Home palliative care and end of life issues in glioblastoma multiforme: results and comments from a homogeneous cohort of patients.

Pompili A, Telera S, Villani V, Pace A.

**Author information**

**Abstract**

**OBJECT:** Glioblastoma multiforme (GBM) is a rare tumor whose prognosis has remained poor over the years despite innovative radio- and chemotherapies, and important technical advances in neurosurgery such as intraoperative imaging, fluorescence, Cavitron ultrasonic surgical aspirator, and neuronavigation. Particular attention has been dedicated in the last years to the end of life (EOL) period in cancer patients for both ethical and socioeconomic issues. Good palliative care at home avoids improper and expensive hospitalizations, and helps and trains families, caregivers, and patients in facing a difficult situation.

**METHODS:** In 2012-2013 the authors’ group cared for 197 patients with brain tumors. Of these there were 122 with GBMs: 64 died and 58 are still receiving assistance. The clinical conditions are periodically evaluated with the following scales: Barthel Index, Karnofsky Performance Scale, and Mini-Mental State Examination. Home care staff includes 2 neurologists, 5 nurses, 2 psychologists, 3 rehabilitation therapists, and 1 social worker. The intensity of care changes at the different stages of disease, ranging from low to medium levels of intensity at the progression stage (more than 1 access weekly) to high levels of intensity at the EOL stage (at least 3 accesses weekly). Control MRI studies are obtained every 3 months before terminal progression.

**RESULTS:** Overall in this sample of patients there were 2838 home visits and 11,714 days of assistance. Thirty-four patients (14 female and 20 male) died at home (53.1%); 22 (13 female and 9 male) at the hospice (34.4%); and 8 (4 female and 4 male) at the hospital (12.5%). A positive impact on caregivers for home assistance was recorded in 97% of cases, for nursing in 95%, communication in 90%, rehabilitation at home in 92%, and social work help in 85%. Also, 72% had an improvement in their quality of life scores due to rehabilitation. End of life palliative sedation with midazolam was necessary in 11% of cases to obtain good control of symptoms such as uncontrolled delirium, agitation, death rattle, or refractory seizures. Intramuscular phenobarbital is the authors' drug of choice for the severe seizures that occurred in 30% of cases. The reduction of steroid dosage is also used to decrease wakefulness. Steroids were withdrawn in 45% of patients dying at home, mild hydration was done in 87%, and tube feeding in 13%. The decision-making process at the EOL stage is time consuming, but the degree of distress of the family is inversely proportional to the extent of the preparatory period.

**CONCLUSIONS:** A previous paper showed the positive cost-effectiveness of home assistance for a larger group of patients dealing with any kind of malignant brain tumors. The same is enhanced for patients with GBM. This requires a well-trained neuro-oncology team that manages neurological deterioration, clinical complications, rehabilitation, and psychosocial problems with a multidisciplinary approach.

**KEYWORDS:** EOL = end of life; GBM = glioblastoma multiforme; KPS = Karnofsky Performance Scale;
QOL = quality of life; brain tumor; end of life; glioblastoma multiforme; home care; malignant glioma; palliative care

PMID: 25434390 [PubMed - in process]

Publication Types
LinkOut - more resources

PubMed Commons
0 comments

PubMed Commons home

How to join PubMed Commons