

## Brief Communication

### Embedding palliative care in a neuro-oncology clinic at an academic medical center: Our structure, experience, and lessons learned

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**Though patients with Glioblastoma (GBM) and other advanced brain tumors meet nationally-defined criteria for early palliative care (PC),<sup>1,2</sup> PC referrals occur less frequently and later in the disease trajectory than for most other cancers.<sup>3,4</sup> This presents potential missed opportunities for PC clinicians to assist with symptom optimization and advance care planning conversations earlier in illness. To address this, we embedded a PC physician within the UCSF Brain Tumor Center. As there are limited published data on PC integration in NeuroOncology,<sup>3,5</sup> in this “Brief Communication” we describe our structure, descriptive data, and lessons learned from our 21-month pilot.**

The UCSF Brain Tumor Center sits within an urban, quaternary care academic medical center staffed by five neuro-oncology (NO) physicians, nurses, one social worker (SW), and robust supportive care services (The Gordon Murray Caregiver Program, The Sherri Sobrato Brisson Survivorship Program, and a Neuro-Cognitive Clinic). After a year of planning meetings between the palliative care (PC) physician, a NO physician champion, and other key stakeholders to discuss current NO and PC resources and model structure, we launched an in-person, embedded PC physician-run clinic, co-located one half-day per week in the BrainTumor Center in September 2019. The PC physician determined when to offer telemedicine video visits (accounting for patients’ cognitive and technological abilities), home visits, and/or include the SW in the PC visit. The PC and NO physicians co-managed patients. Patients were enrolled by NO clinician referral throughout the 21-month pilot. We encouraged PC referrals for glioblastoma (GBM) patients within 3 months of diagnosis, and other brain tumor patients with specialty PC needs. We attempted to alternate NO and PC appointments monthly to ensure clinical follow-up. The PC clinic shifted exclusively to video visits during COVID-19.

In response to an observed need, in September 2020, we established a 30-minute, bimonthly interdisciplinary meeting

for the PC physician, SW, select NO physicians, and supportive care staff to discuss shared patients. We established monthly meetings to discuss programmatic development across the supportive care service groups, including PC. The PC physician joined “The Honor Project,” a monthly ceremony to honor deceased patients cared for by the Brain Tumor Center team.

Demographic data were extracted from the electronic medical record and recorded in the Palliative Care Quality Network Database.<sup>6</sup> At the visit end, the PC physician recorded the three content areas prioritized during the visit: rapport/relationship building, illness understanding, cancer treatment decisions, coping, symptom management, and/or advance care planning.<sup>7</sup> To report on full courses of longitudinal PC, we limited much of our analysis to the 147 visits encompassing 22 GBM patients who died and had at least 3 visits with the embedded PC physician. We placed these visits into categories: first (n = 22), middle (n = 103), and last visit (n = 22). We used percentages to describe the proportion of first, middle, and last visits that addressed particular content areas.

The following surveys were sent: (1) an electronic, satisfaction survey for the patient or family caregiver to complete 9 months into the clinic launch (modeled after a satisfaction survey commonly used at UCSF); (2) an electronic survey for the NO physician to complete at the pilot end. These NO physician survey data were reviewed by the PC physician, NO physician champion, and SW, and collaborated on four “Lessons Learned.” The UCSF Institutional Review Board approved this project.

Between September 4, 2019 and June 23, 2021 (21 months), 66 unique patients with GBM (n = 52) and lower-grade gliomas (n = 14) were seen by PC. We conducted 282 PC visits, 89% by telemedicine (Figure 1a).

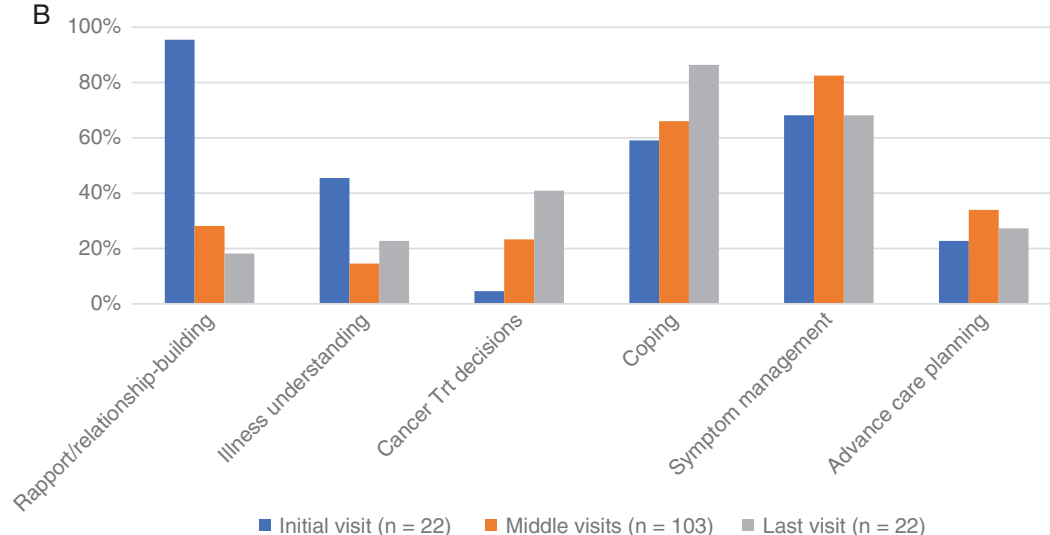
Twenty-two patients with GBM who died had 3 or more PC visits. The majority were white, on first-line treatment, with a median age of 58 years. The median number of PC visits per

A

|   | GBM<br>(n = 52) | GBM Died,<br>3+ PC visits (n = 22) | Lower-grade<br>glioma* (n = 14) |
|---|-----------------|------------------------------------|---------------------------------|
| Median age (yrs)                                    | 61.3            | 57.8                               | 42                              |
| Women N (%)   | 26 (50%)        | 11 (50%)                           | 3 (21%)                         |
| White/caucasian N (%)                               | 44 (85%)        | 21 (95%)                           | 13 (93%)                        |
| Median time from diagnosis to<br>initial PC consult | 15 months       | 14 months                          | 25 months                       |
| On first line treatment N (%)                       | 34 (65%)        | 16 (73%)                           | 12 (86%)                        |
| Median # PC visits/pt                               | 3               | 6.7                                | 3                               |
| Died N (%)  | 37 (71%)        | 22 (100%)                          | 1 (7%)                          |
| 3+ PC visits N (%)                                  | 22 (42%)        | 22 (100%)                          | 10 (71%)                        |

\*Includes patients with astrocytomas (10) or oligodendrogliomas (4).

B



**Figure 1.** (a) Characteristics of brain tumor patients seen by PC embedded in NO. (b) PC visit activity frequency for patients with GBM and 3+ PC visits. Abbreviations: GBM, glioblastoma; NO, neuro-oncology; PC, palliative care.

patient was 6.7. The PC clinician completed a Physician Orders for Life-Sustaining Treatment (POLST) form (a medical order specifying the types of medical treatments a person wishes to receive) with 12 of the 21 patients without one already. Twenty of the 22 patients enrolled in hospice before death, though the timing from enrollment to death was not analyzed.

Rapport-building was the most common activity in the first PC visit and declined over time. Symptom management was frequent across visits, as was supporting coping, which increased in frequency as patients neared death. We performed advance care planning in one-quarter of visits across time (Figure 1b).

Fourteen of the 34 participants (6 patients, 8 caregivers) completed the survey; 79% indicated they would recommend the embedded PC clinic to others. The most frequently reported benefits of PC visits were attention to practical considerations for staying healthy at home, discussing preferences for future medical care, and coping assistance.

Lessons learned from our pilot include:

- (1) A *flexible* clinical model that includes telemedicine, home, and in-person visits may expand PC access to patients with high symptom burden and/or debility.
- (2) *Staggering* NO and PC visits (eg, alternating monthly) may facilitate closer monitoring of symptomatic and/or frail patients; PC by telemedicine makes staggering appointments more possible since it alleviates the burden of traveling to the clinic.
- (3) It is critical to *coordinate* PC with other supportive service offerings to discuss shared patients and align resources.
- (4) An embedded PC-NO model takes time to plan and maintain. *Protected administrative time* and funding should be considered upfront.

The PC-NO clinic was feasible and well received by patients, caregivers, and NO clinicians. In our pilot, symptom

management was one of the most frequently reported PC activities. The symptom burden of patients with brain tumors is significant and differs from other solid tumors.<sup>8–10</sup> Future research to understand the impact of PC involvement on patient-reported symptoms longitudinally will help define PC's role and potentially strengthen the value proposition for PC-NO integration.

The PC-NO clinic continues as an embedded and increasingly integral component of the UCSF Brain Tumor Center. To promote earlier, more timely referrals, we are considering referral standardization for targeted brain tumor populations and the use of validated screening tools that predict PC needs.<sup>5,11</sup> We are also working to include integrative medicine, palliative care in-home assessments, and group visits into our PC offerings.

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## References

1. Dans M, Kutner JS, Agarwal R, et al. NCCN guidelines<sup>®</sup> insights: palliative care, version 2.2021. *J Natl Compr Canc Netw*. 2021;19(7):780–788.
2. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol*. 2017;35(1):96–112.
3. Walbert T. Integration of palliative care into the neuro-oncology practice: patterns in the United States. *Neurooncol Pract*. 2014;1(1):3–7.
4. Hemming LE, Pittman CA, Korones DN, et al. Palliative and end-of-life care in glioblastoma: defining and measuring opportunities to improve care. *Neurooncol Pract*. 2017;4(3):182–188.
5. Kim JY, Peters KB, Herndon JE, Affronti ML. Utilizing a palliative care screening tool in patients with glioblastoma. *J Adv Pract Oncol*. 2020;11(7):684–692.
6. Pantilat SZ, Marks AK, Bischoff KE, Bragg AR, O'Riordan DL. The palliative care quality network: improving the quality of caring. *J Palliat Med*. 2017;20(8):862–868.
7. Hoerger M, Greer JA, Jackson VA, et al. Defining the elements of early palliative care that are associated with patient-reported outcomes and the delivery of end-of-life care. *J Clin Oncol*. 2018;36(11):1096–1102.
8. Walbert T, Khan M. End-of-life symptoms and care in patients with primary malignant brain tumors: a systematic literature review. *J Neurooncol*. 2014;117(2):217–224.
9. Forst DA. Palliative and supportive care in neuro-oncology. *Continuum*. 2020;26(6):1673–1685.
10. Armstrong TS, Vera-Bolanos E, Acquaye AA, et al. The symptom burden of primary brain tumors: evidence for a core set of tumor- and treatment-related symptoms. *Neuro Oncol*. 2016;18(2):252–260.
11. Seekatz B, Lukasczik M, Löhr M, et al. Screening for symptom burden and supportive needs of patients with glioblastoma and brain metastases and their caregivers in relation to their use of specialized palliative care. *Support Care Cancer*. 2017;25(9):2761–2770.