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Prospective assessment of end-of-life symptoms and quality of life in patients with high-grade glioma

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Abstract

Background: Glioblastoma and high-grade glioma (HGG) remain non-curable diseases. Symptoms and Quality-of-life (QoL) in the end-of-life (EoL) phase have not been prospectively studied with validated instruments. Therefore, we prospectively assessed symptom progression, symptom management, and hospice utilization in patients with treatment-refractory progressive HGG.

Methods: Patients failing bevacizumab and presenting with a Karnofsky performance score of ≤ 60 , and their caregivers, were eligible. Symptoms, medication, and clinical management were tracked with serial telephone calls every 2 weeks until death utilizing clinical evaluations and the MD Anderson Symptom Inventory Brain Tumor Module (MDASI-BT). The MDASI-BT rates symptoms on a scale from 0 (no symptoms) to 10 (worst).

Results: Fifty-four patient-caregiver dyads were enrolled in the study. Amongst 50 evaluable patients, the most severe symptoms during the last 2 weeks prior to death were drowsiness (9.09 ± 1.44), difficulty with concentration (8.87 ± 2.29), fatigue (8.63 ± 2.03), difficulty speaking (8.44 ± 2.42), weakness (8.27 ± 3.44), and difficulty with understanding (7.71 ± 2.94). All symptoms, except weakness and memory impairment, which were high at baseline, showed statistically significant progression. Seizures were rare and did not progressively worsen near the end of life (1.38 ± 3.02). The decision-making composite score almost doubled during the EoL phase (8.58 ± 1.53).

Conclusions: This is the first prospective study describing symptoms and QoL issues in patients with HGG. Patients suffer from high morbidity in the EoL phase and should be offered early palliative and hospice care to assure proper symptom management and advance care planning.

Keywords: end-of-life; glioblastoma; glioma; hospice; palliative Care.

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