Neuro-Oncology Practice

Neuro-Oncology Practice 2014; **1**, 8–12, doi:10.1093/nop/npt003

Home care for brain tumor patients

Andrea Pace, Veronica Villani, Antonella Di Pasquale, Dario Benincasa, Lara Guariglia, Sonia Ieraci, Silvia Focarelli, Carmine Maria Carapella, and Alfredo Pompili

Department of Neuroscience, Regina Elena National Cancer Institute, Rome, Italy

Corresponding author: Andrea Pace, MD, Neurology Unit, Regina Elena National Cancer Institute, Via Chianesi, 53, 00144 Rome, Italy (pace@ifo.it).

Background. Brain tumor patients are quite different from other populations of cancer patients due to the complexity of supportive care needs, the trajectory of disease, the very short life expectancy, and resulting need for a specific palliative approach.

Methods. A pilot program of comprehensive palliative care for brain tumor patients was started in the Regina Elena National Cancer Institute of Rome in October 2000, supported by the Lazio Regional Health System. The aim of this model of assistance was to meet patient's needs for care in all stages of disease, support the families, and reduce the rehospitalization rate. The efficacy of the model of care was evaluated analyzing the place of death, caregiver satisfaction, rehospitalization rate, and the impact on costs to the health system.

Results. From October 2000 to December 2012, 848 patients affected by brain tumor were enrolled in a comprehensive program of neuro-oncological home care. Out of 529 patients who died, 323 (61%) were assisted at home until death, 117 (22.2%) died in hospital, and 89 (16.8%) died in hospice. A cost-effectiveness analysis demonstrated a significant reduction in hospital readmission rates in the last 2 months of life compared with the control group (16.7% vs 38%; $P < .001$).

Conclusions. Our findings concerning death at home, rehospitalization rate, quality of life, and satisfaction of patients and their relatives with the care received suggest that a neuro-oncologic palliative home-care program has a positive impact on the quality of care for brain tumor patients, particularly at the end of life.

Keywords: brain tumors, end-of-life, home care, palliative care, place of death.

Despite aggressive antitumor treatments, the prognosis for brain tumor (BT) patients remains poor, even if current treatments have yielded a modest impact on survival.[1] In the meantime, there is increasing attention on the need to improve quality of care for BT patients, and existing data suggest that too many patients do not receive adequate palliative care in the last stages of disease.[2,3]

To date, palliative care in neuro-oncologic patients and their ongoing needs of care from discharge to the terminal phase of disease are not well documented. From diagnosis to the end of life (EoL), the care needs of these patients are high, underestimated, and often neglected.[4]

Needs of care increase in the last stage of disease, with a high incidence of neurological symptoms and psychosocial problems,[5] often inducing caregivers and/or family members to hospitalize the patient.

Brain tumor patients are quite different from other populations of cancer patients due to the complexity of supportive care needs, the trajectory of disease, the very short life expectancy, the presence of specific symptoms related to neurological deterioration, and therefore the need for an appropriate palliative approach.[6] Supportive care in BT patients during the course of disease includes relevant issues such as management of peritumoral brain edema, venous thromboembolism, seizures, rehabilitation, depression, opportunistic infections, psychological support/communication, and EoL issues/treatment decisions.[7] BT caregivers have also been reported to have a high level of stress during the course of disease and a high need for help in dealing with the changes in patients' mental health and their difficult behaviors, particularly in the last stage of disease.[8,9]

There is a large consensus on the need to improve the quality of palliative and supportive care for neuro-oncologic patients. The complex needs of malignant BT patients at the end of life require comprehensive palliative interventions, with a multidisciplinary approach performed by a well-trained neuro-oncological team for control of pain, confusion, agitation, or delirium or management of seizures, with the aim of allowing the patient to experience a peaceful death.

The goal of palliative care in BT patients is to offer adequate symptom control, promote the quality of life for patients, avoid futile treatments, and give psychological support to patients

Received 27 November 2013; accepted 26 November 2013

and their families.[10] However, discussion is ongoing about the best timing of such interventions programs. Usually, BT patients, like other cancer patients, are referred to palliative care services in the last stage of disease. Recent studies suggest that palliative care services must be provided earlier in the course of the disease to have a meaningful effect on patients' quality of life and EoL care.[11]

From October 2000, a pilot program of comprehensive palliative care for BT patients has been operating at the National Cancer Institute of Rome, supported by the Lazio Regional Health System. The aims of this model are to promote the continuity of care between hospital and the local health system, meet patient's care needs in every stage of disease, support the family, and to reduce the rate of rehospitalization. The measures of the efficacy of this model of patient-centered neuro-oncological home care are based on the evaluation of place of death, of rehospitalization rate in the last months of life and of caregivers satisfaction for the care received. The aim of the project was also to evaluate the cost-effectiveness of this model of care by assessing the economic impact in terms of health care costs due to hospital readmission in the last stage of disease. This program represents the first experience, as far as we know, of a neuro-oncology palliative home-care team and may offer original data about the quality of care during the course of disease and the end of life for BT patients. We report the results of 12 years of activity.

Methods

From October 2000 to December 2012, 848 patients affected by BT and discharged from our institution were enrolled in a comprehensive program of neuro-oncological home care supported by the Regional Health System. Assistance included neurological visits at home, neuro-rehabilitation at home, psychological support for patients and their families, and nursing assistance. In the late stages of disease, the intensity of assistance increased, and the home-care activity reached a level of "hospice at home".

The outcome of patients was periodically evaluated with the following scales: Barthel Index, Karnofsky Performance Status, and Mini Mental Test.

Home staff included 2 neurologists, 5 nurses, 2 psychologists, 3 rehabilitation therapists, and 1 social worker. The management of patients at home was discussed by home staff in weekly meetings and coordinated by the Neuro-Oncological Centre at Regina Elena Cancer Institute. Home-care interventions were patient centered and differed according to the patients' and their families' care needs in different stages of disease. The intensity of care changes in different stages of disease ranged from low intensity (weekly home visit or contact by phone) to medium level of intensity in the disease-progression stage (more than one weekly visit, nursing assistance, psychological assistance, palliative advance-care planning), and high level of intensity in the EoL stage (at least 3 weekly visits). The personalized intervention plan also involved the general practitioner and Health District Services.

Each case was assigned a dedicated member of the care team to be the case manager responsible for identification of care needs and early evaluation of clinical modifications and emerging problems. Usually, the case manager was a nurse who was supervised by the neurologist assigned to the patient. Every new case was presented and discussed in the weekly home-care team meeting. Critical cases and patients in the EoL stage were also discussed at the weekly meetings.

Results

Of the 848 patients enrolled, 425 were affected by glioblastoma, 191 by anaplastic astrocytoma, 66 by anaplastic oligodendroglioma, 166 by other histology (ependymoma, medulloblastoma, primary CNS lymphoma). Of the 529 patients who died, 323 (61%) were assisted at home until the end of life, 117 (22.2%) died in hospital, and 89 (16.8%) died in hospice.

Psychological Support

The role of psychological intervention was to assess the psychological morbidity in both the patients and their caregivers, facilitate communication of diagnosis and prognosis in different stages of disease, evaluate patient and family compliance, and promote advance-care planning and early assessment of EoL issues. Psychological intervention was also aimed at supporting the team itself and detecting and managing early symptoms of team member burnout. In the home-care setting, the role of the caregiver was particularly important, and psychological support was dedicated to family caregivers during the entire course of the disease, especially at the end of life. Bereavement support represents an important aspect of the palliative care approach.

The perception of quality of care perceived by the caregivers was used in the home palliative-care program as a surrogate indicator of efficacy and was measured periodically with a "customer satisfaction" survey. The results indicated a positive impact on the caregiver's perception of global home-care assistance (98%), communication (93%), nursing (95%), rehabilitation at home (92%), and social work help (88%).

Nursing

Every case was assigned a nurse who was considered the case manager. Among the nurse's tasks in home-care assistance were assessment of the patient's care needs and early detection of clinical changes in the progression and EoL phase. The nurseing activity involved periodic home visits with different frequencies according to different intensities of care, nursing interventions, caregiver education, and activation of other interventions by the home-care team (neurologist, psychologist, and physiotherapist).

Nursing activity also involved communication with the patient's general practitioner and District Health Services.

Rehabilitation at Home

During the course of the disease, patients affected by malignant brain tumor present multiple neurological deficits due to primary tumor effects and the adverse effects of treatment (surgery, radiotherapy, and chemotherapy). All patients assisted at home by this care model were evaluated by the neurologist and the physiotherapist to assess rehabilitation needs. When neurological deficits were detected (motor deficits, gait alteration, language disturbances), a personalized program of home rehabilitation was activated. Home rehabilitation interventions included neurological rehabilitation treatment (twice a week for 3 months), speech therapy, and cognitive training. Rehabilitation results were evaluated with baseline and posttreatment evaluation with an activities of daily living scale (Barthel Index), performance scale (Karnofsky Performance Scale), and neurological examination. The positive impact of rehabilitation on disability, patient autonomy, and quality of life (assessed with EORTC QLQ-C30-BM) have already been reported in a previous study by our group.[12] After 3 months of home rehabilitation, Barthel Index score improved in 39% of patients, while 72% of patients were found to have an improvement in quality-of-life scores in at least one domain compared with their baseline scores.

Rehabilitation interventions at home have different goals in different stages of disease. In the acute phase of disease, they are aimed at obtaining functional improvement, while in the phase of progression at the last stage of disease, they are focused on the patient's quality of life, palliation of symptoms, prevention of complications, and improvement in mobility and daily living activities.[13] An important aspect, particularly in the advanced stage of disease, is educating caregivers about several issues that may influence the patient's quality of life and autonomy, such as mobilization from bed to wheelchair, adequate nutrition in patients with dysphagia, and prevention of bedsores.

Cost-effectiveness Analysis

The economic impact of models of palliative care on the health system is very important. We recently demonstrated that our model of home assistance can reduce the high economic cost of brain tumors by reducing the rehospitalization rate in the last period of life.

A cost-effectiveness analysis was performed in a subgroup of glioblastoma (GBM) patients by evaluating the rehospitalization rate in the last 2 months of life. The cost-effectiveness analysis was carried out in a consecutive series of 72 patients discharged from our institution after surgical procedures for GBM from January to December 2006 (group 1). All patients of group 1 received home-care assistance. The control group was represented by 72 GBM patients discharged in the same period of time from the neurosurgical ward of Policlinico Umberto I, Sapienza University of Rome (group 2 was not assisted at home). Data regarding the number of hospital readmissions in the last 2 months of life and the length and the cost of hospitalizations in the 2 groups of patients were analyzed from hospital discharge records stored in the database of the Regional Public Health Agency (Agenzia di Sanita'Pubblica-ASP).

The results of the cost-effectiveness analysis showed that the group of patients assisted by our home-care program had a significantly lower hospital readmission rate and intensive care unit utilization in the last 2 month of life than the control group of BT patients, who did not receive home assistance (16.7% vs 38%, respectively; $P < .001$). There was also a significant difference in economic cost for care delivered during hospital stays in the same period (€7 400 vs €57 000; $9 990 vs 76 000; $P < .001$).[14]

End of Life Issues/Treatment Decisions

The main goals in the home-care palliative program was to offer adequate symptom control at the end of life, provide relief from suffering, avoid inappropriate prolongation of dying, and support the psychological and spiritual needs of patients and their families. The lack of symptom control for patients not included in palliative home-care programs often leads to rehospitalization, with a resulting cost increase to the health care system and a worsening of patient quality of life.[14,15] Recent papers have reported that BT patients at the end of life present a high incidence of distressing symptoms that may impact their quality of life during the process of dying.[16,17] In order to allow the patient to experience a peaceful death, specific palliative interventions are necessary to control pain, confusion, agitation, delirium, or seizures.[18]

In the large population of BT patients assisted until death by our neuro-oncological palliative home-care team since 2000, we have observed a high incidence of distressing symptoms impacting their quality of life during the last stage of disease and the process of dying. The most frequent symptoms observed in the last 4 weeks of life were epilepsy (30%), headache (36%), drowsiness (85%), dysphagia (85%), death rattle (12%), delirium 15%.[19] Similar data have recently been reported about EoL symptoms in BT patients dying in different care setting (inpatients, outpatients, hospice).[17,19]

Some of these symptoms are commonly observed in the general cancer population, while others such as seizures and dysphagia require specific neuro-oncological intervention.

Seizures

The occurrence of seizures in the last period of life may impact patients and their families' quality of life and requires adequate supportive care and treatment modifications. In a recent study by our group, the incidence of seizures at the end of life was evaluated in a population of 157 BT patients. Seizures occurred in 51 patients (30%) in the last 4 weeks before death and were partial in 85% of cases and generalized in 15% of cases. Six percent of patients presented repeated seizures or status epilepticus. The lack of control of epilepsy often leads to rehospitalization, with increased costs to the health care system and worsening of the patient's quality of life. Correct management and education of the families may prevent inappropriate hospital readmission for uncontrolled seizures. Most patients (53%) who had seizures in the last months of life had experienced seizures in the past and were being treated with antiepileptic drugs; in 24 cases (47%), seizures occurred in patients who had not presented with epilepsy in the past.[20]

The majority of patients in their last month of life had difficulty taking oral medications due to dysphagia, disturbances in consciousness or both, which makes the use of the more commonly utilized oral antiepileptic drugs problematic at the end of life.[16,17] Thus, the anticonvulsant treatment in this stage of disease needs to be optimized, and oral treatment has to be adapted to find the optimal route for administering the drugs (intramuscular, rectal, transdermal, or subcutaneous).

Dysphagia

Dysphagia is reported to be one of the more frequent symptoms in the last weeks of life in neurologic patients. The incidence of dysphagia in our population of BT patients was about 85%. Mild dysphagia usually occurs a few weeks before death, and its onset may be considered the first symptom of the EoL phase. Loss of the ability to swallow may induce pulmonary inhalation and may affect nutrition and hydration. Moreover, the patient's difficulty with oral intake of liquids, food, and drugs requires appropriate training of caregivers in nutrition, modification of treatment, and early discussion with families and the home-care team about EoL treatment decisions concerning nutrition and hydration.[18]

End of Life Treatment Decision-making Process

EoL treatment decisions for BT patients have unique circumstances that require specific approaches including decisions about nutrition and hydration of patients in irreversible coma, withholding of steroid treatment, and administration of palliative sedation.[19] As reported in Table 2, the vast majority of the 323 patients assisted at home until death have died what may be defined as a "peaceful death" process, with gradual neurological deterioration, progressive reduction of consciousness until deep coma, and death. In some cases, however, patients experienced poor symptom control with an agitated death that required use of pharmacological sedation. The decisions about EoL treatments mainly pertain to "no -treatment" decisions: withdrawal of supportive treatment (steroids, anticonvulsants), and withdrawal/withholding of artificial nutrition/hydration for patients in a prolonged vegetative state. In our patients, pharmacological palliative sedation was necessary in 11% of cases to obtain satisfactory control of symptoms such as uncontrolled delirium, agitation, death rattle, or refractory seizures.

In many cases, the tapering of steroid dosage may help to induce reduction of vigilance.

Ethical Concerns

Because the vast majority of BT patients lose their competence to participate in a shared decision-making process, it is of the utmost importance to plan treatment decisions about nutrition and hydration in advance and discuss them with families and with patients when possible. Indeed, discussing EoL issues with BT patients becomes progressively more difficult during the course of their disease because of cognitive disturbances, confusion, and decreasing consciousness.[20,21] According to a recent review about supportive care in neuro-oncology,[4] only a small proportion of BT patients had established advance directives on EoL treatments, and progressive neurological deficits and loss of consciousness often meant that decisions had to be made on their behalf. In the large population of patients observed in our experience, only 6% presented advance directives for treatment. A study exploring the decision-making process in the EoL phase of high-grade glioma patients reported that the physician did not discuss EoL treatment-decision preferences in 40% of cases.[21] According to recent studies, timely advance care planning could contribute to improved EoL decision-making.[11]

Because the "shared decision", made together by physicians, patients (if possible), nurses, and family, may be the best approach to EoL decisions, common guidelines are needed. This decision process is time consuming, but the degree of family distress seems to be inversely proportional to the extent in which advance planning and preparation take place. The time spent preparing families is likely to be very worthwhile. The aim is to obtain a consensus among all participants, while respecting patient and family values, about the withholding/withdrawing decisions. Nevertheless, the process of EoL treatment decisions for BT patients needs better definition, and the role of the person with legal authority to make health care decisions on a patient's behalf (surrogate decision-maker) should be defined.

Table 1. Characteristics of patients ($n = 848$)

Male/female ratio	439:409
Mean age (range)	57 years (17–89 years)
Glioblastoma	425
Anaplastic astrocytoma	191
Anaplastic oligodendroglioma	66
Other histology*	166
Place of death	
Home	323 (61%)
Hospital	177 (22.2%)
Hospice	89 (16.8%)

*ependymoma, medulloblastoma, CNS lymphoma.

Table 2. End-of-life treatment decisions in 323 brain tumor patients dying at home

Steroid withdrawal	45%
Mild hydration	87%
Tube feeding	13%
Palliative sedation	11%
Advanced directives	6%

Caregivers Perspective

Very little is known about quality of life and well-being of caregivers for patients with brain tumors. Usually, the caregiver's own needs are neglected because the focus is on the patient. Recent data report that, in the context of this severe and often devastating disease, the caregiver's burden of suffering and despair is often neglected, suggesting the need for a more global, comprehensive approach to the care of the affected family.[8] The role of caregiver support is particularly important in the home-care setting. Strategies for supporting the caregiver's emotional needs include information about patient symptoms and problems, training about optimal management of the disabled patient, and early discussion about treatment decisions in the last stage of disease. Decisions about place of death and about nutrition and hydration need to be planned in advance to avoid hospitalization or emergency room care in case of acute symptoms. Caregiver support in the palliative-care approach also includes family consultation for bereavement support after the patient's death.

Discussion

Although the lack of a randomized trial design does not make it possible to demonstrate the efficacy of our model of assistance, our findings concerning death at home, rehospitalization rate, quality of life, and satisfaction of patients and their families with the care received suggest that a neuro-oncologic palliative home-care program has a positive impact on the care needs of BT patients. Strategies to improve continuity of care and decrease the rehospitalization rate are becoming increasingly important in oncology, both to improve the quality of care for cancer patients and to reduce economic costs for the health care system.

Home-care models of assistance for different chronic diseases, particularly cancers, have already been proposed in different countries with different systems for health care.[22] The results obtained from our study demonstrate that this model of continuous home care for BT patients is feasible and cost effective.

Other recent studies have confirmed that early palliative care may improve the quality of care for BT patients at the end of life.[15] The complex needs of patients with advanced malignant BT require management of neurological deterioration, clinical complications, rehabilitation, and psychosocial problems with a multidisciplinary approach performed by a well-trained neuro-oncological team.

Studies specifically addressing palliative care and EoL issues in BT patients are lacking. However, there is a great need for education in palliative care and EoL care for BT patients. Better knowledge of clinical and ethical issues could help to improve the educational training and quality of care in neuro-oncology services.[23,24] Future clinical research strategies should include new models of care for BT patients, with special attention to palliative home-care models. Palliative programs and home-care models of assistance may represent an alternative to inhospital care for managing patients dying from a brain tumor and may improve their quality of care, especially in the last stage of disease.

Funding

The program of Palliative Home Care for Brain Tumor patients is supported by Lazio Regional Health System funds.

Conflict of interest statement. None declared.

References

1. Stupp R, Hegi ME, Mason WP, et al. Effects of radiotherapy with concomitant and adjuvant temozolomide versus radiotherapy alone on survival in glioblastoma in a randomised phase III study: 5-year analysis of the EORTC-NCIC trial. *Lancet Oncol*. 2009;10(5): 459–466.
2. Ostgathe C, Gaertner J, Kotterba M, et al. Hospice and Palliative Care Evaluation (HOPE) Working Group in Germany. Differential palliative care issues in patients with primary and secondary brain tumours. *Support Care Cancer*. 2010;18(9):1157–1163.
3. Faithfull S, Cook K, Lucas C. Palliative care of patients with a primary malignant brain tumour: case review of service use and support provided. *Palliat Med*. 2005;19(7):545–550.
4. Ford E, Catt S, Chalmers A, et al. Systematic review of supportive care needs in patients with primary malignant brain tumors. *Neuro Oncol*. 2012;14(4):392–404.
5. Catt S, Chalmers A, Fallowfield L. Psychosocial and supportive-care needs in high-grade glioma. *Lancet Oncol*. 2008;9(9):884–891.
6. Batchelor TT, Byrne TN. Supportive care of brain tumor patients. *Hematol Oncol Clin North Am*. 2006;20(6):1337–1361.
7. Pace A, Metro G, Fabi A. Supportive care in neurooncology. *Curr Opin Oncol*. 2010;22(6):621–626.
8. Finocchiaro CY, Petruzzi A, Lamperti E, et al. The burden of brain tumor: a single-institution study on psychological patterns in caregivers. *J Neurooncol*. 2012;107(1):175–181.
9. Flechl B, Ackerl M, Sax C, et al. The caregivers' perspective on the end-of-life phase of glioblastoma patients. *J Neurooncol*. 2013; 112(3):403–411.
10. Voltz R, Borasio GD. Palliative therapy in the terminal stage of neurological disease. *J Neurol*. 1997;244(4):S2–10.
11. 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.
12. Pace A, Parisi C, Di Lelio M, et al. Home rehabilitation for brain tumor patients. *J Exp Clin Cancer Res*. 2007;26(3):297–300.
13. Santiago-Palma J, Payne R. Palliative care and rehabilitation. *Cancer*. 2001;92(4):1049–1052.
14. Pace A, Di Lorenzo C, Capon A, et al. Quality of care and rehospitalization rate in the last stage of disease in brain tumor assisted at home: a cost effectiveness study. *J Palliat Med*. 2012; 15(2):225–227.
15. Sundararajan V, Bohensky MA, Moore G, et al. Mapping the patterns of care, the receipt of palliative care and the site of death for patients with malignant glioma. *J Neurooncol*. 2014;16(1):119–126.
16. Oberndorfer S, Lindeck-Pozza E, Lahrmann H, et al. The end of life hospital setting in patients with glioblastoma. *J Palliat Med*. 2008; 11(1):26–30.
17. Sizoo EM, Braam L, Postma TJ, et al. Symptoms and problems in the end-of-life phase of high-grade glioma patients. *Neuro Oncol*. 2010; 12(11):1162–1166.
18. Pace A, Di Lorenzo C, Guariglia L, et al. End of life issues in brain tumor patients. *J Neurooncol*. 2009;91(1):39–43.
19. Bausewein C, Hau P, Borasio GDI, et al. How do patients with primary brain tumours die?. *Palliat Med*. 2003;17(6):558–559.
20. Pace A, Villani V, Di Lorenzo C, et al. Epilepsy in the end of life phase in paients with high grade gliomas. *J Neurooncol*. 2013;111(1):83–86.
21. Sizoo EM, Pasman HR, Buttolo J, et al. Decision-making in the end-of-life phase of high-grade glioma patients. *Eur J Cancer*. 2012;48(2):226–232.
22. Tralongo P, Ferraù F, Borsellino N, et al. Cancer patient-centered home care: a new model for health care in oncology. *Ther Clin Risk Manag*. 2011;7:387–392.
23. Sizoo EM, Taphoorn MJ, Uitdehaag B, et al. The end-of-life phase of high-grade glioma patients: dying with dignity?. *Oncologist*. 2013; 18(2):198–203.
24. Carver AC, Vickrey BG, Bernat JL, et al. End-of-life care. A survey of US neurologists' attitudes, behavior and knowledge. *Neurology*. 1999; 53(2):284–293.