

Prognostication in Hospice Care: Challenges, Opportunities, and the Importance of Functional Status

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Background: Predicting life expectancy and providing an end-of-life diagnosis in hospice is very challenging for most clinicians given their generally poor training for this role and limited medical education. End-of-life diagnosis alone is often used to certify hospice appropriateness. It is essential, however, to document good supporting evidence of decline and comorbidities. Functional status can be a helpful criterion prior to hospice admission and during required 90-day certifications.

Case Presentation: An 80-year-old male who was diagnosed with Stage IV glioblastoma multiforme was transferred from an acute care hospital to a community living center hospice service for end-of-life care. After 6 months of care, the veteran was able to graduate from hospice and transfer to an adult living facility with minimal care needs. **Conclusions:** Recognizing the importance of documenting and using functional scales in individuals receiving hospice care is extremely helpful in prognostication.

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Predicting life expectancy and providing an end-of-life diagnosis in hospice and palliative care is a challenge for most clinicians. Lack of training, limited communication skills, and relationships with patients are all contributing factors. These skills can improve with the use of functional scoring tools in conjunction with the patient's comorbidities and physical/psychological symptoms. The Palliative Performance Scale (PPS), Karnofsky Performance Scale (KPS), and Eastern Cooperative Oncology Group Performance Status Scale (ECOG) are commonly used functional scoring tools.

The PPS measures 5 functional dimensions including ambulation, activity level, ability to administer self-care, oral intake, and level of consciousness.¹ It has been shown to be valid for a broad range of palliative care patients, including those with advanced cancer or life-threatening noncancer diagnoses in hospitals or hospice care.² The scale, measured in 10% increments, runs from 100% (completely functional) to 0% (dead). A PPS \leq 70% helps meet hospice eligibility criteria.

The KPS evaluates functional impairment and helps with prognostication. Developed in 1948, it evaluates a patient's functional ability to tolerate chemotherapy, specifically in lung cancer, and has since been validated to predict mortality across older adults and in chronic disease populations.^{3,4} The KPS is also measured in 10% increments ranging from 100% (completely functional without assistance) to 0% (dead). A KPS \leq 70% assists with hospice eligibility criteria (Table 1).⁵

Developed in 1974, the ECOG has been identified as one of the most important functional status tools in adult cancer care.⁶ It describes a cancer patient's functional ability, evaluating their ability to care for oneself and participate in daily activities.⁷ The ECOG is a 6-point scale; patients can receive scores ranging from 0 (fully active) to 5 (dead). An ECOG score of 4 (sometimes 3) is generally supportive of meeting hospice eligibility (Table 2).⁶

CASE PRESENTATION

An 80-year-old patient was admitted to the hospice service at the Veterans Affairs Puget Sound Health Care System (VAPSHCS) community living center (CLC) in Tacoma, Washington, from a community-based acute care hospital. His medical history included prostate cancer with metastasis to his pelvis and type 2 diabetes mellitus, which was stable with treatment with oral medication. Six weeks earlier the patient reported a severe frontal headache that was not responding to over-the-counter analgesics. After 2 days with these symptoms, including a ground-level fall without injuries, he presented to the VAPSHCS emergency department (ED) where a complete neurological examination, including magnetic resonance imaging, revealed a left frontoparietal brain lesion that was 4.2 cm \times 3.4 cm \times 4.2 cm.

The patient experienced a seizure during his ED evaluation and was admitted for treatment. He underwent a craniotomy where most, but not all the lesions were successfully removed. Postoperatively, the patient exhibited right-sided

TABLE 1 Karnofsky Performance Scale⁵

Score, %	Description
100	Normal; no complaints; no evidence of disease
90	Able to carry on normal activity; minor signs or symptoms of disease
80	Normal activity with effort; some signs or symptoms of disease
70	Cares for self; unable to carry on normal activity or do work
60	Requires occasional assistance, but is able to care for most personal needs
50	Requires considerable assistance and frequent medical care
40	Disabled; requires special care and assistance
30	Severely disabled; hospitalization indicated although death not imminent
20	Very sick; hospitalization necessary; requires active support treatment
10	Moribund; fatal processes progressing rapidly
0	Dead

neglect, gait instability, emotional lability, and cognitive communication disorder. The patient completed 15 of 20 planned radiation treatments but declined further radiation or chemotherapy. The patient decided to halt radiation treatments after being informed by the oncology service that the treatments would likely only add 1 to 2 months to his overall survival, which was < 6 months. The patient elected to focus his goals of care on comfort, dignity, and respect at the end of life and accepted recommendations to be placed into end-of-life hospice care. He was then transferred to the VAPSHCS CLC in Tacoma, Washington, for hospice care.

Upon admission, the patient weighed 94 kg, his vital signs were within reference range, and he reported no pain or headaches. His initial laboratory results revealed a 13.2 g/dL hemoglobin, 3.6 g/dL serum albumin, and a 5.5% hemoglobin A_{1c}, all of which fall into a normal reference range. He had a reported ECOG score of 3 and a KPS score of 50% by the transferring medical team. The patient's medications included scheduled dexamethasone, metformin, senna, levetiracetam, and as-needed midazolam nasal spray for breakthrough seizures. He also had as-needed acetaminophen for pain. He was alert, oriented ×3, and fully ambulatory but continuously used a 4-wheeled walker for safety and gait instability.

After the patient's first night, the hospice team

met with him to discuss his understanding of his health issues. The patient appeared to have low health literacy but told the team, "I know I am dying." He had completed written advance directives and a Portable Order for Life-Sustaining Treatment indicating that life-sustaining treatments, including cardiopulmonary resuscitation, supplemental mechanical feeding, or intubation, were not to be used to keep him alive.

At his first 90-day recertification, the patient had gained 8 kg and laboratory results revealed a 14.6 g/dL hemoglobin, 3.8 g/dL serum albumin, and a 6.1% hemoglobin A_{1c}. His ECOG score remained at 3, but his KPS score had increased to 60%. The patient exhibited no new neurologic symptoms or seizures and reported no headaches but had 2 ground-level falls without injury. On both occasions the patient chose not to use his walker to go to the bathroom because it was "too far from my bed." Per VA policy, after discussions with the hospice team, he was recertified for 90 more days of hospice care. At the end of 6 months in CLC, the patient's weight remained stable, as did his complete blood count and comprehensive medical panel. He had 1 additional noninjurious ground-level fall and again reported no pain and no use of as-needed acetaminophen. His only medical complication was testing positive for COVID-19, but he remained asymptomatic. The patient was graduated from hospice care and referred to a nearby non-VA adult family home

TABLE 2 Eastern Cooperative Oncology Group Performance Status Scale⁶

Score	Description
0	Fully active, able to carry on all predisease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature (eg, light housework or office work)
2	Ambulatory and capable of self-care but unable to carry out any work activities; up and about > 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair > 50% of waking hours
4	Disabled; unable to perform any self-care and totally confined to bed or chair
5	Dead

in the community after 180 days. At that time his ECOG score was 2 and his KPS score had increased to 70%.

DISCUSSION

Primary brain tumors account for about 2% of all malignant neoplasms in adults. About half of them represent gliomas. Glioblastoma multiforme derived from neuroepithelial cells is the most frequent and deadly primary malignant central nervous system tumor in adults.⁸ About 50% of patients with glioblastomas are aged \geq 65 years at diagnosis.⁹ A retrospective study of Centers for Medicare and Medicaid Services claims data paired with the Surveillance, Epidemiology, and End Results database indicated a median survival of 4 months for patients with glioblastoma multiforme aged > 65 years, including all treatment modalities.¹⁰ Surgical resection combined with radiation and chemotherapy offers the best prognosis for the preservation of neurologic function.¹¹ However, comorbidities, adverse drug effects, and the potential for postoperative complications pose significant risks, especially for older patients. Ultimately, goals of care conversations and advance directives play a very important role in evaluating benefits vs risks with this malignancy.

Our patient was aged 80 years and had previously been diagnosed with metastatic prostate malignancy. His goals of care focused on spending time with his friends, leaving his room to eat in the facility dining area, and continuing his daily walks. He remained clear that he

did not want his care team to institute life-sustaining treatments to be kept alive and felt the information regarding the risks vs benefits of accepting chemotherapy was not aligned with his goals of care. Over the 6 months that he received hospice care, he gained weight, improved his hemoglobin and serum albumin levels, and ambulated with the use of a 4-wheeled walker. As the patient exhibited no functional decline or new comorbidities and his functional status improved, the clinical staff felt he no longer needed hospice services. The patient had an ECOG score of 2 and a KPS score of 70% at his hospice graduation.

Medical prognostication is one of the biggest challenges clinicians face. Clinicians are generally “over prognosticators,” and their thoughts tend to be based on the patient relationship, overall experiences in health care, and desire to treat and cure patients.¹² In hospice we are asked to define the usual, normal, or expected course of a disease, but what does that mean? Although metastatic malignancies usually have a predictable course in comparison to diagnoses such as dementia, chronic obstructive pulmonary disease, or congestive heart failure, the challenges to improve prognostic ability and predict disease course continue.¹³⁻¹⁵ Focusing on functional status, goals of care, and comorbidities are keys to helping with prognosis. Given the challenge, we find the PPS, KPS, and ECOG scales important tools.

When prognosticating, we attempt to define quantity and quality of life (which our patients must define independently or from

the voice of their surrogate) and their ability to perform daily activities. Quality of life in patients with glioblastoma is progressively and significantly impacted due to the emergence of debilitating neurologic symptoms arising from infiltrative tumor growth into functionally intact brain tissue that restricts and disrupts normal day-to-day activities. However, functional status plays a significant role in helping the hospice team improve its overall prognosis.

CONCLUSIONS

This case study illustrates the difficulty that comes with prognostication(s) despite a patient's severely morbid disease, history of metastatic prostate cancer, and advanced age. Although a diagnosis may be concerning, documenting a patient's status using functional scales prior to hospice admission and during the recertification process is helpful in prognostication. Doing so will allow health care professionals to have an accepted medical standard to use regardless how distinct the patient's diagnosis. The expression, "as the disease does not read the textbook," may serve as a helpful reminder in talking with patients and their families. This is important as most patient's clinical disease courses are different and having the opportunity to use performance status scales may help improve prognostic skills.

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Disclaimer

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Ethics and consent

Written informed consent was obtained from the patient and patient identifiers were removed to protect the patient's identity.

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