

End of life issues in brain tumor patients

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Abstract Despite aggressive antitumor treatment, the prognosis of brain tumor (BT) patients remains poor. In the last stage of disease, BT patients present severe symptoms due to the growing tumor or to treatment side-effects, which require adequate palliative management and supportive therapy. However, studies specifically addressing palliative care and end-of-life (EoL) issues in BT patients are lacking. This study explores symptoms experienced by BT patients in the last weeks of disease and EoL issues observed in a population of brain tumor patients followed at home until death by a neuro-oncological home care palliative unit set up in our Institution in 2000. From October 2000 to December 2005, 324 patients affected by brain tumor and discharged from our Institution were enrolled in a comprehensive program of neuro-oncological home care supported by the Regional Health System. Out of 324 patients enrolled in the home care program, 260 patients died of which 169 (65%) were assisted at home until the end of life and have been included in this study. Clinical symptoms, palliative treatments and EoL treatment decisions were collected from home clinical records. Among the 169 patients assisted at home until death, the most frequent symptoms observed in the last four weeks of life were: epilepsy 30%, headache 36%, drowsiness 85%, dysphagia 85%, death rattle 12%, agitation and delirium 15%. Palliative management of brain

tumor patients requires a multidisciplinary approach performed by a well trained neuro-oncology team. Development of home care models of assistance may represent an alternative to in-hospital care for the management of patients dying of brain tumor and may improve the quality of end-of-life care.

Keywords Palliative care ·
End of life treatment decisions · Brain tumor

Introduction

Despite aggressive antitumor treatment, the prognosis of brain tumor (BT) patients remains poor. Survival of malignant gliomas is less than 1 year for glioblastoma and 24–36 months for anaplastic astrocytoma. In the last stage of disease, BT patients present severe symptoms due to the growing tumor or to treatment side-effects, which require adequate palliative management and supportive therapy [1, 2]. Increasing attention has been focused on the need to improve quality of care at the end-of-life in cancer patients and existing data suggest that too many patients do not receive adequate palliative care in the last stage of disease [3, 4]. A recent European study, the EurELD study, evaluating EoL decision making in six European countries, revealed that only 40% of competent patients are involved in end-of-life medical decisions; fewer than 7% express their wishes in advance and more than 50% of decisions are made without involving the patients or their families [5]. EoL issues in neuro-oncology concern the decisions relating to medical treatment, including nutrition and hydration of patients in coma, withholding of steroid treatment and palliative sedation [6]. The process of treatment decision making in the terminal stage of brain tumor patients is

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