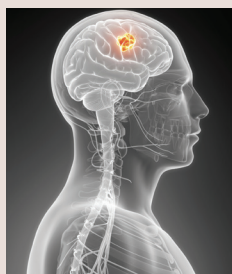


Australian Experience of Neuro-Oncology Care Coordination: A Conversation

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Background: The role of care coordinator was introduced to support patients, caregivers, and healthcare professionals who work within a specialty, as well as to optimize and standardize care. Specifically, the role of neuro-oncology care coordinator is a developing one—and one that has encountered various barriers and difficulties. Patients diagnosed with neurologic cancer must endure a disease trajectory and multimodal treatment approach that present unique challenges to themselves and to the healthcare system. Consequently, the care coordinator role is needed.

Objectives: This article focuses on the role of the neuro-oncology care coordinator, including its challenges, the needs of patients with neurologic cancer, and the benefits this role can bring.

Methods: Three neuro-oncology care coordinators from New South Wales, Australia, discussed their role in the healthcare system via structured meetings, conversations, and email correspondence.

Findings: Making others aware of the issues faced by neuro-oncology care coordinators, as well as their patients, may help to solidify necessary supportive roles within the healthcare system.

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Neuro-oncology is a unique field of nursing practice relating to primary and metastatic tumors within the central nervous system, including the brain and spine. The term *primary brain tumor* (PBT) is used to describe tumors originating in the brain, excluding tumors that have metastasized to the brain from other primary cancers. More than 100 known brain and spinal tumors exist. However, a glioma, which is the most common PBT, is often malignant (Cancer Council NSW, 2011). Gliomas can arise from two different cells of origin—oligodendrocytes and astrocytes—and range in grade from 1–4. Grades 1 and 2 are considered to be low grade, or benign, whereas grades 3 and 4 are considered to be malignant, or cancerous. The introduction of the Stupp protocol for grade 4 gliomas—which involves treatment with radiation and chemotherapy combined, followed by six months of adjuvant chemotherapy—increased the two-year survival rate from about 10% to 27% (Stupp et al., 2005). However, grade 4 gliomas still have an average survival of only 12–14 months (Cancer Council Australia, 2011). In Australia,

1,724 cases of brain cancer were diagnosed in 2011, with 1,241 resultant deaths (Cancer Australia, 2014b).

A cancer diagnosis is a significant psychological burden, influencing not only the well-being of the person diagnosed but also that of his or her family and friends (Palos & Hare, 2011). PBTs, whether malignant or benign, glioma or otherwise, are often associated with significant disability (Cahill & Armstrong, 2011). Depending on the location and size of the PBT, the patient diagnosed will live with varying degrees of neurologic deficit and/or neurocognitive burden. PBTs differ from other tumors in that patients will experience physical and/or cognitive dysfunction (e.g., aphasia, hemiparesis, behavioral changes) throughout their illness. Such dysfunction may affect patients' ability to perform activities of daily living and meet the financial, social, and familial obligations they may previously have been able to support (Madsen & Poulsen, 2011). Therefore, in addition to a poor prognosis, those affected by PBTs may deal with disability, personality and behavior changes, and impaired decision making (Cahill & Armstrong, 2011).