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Palliative care for children with central nervous system tumors: results of a Spanish multicenter study

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Abstract

Background: Brain tumors represent the most common cause of cancer-related death in children. Few studies concerning the palliative phase in children with brain tumors are available.

Objectives: (i) To describe the palliative phase in children with brain tumors; (ii) to determine whether the use of palliative sedation (PS) depends on the place of death, the age of the patient, or if they received specific palliative care (PC).

Methods: Retrospective multicenter study between 2010 and 2021, including children from one month to 18 years, who had died of a brain tumor.

Results: 228 patients (59.2% male) from 10 Spanish institutions were included. Median age at diagnosis was 5 years (IQR 2-9) and median age at death was 7 years (IQR 4-11). The most frequent tumors were medulloblastoma (25.4%) and diffuse intrinsic pontine glioma (DIPG) (24.1%). Median number of antineoplastic regimens were 2 (range 0-5 regimens). During palliative phase, 52.2% of the patients were attended by PC teams, while 47.8% were cared exclusively by pediatric oncology teams. Most common concerns included motor deficit (93.4%) and asthenia (87.5%) and communication disorders (89.8%). Most frequently prescribed supportive drugs were antiemetics (83.6%), opioids (81.6%), and dexamethasone (78.5%). PS was administered to 48.7% patients. Most of them died in the hospital (85.6%), while patients who died at home required PS less frequently (14.4%) ($p = .01$).

Conclusion: Children dying from CNS tumors have specific needs during palliative phase. The optimal indication of PS depended on the center experience although, in our series, it was also influenced by the place of death.

Keywords: Brain tumor; CNS tumor; Childhood cancer; End-of-life; Neuro-oncology; Palliative.

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