

## Simultaneous care in neuro-oncology

Andrea Pace and Tobias Walbert

Neuro-oncology Unit, Regina Elena National Cancer Institute, Rome, Italy (A.P.); Hermelin Brain Tumor Center, Henry Ford Health System, Detroit, Michigan, USA (T.W.)

**Corresponding Author:** Andrea Pace, Neuro-oncology Unit, Regina Elena National Cancer Institute, Via Chianesi 53, 00144, Rome, Italy ([andrea.pace@ifo.gov.it](mailto:andrea.pace@ifo.gov.it)).

See the article by Philip et al on pp. 391–399.

Palliative care is often considered to be synonymous with end-of-life care. However, the modern concept of palliative care highlights the importance of early integration of palliative care with oncological treatments. It has been proposed that for patients with glioma, and for patients with cancer in general, palliative care should not be confined to the end-of-life phase but should start early in the disease and cover the entire disease trajectory from diagnosis and initial tumor treatment until death.<sup>1,2</sup>

Palliative care aims to relieve suffering, in all of its dimensions, during the entire course of a patient's illness. The American Society of Clinical Oncology recommends the early initiation of palliative care for newly diagnosed patients with advanced cancer within 8 weeks of diagnosis and to address advanced care planning for patients with a life expectancy of less than 12 months.<sup>3</sup> This is particularly true in the case of brain tumors, in which the life expectancy is very short and the aim of treatment is often palliative.

To date, the ongoing palliative care needs of neuro-oncological patients between first-line treatment and the terminal phase of disease are not well documented. From diagnosis to end of life, according to the existing literature, the care needs of these patients are high, underestimated, and often neglected.<sup>4</sup>

Brain tumor patients, in particular, are quite different from other cancer or neurological patients and require a specific palliative approach. Data show this to be a heterogeneous group of patients with complex needs.<sup>5,6</sup> However, there is scarce evidence to guide palliative and supportive care in brain tumor patients.

One of the most important issues in palliative care is the timing of delivery. In the last few years several randomized controlled trials have documented the potential benefits of early provision of palliative care to cancer patients.<sup>7,8</sup> Data about the positive effect of early palliative care are emerging, particularly in the general cancer population.<sup>9</sup> Early integration of palliative care produces, when compared with normal care,

significant gains in quality of life, better symptom control, reduction of health expenditures, and in some cases also an improvement of survival.<sup>7</sup> Unfortunately, in most countries, specialized palliative care is utilized only a few weeks or days before death.

The evidence in brain tumor patients remains scarce, but the neuro-oncological literature in recent years highlights the need to improve the approach to palliative care in brain tumor patients and to identify delivery models to better answer patients' and caregivers' needs. Generally, brain tumor patients are only referred to palliative care services in the last stage of disease.<sup>2,10</sup> However, an earlier and integrative approach was found to have a positive effect on the quality of end-of-life care and has been recommended by several studies.<sup>1,10,11</sup>

Recently, the European Association for Neuro-Oncology guidelines on palliative care in neuro-oncology have underscored the need to establish the best methods to provide palliative care and to develop and assess new supportive care interventions in clinical trials.<sup>1</sup> Considering that patient and caregiver needs change over time from diagnosis to disease progression, a continuous reevaluation of the patient's support needs, including the need for information, is required.

In this issue of *Neuro-Oncology*, Philip et al describe a collaborative framework of supportive and palliative care for patients with high-grade glioma.<sup>12</sup> Based on a review of the neuro-oncological literature, the authors used a qualitative as well as an epidemiological approach to create a framework for the integration of palliative care into neuro-oncology. The key principles guiding the authors' framework are: (i) alignment of patient/family caregiver needs with illness transition points; (ii) continuous monitoring of patient/family caregiver needs; (iii) proactive management of anticipated concerns; (iv) routine bereavement support; and (v) appropriate partnership with patients/families. The authors identified these principles to ensure proactive support for patients and their families at illness transition points such as diagnosis, conclusion of

radiotherapy, tumor recurrence, deterioration to death, and following death. The framework proposed may be considered a simultaneous care model based on early provision of supportive and palliative care interventions during the course of disease.

The methodology of this study is based on a unique mixed-methods research approach integrating data from a qualitative study, exploring experiences through systematic literature review, epidemiological cohort study, and expert recommendations based on a multidisciplinary advisory committee. This kind of approach is in line with American Society of Clinical Oncology recommendations reporting that the early integration of palliative care with active treatment in cancer patients may allow practitioners to improve quality of care, to deliver the best supportive care and symptoms control, and to prepare the end-of-life treatment decision process in a timely manner, respecting patient and family preferences.<sup>3</sup> Although palliative care delivery models for oncology patients are varied, the unifying elements among successful models include a palliative care provision by an interdisciplinary team available as a consultation service, in both the outpatient and inpatient settings.

Short of providing evidence-based models for palliative care in the care pathway of brain tumor patients, the authors' model might help neuro-oncology practitioners to establish a care model that encompasses assessment as well as anticipation of patient and caregiver needs along the disease trajectory. This model is based on the emerging evidence in other cancer patients that an integrated model of care may have a positive effect on quality of life as well as other patient outcomes. Considering that randomized controlled trials are difficult to conduct in the palliative care setting and are sometimes unethical, alternative research methodologies need to be utilized, including qualitative studies, observational studies, and expert opinion recommendations used in combination in a "mixed-method" approach.

## References

1. Pace A, Dirven L, Koekkoek JAF, et al; European Association of Neuro-Oncology palliative care task force. European Association for Neuro-Oncology (EANO) guidelines for palliative care in adults with glioma. *Lancet Oncol*. 2017;18(6):e330–e340.
2. Walbert T. Integration of palliative care into the neuro-oncology practice: patterns in the United States. *Neurooncol Pract*. 2014;1(1):3–7.
3. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol*. 2017;35(1):96–112.
4. Ford E, Catt S, Chalmers A, Fallowfield L. Systematic review of supportive care needs in patients with primary malignant brain tumors. *Neuro Oncol*. 2012;14(4):392–404.
5. Walbert T, Khan M. End-of-life symptoms and care in patients with primary malignant brain tumors: a systematic literature review. *J Neurooncol*. 2014;117(2):217–224.
6. Sizoo EM, Pasman HR, Dirven L, et al. The end-of-life phase of high-grade glioma patients: a systematic review. *Support Care Cancer*. 2014;22(3):847–857.
7. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733–742.
8. McDonald J, Swami N, Hannon B, et al. Impact of early palliative care on caregivers of patients with advanced cancer: cluster randomised trial. *Ann Oncol*. 2017;28(1):163–168.
9. Haun MW, Estel S, Rucker G, et al. Early palliative care for adults with advanced cancer. *Cochrane Database Syst Rev*. 2017;6:CD011129.
10. Diamond EL, Russell D, Kryza-Lacombe M, et al. Rates and risks for late referral to hospice in patients with primary malignant brain tumors. *Neuro Oncol*. 2016;18(1):78–86.
11. Forst D, Adams E, Nipp R, et al. Hospice utilization in patients with malignant gliomas. *Neuro Oncol*. 2017; doi: 10.1093/neuonc/nox196.
12. Philip J, Collins A, Brand C, et al. A proposed framework of supportive and palliative care for people with high grade glioma. *Neuro Oncol*. 2018;20(3):391–399.