

Palliative care in neuro-oncology: The elephant in the room

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Extract

Palliative care is still relatively unknown and commonly mistaken for hospice care by the general public (certainly in the United States), and many who work in healthcare themselves do not know the difference. Oncologists including neuro-oncologists like all other clinicians are responsible for providing primary palliative care to their patients—the people they are privileged to care for.^{1–3} In this issue of Neuro-Oncology Practice, Crooms and colleagues report on their study exploring themes elicited from 10 neuro-oncologists (2 had also completed hospice and palliative medicine fellowship) about their role in providing primary palliative care and 10 specialty palliative care physicians about their role in providing palliative care for persons with high-grade glioma in light of the low referral rates to specialty palliative care despite well-recognized high multidimensional palliative care needs of persons living with high-grade glioma.⁴ Neuro-oncologists as “medical home” leaders and the most consistent of all clinicians across the disease trajectory emerged as “a source of hope in the face of incurable, rapidly progressive illness” which also cultivated a sense of obligation to serve as a sole support when the end of life phase arrives. This then confounds their referral to specialty palliative care lest it be viewed by patients as an outsourcing of goals of care and advancing care planning discussions. Interestingly, the neuro-oncologists interviewed considered the timing of specialty palliative care’s role to be at the end of life. And they expressed concerns about their patients experiencing distress when recommended they be referred to specialty palliative care given the perception that this signals the end-of-life phase has arrived. If patients are only referred to specialty palliative care when they are at the end-of-life phase, it becomes a self-fulfilling prophesy that only people who are dying are seen by specialty palliative care. Conspicuously absent were comments about how frightened, isolated, and overwhelmed patients and their caregivers might feel as they experience the clinical decline which they know will ultimately end in death and the consideration of prioritizing their need to address death and dying, to support them in achieving other things they are hoping for from their list of goals and must-do tasks such as mending relationships, family events, legacy work, financial affairs, arrangements for being able to die in their place of choice. It is once the end of life arrives that the biomedical model dedicated to managing the disease has run its course and is ceded to the biopsychosocial model dedicated to the illness experience of the person when all along both could have been delivered concurrently, avoiding abrupt step-offs in care for all involved.