

## Psychosocial care

### ADVANCE CARE PLANNING FOR PATIENTS WITH METASTATIC BRAIN TUMOURS: BENEFITS AND BARRIERS

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#### **TRIAL SUMMARY:** Enhanced communication through advance care planning relieves stress and ensures patients' participation in decision making

Leckie CJ, Enns B. The art of communication: normalizing advance care planning in the neurooncology population. CANO 2011. Abstract III-03A.

This presentation identified the elements and benefits of, and barriers to, advance care planning (ACP) in the experience of neurooncology clinics at the Tom Baker Cancer Centre, Alberta Health Services.

High-grade gliomas (HGG) are the most common type of primary brain tumours in adults; median survival ranges from 6 months to 3 years. Generally, treatments aim to increase survival time and quality of life rather than to cure.

**COMMENTARY:** In 2008, the Advance Care Planning: Goals of Care Designation (Adult) policy was implemented in the Calgary area of the Alberta Health System.<sup>1</sup> Despite this and other nationally led initiatives, ACP is still not happening. ACP is a process of reflection and communication, while individuals are still capable, about their wishes for care in the future, when they may become incapable. It promotes informed decision making by individuals and the healthcare team. Reported impacts of ACP from the literature include significantly increased satisfaction with all aspects of care for patients and families and a decrease in symptoms of post-traumatic stress disorder after the loss of a loved one.<sup>2</sup>

Only about 20% of people diagnosed with malignant brain tumours survive 5 years.<sup>3</sup> Patients with HGG make up >75% at diagnosis, and those with the poorest prognosis, glioblastoma multiforme (GBM), account for >50%. HGG median survival is 6 months to 3 years, with an average of 14 months.<sup>4</sup> Treatment for this group focuses on increasing overall survival time and improving quality of life. With such a poor and often shortened prognosis, ACP should begin at diagnosis.

Leckie and Enns identified the importance of introducing earlier discussions and planning about end-of-life care in the neurooncology population, particularly because these patients often present with motor and cognitive deficits in addition to their poor prognosis. A new multidisciplinary brain metastases clinic established with palliative care consultants, radiation oncologists, a spiritual care consultant and an advanced practice nurse identified the benefits of this process. With the inclusion of palliative care consultants, both medical treatment and end-of-life care were discussed with patients and their families at the onset of the diagnosis of brain metastases. Integrating these conversations at the time of the initial consultation helped to clarify the goals of

This time is particularly stressful as the prognosis is dire, life expectancy is short, and patients experience cognitive changes. It is important for patients and their caregivers to understand the illness and treatment options, and for healthcare providers to recognize how patients' values, beliefs and wishes inform their decision making regarding their care.

ACP enhances communication and ensures that healthcare decisions are based on a shared understanding of the benefits and burdens of treatments, as well as patients' goals and wishes. These conversations often take place late, when urgent end-of-life decisions are being made, rather than at the time of diagnosis. Incorporating ACP into clinic routines earlier and regularly normalizes the process and ensures patients' opportunity to contribute.

care and avoid prolonging treatments that weren't effective.

Patients and families welcomed these discussions and felt they promoted informed decision making with the healthcare team. Caregivers experienced a shift in their roles, as their loved ones were often completely dependent on them for all life skills and finances (for example, patients are often unable to drive and return to work after a diagnosis). While these shifting responsibilities increased anxiety about end-of-life decisions, the introduction of ACP discussions enhanced decision making and decreased stress for caregivers as their loved ones' wishes became clearer.

The neurooncology team members utilize the "My Voice" workbook, available online at [www.calgaryhealthregion.ca/programs/advancecareplanning](http://www.calgaryhealthregion.ca/programs/advancecareplanning), to help individuals consider options about future healthcare decisions and identify their wishes. The workbook can also be a useful guide for others

## IN BRIEF

### Already known

- Advance care planning (ACP) avoids prolonging ineffective treatments and helps to prepare patients and their families for the end of life and death.

### What this study showed

- Patients and families welcomed the process and felt it improved informed decision making.

### Next steps

- Further experience will evaluate the impact of ACP on planned outcomes.

when patients are no longer able to speak for themselves on questions regarding: who they wish to speak on their behalf; the type of treatment they would want/not want; their wishes for their end-of-life experience; and the values that guided them in making those significant decisions.

The experience of the multidisciplinary brain metastases team was very positive and will be used to guide the team members in the implementation and evaluation of ACP for the neurooncology population in the future.

**References**

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**Disclosure:**

The author reports no conflicts of interest relevant to this article.