department dedicated to pediatric palliative care for neurological patients should be considered. Palliative care can be introduced to neurological patients as soon as needed. This enables the rapid assessment and treatment of pain and other problems, which can lead to less aggressive treatment and better end-of-life outcomes. This paper provides fresh and valuable information.

See the article “Need for palliative care from birth to infancy in pediatric patients with neurological diseases” via <https://doi.org/10.3345/cep.2023.00129>.

Footnote

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