

Maintaining quality of life near the end of life: hospice in neuro-oncology

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See article by Forst et al, pp. 538–545.

For most patients with high-grade glioma, long-term survival remains elusive. Therefore, quality of life not only in the early phases of the disease but during end of life is of high importance for patients and their families. Hospice is defined as palliative care when a cure of life-threatening disease is no longer expected or when patients are clearly approaching the end of life. Its goal is to provide relief from pain and other distressing symptoms while affirming life and regarding dying as a normal process.

In the past several years, public awareness and academic research have focused on end-of-life care and how to improve the process of dying.¹ Hospice and early palliative care have shown to help patients to die according to their wishes and to improve quality of life. Cancer patients on hospice are less likely to be hospitalized, to be admitted to an intensive care unit, or to undergo invasive procedures during the last weeks of life. One particular study found that only 11% of cancer patients on hospice died at a hospital compared with 75% of nonhospice patients.²

In this issue, Dr Forst and her colleagues look at the hospice use pattern of US high-grade glioma patients utilizing a Medicare-linked database.³ Analyzing the data of 12 437 Medicare patients, covering approximately one quarter of the US population, 63% of all patients were enrolled in hospice at the end of life. Eighty-nine percent of these patients were enrolled for >3 days, but only 77% were enrolled for >7 days. Older age, female sex, and urban residence were predictors of longer length of enrollment. One earlier study assessed rates and risks for late referral to hospice in patients with primary malignant brain tumors in a large academic center⁴; however, this is the first effort to describe the pattern of hospice use in a larger cohort of glioma patients. While large population-based studies give us important insights, it should be pointed out that much has changed in the field of palliative care in the last 5–10 years that will not be reflected in this study, which covers high-grade glioma patients who died between 2002 and 2012.

The hospice referral percentage of 63% for high-grade glioma patients is comparable to hospice enrollment in other

cancer populations,^{3,5} but nevertheless the authors' findings raise fundamental questions. Why do 37% of malignant glioma patients never find their way to hospice and why do almost a quarter of patients enrolled into hospice spend less than a week on hospice care? An earlier study by Diamond et al⁴ showed a similar percentage (22.5%) of late referrals to hospice in glioma patients. These late referred patients suffer from a higher symptom burden, and late hospice referrals are known to limit the benefits that patients and their families derive from this service.^{6,7} Because of the short time between enrollment and death, malignant glioma patients might not derive the benefits from hospice.

One of the main benefits of hospice is to help patients and their families with advance care planning and to help patients die at the location of their choice. Over the years, surveys have consistently shown that the majority of patients prefer home as the place to die.⁸ However, 77% of patients in Forst et al's study died in the hospital. This might be due to short stays in hospice and an indicator that care might be shifted to supportive care shortly before death while patients were already admitted to the hospital. Earlier referral to hospice might offer one way to evaluate and respect patients' wishes to die at the place of their preference, especially as hospitalizations correlate with more procedures and intensive care utilization at the end of life.²

Forst et al found lower odds of hospice enrollment and shorter lengths of stay for younger, male, less educated, non-white, and rural patients. These parameters suggest systemic barriers to hospice access. Patients and their families might still perceive hospice as "giving up" or might not be familiar with the benefits it can offer. These findings also suggest that the neuro-oncology community is not prepared to introduce the ideas of hospice and palliative care and to integrate referrals in a routine pattern as part of systematic disease management. A prior study assessing palliative care referral patterns of neuro-oncologists showed that there are significant differences in referral patterns based on provider specialty, sex,

and palliative care training.⁹ Medical neuro-oncologists and physicians exposed to palliative care training reported higher levels of patient referral to palliative care and hospice. These findings suggest that formal training in palliative care, advance care planning, and communication can improve practice pattern.

Why are these factors important for our clinical practice? For most patients, malignant glioma remains an incurable disease. Early hospice utilization is one way to ensure that patients and their families experience end-of-life care consistent with their wishes and the best quality of life possible. In practical terms, more research is needed to determine at what time during the disease trajectory and in what way it is best to introduce end-of-life care options to empower patients and caregivers to make the right choices.

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