

Neuro-Oncology

LETTER TO THE EDITOR

Dr. Kendra Peterson is a Faculty Scholar of the Soros Foundation Project on Death in America.

Finding the Balance

Kendra Peterson

Dear Editor:

I am writing in response to David Bailey's evocative letter about the essential element of hope that must be included in physicians' conversations with patients who have brain tumors (Bailey, 2000). Mr. Bailey, a survivor of glioblastoma multiforme, spotlights a particularly difficult setting in which neuro-oncologists speak to patients with brain tumors, the lecture arena. In this setting there is no mechanism for counseling individuals about the specifics of their own disease or consoling those impacted by the outcome statistics of the group as a whole. It is, therefore, unconscionable to present the poor outcomes of groups of patients without stressing the individual nature of the disease. In addressing groups of patients, the thoughtful speaker would emphasize that individual patients may do far better than the norm, that scientific and clinical advances are being made in this field, and that each member of the audience is encouraged to maintain hope that he or she will be among the group that "beats the odds."

In our interactions with individual patients, neuro-oncologists walk a fine line between expressing the hope for cure and informing patients of the known prognosis of a malignant brain tumor. We are trained to look at the behavior of groups of patients in order to predict the clinical course of an individual. Our predictions are often right; but, sometimes we are wrong. We hope that each patient will be in the group that "beats the odds." We balance our own hope with the known statistics. We and our patients hold these two elements of hope on one hand and knowledge of the most probable outcome on the other. The balance between the two shifts over time for both patient and physician, not in a smooth conversion from one to the other but in an oscillating, irregular, and unpredictable pattern.

Every caring physician hopes for a cure for each of his or her patients. At the same time, avoiding a discussion that a malignant brain tumor may end a patient's life does not allow the patient and caregivers the opportunity and permission to prepare for life's end. It does not allow the physician, patient, and caregivers to anticipate symptoms and their management, to discuss practical issues such as advance directives or financial planning, and to process the psychological, social, and spiritual ramifications of facing life's end.

This is not a discussion to be held in a lecture setting with a group of hopeful patients. This is a conversation that must be held in a more personal setting, with an individual patient and the patient's family. It is typically a conversation that occurs not at first meeting, and not at only one point in time, but a conversation that evolves during numerous encounters as the patient and physician come to know one another. It is a conversation that requires sensitivity and thoughtfulness, deserves not to be interrupted by a bleating pager, and requires time.

Yet despite the frequency of our interactions with patients who have life-ending illnesses, neurologists in general, and neuro-oncologists in particular, are not well versed in the common principles and practices of palliative medicine. In a survey of neurologists' attitudes, behavior, and knowledge about end-of-life care, slightly more than half the patients of neuro-oncologists had discussed their wishes regarding "Do Not Resuscitate" orders and less than one-third had completed advance directives. We, as a group, are in disagreement, confused, or uninformed about existing medical, legal, and ethical guidelines regarding end-of-life care (Carver et al., 1999). In addition to knowledge, we lack sufficient support for ourselves as we deal with the anguish that arises in confronting dying patients on a regular basis.

The Society for Neuro-Oncology appropriately devotes the majority of its time, effort, and resources to finding a cure for malignant brain tumors. We devote a moderate amount of our effort to assessing and maintaining the quality-of-life of patients undergoing treatment for malignant brain tumors. However, we devote very little effort to examining what happens to patients who have progressive disease and have ended treatment—patients who are dying. There is little in the medical literature focusing on the symptoms of patients dying with brain tumors and the management of those symptoms, little known about the spiritual, psychological, and existential suffering that patients endure, where they die, who takes care of them, advance directives, and other practical issues. Each of us takes care of many patients who ultimately die from their disease. We do so with varying degrees of skill and comfort. There are few resources to assist us in this task, and the medical literature is bereft of data specific to this aspect of our practice.

In advocating for patients with brain tumors, we need to seek cures; we also need to care well for those who are dying. Our patients would benefit from our improved knowledge in this aspect of care.

I share Mr. Bailey's profound hope that there soon will be a cure for all patients with malignant brain tumors. In the meantime, we need to bring the topic of caring for dying patients to the table of intellectual dialogue of practicing neuro-oncologists throughout the country and improve the care of patients who ultimately die from their disease.

Sincerely,
Kendra Peterson, M.D.
Assistant Professor of Neurology and Neurological
Sciences, and Medical Oncology
Stanford University
Stanford, CA 94305

Neuro-Oncology 3, 55-56, 2001 (Posted to *Neuro-Oncology* [serial online], Doc. 00-037, October 13, 2000. URL <neuro-oncology.mc.duke.edu>)

References

Bailey, D.M. (2000) A patient's plea—breaking the news. *Neuro-Oncology* [serial online], Doc. 99-57, March 6, 2000. URL <neuro-oncology.mc.duke.edu>. *Neuro-Oncology* 2, 125-126.

Carver, A.C., Vickrey, B.G., Bernat, J.L., Keran, C., Ringel, S.P., and Foley, K.M. (1999) End-of-life care: A survey of US neurologists' attitudes, behavior, and knowledge. *Neurology* 53, 284-293.