Care for Dying Patients With Primary Malignant Brain Tumor

—Respecting Dignity—

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Abstract

Patients with primary malignant brain tumor experience deterioration of multi-focal neurological deficits such as hemiparesis, aphasia, visual field defects, dysphagia, and disturbance of recent memory at the advanced stage of disease. With these advancing neurological deficits, many patients will inevitably prepare for death and may experience psychological and spiritual distress. Active listening is an important skill to explore the fears of patients with a terminal illness but in the advanced stage of a primary brain tumor, patients usually have great difficulty with verbal expression. Even if patients do not suffer from complete expressive aphasia, they often have difficulty verbalizing their thoughts and feelings. Sadly, disturbance of vocal expression is a common accompaniment of this pathology. Unless the pathophysiology is understood, an observer may fail to comprehend the patient's non-verbal communication. Seeking to understand these issues is a prerequisite of the preservation of dignity and provision of ethical care for such patients.

Key words: brain tumor, dignity, holistic care, palliative care, spiritual care

Introduction

The development of palliative medicine as a specialty has seen great progress in the palliation of many symptoms of advanced cancer. However, such progress has been more limited in the management of primary malignant brain tumors. Neurosurgeons, neurooncologists, and radiologists necessarily concentrate on treatment, operation, and postoperative ad-

juvant therapies until recurrence is apparent, but for many patients the major difficulty comes not during these treatment phases but after recurrence and failure of chemoradiotherapy to produce an adequate response.

The progress of neurological deficits is sometimes difficult to predict. As the disease advances, patients may experience multi-focal neurological deficits such as hemiparesis, aphasia, visual

field defects, dysphagia, and disturbance of recent memory. If their spontaneous movement and speech are severely reduced, patients may appear to be in a vegetative state, like that normally seen after diffuse brain damage caused by injury or vascular disease. With these advancing neurological deficits, many patients will inevitably prepare for death and may experience psychological and spiritual distress. Understandably

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many patients may experience anxieties caused by rapid deterioration of neurological function and difficulty may be encountered in expressing their thoughts in the later stages of the disease. Sadly, disturbance of vocal expression is a common accompaniment of this pathology. Unless the pathophysiology is understood, an observer may fail to comprehend the patient's non-verbal communication. The patient may be able to hear and understand the discussions between physicians and their family, and their frustration may be difficult to express. How can we become aware of what they are aware of? Seeking to understand these issues is a prerequisite of the preservation of dignity and provision of ethical care for such patients.

Disease progression brings with it the multi-focal neurological deficits previously mentioned. The situation is often further complicated by convulsions and symptoms due to raised intracranial pressure: headache, nausea, and vomiting. Even if patients do not suffer from complete expressive aphasia, they often have difficulty verbalizing their thoughts and feelings. They may have difficulty answering simple questions. Because of the disturbance of recent memory, they often repeat themselves. At this phase of the illness, staff and family may find their patience tried and a sense of frustration developing.⁸⁾

Respecting Dignity

Active listening is an important skill to explore the fears of patients with a terminal illness but in the advanced stage of a primary brain tumor, patients usually have great difficulty with verbal expression. To ensure that patients are treated

with due respect and dignity in the advanced stage of their illness, their wishes should be elicited in the early stages, when communication is still clear. They should be informed of the likely course of their disease in as much detail as possible. Difficult or contentious issues such as tube feeding and resuscitation should be sensitively explored. When these measures are ultimately necessary, the patient is unlikely to be well enough to discuss them, and opinions may be expressed by relatives that are contrary to the patient's wishes. Because patients with primary brain tumors frequently have disturbed consciousness in the terminal phase, some reports have suggested that the main focus of mental and psychological care should shift from the patient to the family.^{4,6)} This is not always, however, the most appropriate path. For example, we have experience of a patient with a brain tumor, who did not move or speak spontaneously, however, if he felt his pet dog, his arms moved slowly to the dog and his eyes became watery. One extreme situation is the "locked-in syndrome" in which the patient is fully aware but unable to respond due to paralysis and dysarthria. Such patients can feel frustrated and humiliated if staff and family assume they are in a vegetative state and carry on conversations in their hearing as if they do not exist.

Communication can be frustrating and time consuming if patients maintain a desire to speak. This may be promoted if we focus on the inner, more personal aspects of their life such as hobbies, work, achievements, pleasant memories, and other diversion therapies rather than just clinical questions. When we are trying to communicate, we must be alert to the

patient's non-verbal expression. By endeavoring to treat patients with as much dignity and respect as is possible in the terminal stage of the disease, the suffering of both the patient and the family can be eased. Whilst it may seem self evident to some basic human needs such as touch sight, and sound (in the form of music as therapy) must be maintained as the end of life approaches.⁹⁾ Touch can vary from whole body massage at one end of a spectrum to simple hand massage or hand holding at the other.

Music therapy can be useful in the management of people with malignant brain tumors.⁹⁾ Music therapy in palliative care is the controlled use of music, its elements and their influences on the human being to aid in the physiological, psychological, and emotional integration of the individual. In many ways advancing cerebral malignant disease is a powerful influence on the potential 'dis-integration' of an individual. By mobilizing deep memories and feelings it can assist in communication. Music can be shared by the family — reminiscing to the sounds of their shared history, recreating a bond and a sense of community within the family and as a link to the patient's life before illness. It can also be seen simply as entertainment and diversion.³⁾ Music therapy is a useful adjunct in the management of the agitated behavior so commonly seen in advancing cerebral disease.^{2,5)}

In their study on dignity in the terminally ill, Chochinov et al.¹⁾ identified three main areas for attention whilst undertaking work with people with advanced cancer: illness-related concerns — these related to the level of independence (cognitive acuity and functional capacity) and the level of

symptom distress (both physical and psychological); dignity conserving repertoire—these included dignity-conserving perspectives (such as the continuity of self, role preservation, the maintenance of pride, hopefulness, autonomy/control, acceptance, and resilience) and dignity-conserving practices (such as living in the moment, maintaining normalcy, and seeking spiritual comfort); social dignity inventory—these identified sub-themes such as privacy boundaries, social support, the concept of being a burden to others, and concerns about the aftermath of their dying, along with the attitudes to caring of those around them.

By matching these categories with the likely decrease in function over a number of domains it is easy to see that the maintenance of dignity may become problematic in people with primary malignant brain tumor. Loss of dignity may enhance depression, hopelessness, and a desire for hastened death, so early identification of key elements in the maintenance of dignity is essential, particularly in this group of people.

The maintenance of quality of life remains a key objective in all palliative care, none less so than in this group of people. There are a large number of tools available for use with this population but all tend to rely on patient reporting. From the work of the WHOQOL group, there are a number of key areas that transcend culture, country, and beliefs. The WHOQOL group has published extensively on their findings, which are selected from a wide range of countries and a cross section of disciplines and specialisms within social science and medicine.^{7,10} Perhaps two of the most pertinent here are the

ability of patients to maintain the presence of meaningful relationships and the ability to feel light hearted. Both of these items may be relatively simple to address if we ensure that we treat all people with the dignity that they deserve and focus on what their needs are rather than the needs of the clinicians or family.

The focus of care then, in the management of people with primary malignant brain tumors, is to maintain effective function, communication, and the highest possible quality of life as determined by the patient and family before the physical and psychological deterioration that accompanies this disease. Attending to detail in every facet of communication will enhance the life of this group and perhaps enable the clinicians involved to feel less helpless themselves in these challenging situations.

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