When Have We Done Enough? Provider-Patient Discord in Terminal Head and Neck Cancer

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Case
The patient is a 43-year-old man with T4bN1M0 squamous cell carcinoma of the hypopharynx. He initially elected treatment with definitive chemoradiation. Five months later, he had a local recurrence. He was in poor health at this time and deferred salvage surgery in favor of palliative chemotheraphy. He declined the offer of do not resuscitate (DNR) status and opted for all available therapeutic measures with the goal of prolonged life. He presented with hemoptysis 8 months after initial treatment and eventually required cardiopulmonary resuscitation. Angiography revealed a carotid artery pseudoaneurysm, which was treated with an endovascular stent in the same setting. He recovered without cognitive issues and met with the palliative care team. His significant disease burden, poor prognosis, and various care options were presented to him and his family. He deferred hospice care and remained insistent on surgical cure. He was discharged to home with full-code status. He was brought in 9 days later after being found unresponsive. He was resuscitated, and angiography demonstrated brisk bleeding adjacent to his previous stent. A second endovascular procedure with stent placement was performed. He recovered and agreed to DNR with hospice. He was discharged and died 2 weeks later. This case was exempt from review by the Institutional Review Board of the University of Nebraska Medical Center.

Point: Physicians Should Caution against Heroic Lifesaving Measures for Patients with Terminal Disease
This narrative is not rare during end-of-life care. Many providers are willing to perform heroic procedures in the terminal phase of patient care. In this narrative, heroic implies taking an excessive risk to obtain an expected outcome. These risks are often well motivated and may include comfort measures or lifesaving procedures to allow time to say goodbye to loved ones. However, patient goals may change on weekly or even daily basis, depending on new clinical information. Additionally, some patients struggle to fully understand the terminal nature of their disease, mistaking palliative measures, such as those described here, as treatments of their underlying disease even when the disease has progressed beyond a curable state. Previous studies demonstrated that patients and providers are not often in tune with each other during the terminal phases of care. This disconnect may cause a patient to maintain unachievable goals, as demonstrated in the present case. Because of an unrealistic focus on cure, this patient received 2 costly and high-risk procedures “so he could keep on fighting.” While the appropriateness of these interventions for this patient and others like him cannot be proven, it is certainly questionable. There is a 10% to 30% mortality rate for patients receiving endovascular embolization or carotid stenting for a carotid blow-out, and rebleeding may occur for 20% to 45% of patients.1 It is difficult to predict which patients will benefit from the intervention, but it is always a trying experience for patients and their loved ones due to the associated financial costs and the mental toll of such an emotionally traumatic experience. This highlights the need for intentional directed conversations between patients and trusted providers who have developed strong rapport with the patient and his or her family. Strong consideration should also be given to early consultation from a palliative care, hospice, or ethics team.

In the case presented here, the patient had known residual disease and was deemed too high risk to undergo surgery to treat his hypopharyngeal disease. The patient required counseling to define the goals of care, including the definitions of appropriate and inappropriate care. For a patient with terminal disease manifesting signs of approaching death, such as carotid exposure with blowout, one would likely consider

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invasive and expensive interventions with minimal life-prolonging benefit to be inappropriate. In 2015, the American Thoracic Society, in combination with several other societies, published a consensus statement on how to respond to requests for inappropriate treatment. Their first recommendation is the most widely applicable, with an emphasis on proactive communication strategies and early involvement of expert consultants (including palliative care and ethics).

While end-of-life discussions begin with the primary treating physician or the hospice or palliative care team, involvement should be considered soon thereafter. Incorporation of palliative medicine early within the process of a cancer diagnosis improves patient quality of life and mood, and early incorporation of palliative services leads to diminished emergency room visits, hospitalizations, and hospital deaths.

Additionally, head and neck cancers already rank among the most expensive cancers to treat, especially when multiple modalities are employed. Hospice services for terminally ill patients with head and neck cancer were shown to effectively reduce all care costs within the last month of life. As mentioned, this does not even account for the emotional turmoil experienced by patients and their families during aggressive end-of-life interventions.

In this case, we believe that resuscitation and carotid artery repair should not have been offered at all, especially in the context of unresectable recalcitrant malignancy with poor chance of meaningful life prolongation. Patients may choose costly and toxic treatment options despite poor prognosis and significant adverse side effects. Patients may choose to suffer physically, emotionally, and financially to “fight on.” A physician’s responsibility includes protecting patients from poor decisions that may damage them and their families. This may be accomplished through informing and educating. In the current case, the patient’s perception of his disease fueled 2 extreme interventions without change in his final outcome or significant improvement in his quality of life. It falls to the physicians to maintain their conviction in a particular treatment or nontreatment option, even to the point of refusing to participate in potentially inappropriate treatments when they may potentially lead to increased patient suffering. The American Thoracic Society guidelines recommend that in such cases, it is vital that providers perform due diligence for their patients, which may include options ranging from a second medical opinion to transfer to an alternate institution.

In this case, earlier consultation with palliative or hospice services may have been warranted. If other providers and patients are unable to reach a consensus about management, then clear limits should be established to guard against potentially inappropriate treatments.

**Counterpoint: Physicians Should Encourage Any Lifesaving Measures for Patients with Terminal Disease**

One of the core principles of modern medicine is patient-centered care. Patient autonomy has been championed and encouraged as the era of more paternalistic medical practice has passed away. Therefore, the importance of allowing patients to make their own decisions regarding end-of-life care, with appropriate guidance, cannot be ignored. This patient cannot be simply pushed by his care team into “comfort care” or DNR status; he must instead be helped to make these decisions when he is ready. Maslow’s hierarchy of needs is a popular basis for many patient-center medical endeavors, including hospice care, and includes the concept of self-actualization at the peak. In terminal care of head and neck cancer, self-actualization must be the ideal goal to give patients and families the opportunity to grieve and come to a proper end-of-life care plan. More basic needs related to safety and physiology can be met through medication administration and skilled caregivers, but the higher-order needs require more personal involvement with the patients. Much focus is often given to the cost of these end-of-life procedures, but we cannot focus on the patients as solely items on a balance sheet and instead must consider these costs in the context of patient experience and adjustment to death.

To help control medical costs, we should approach end-of-life decisions more aggressively early in the treatment of patients with more advanced head and neck cancer. Indeed, for patients pursuing treatment for stage III and IV disease, we should consider palliative discussions and decision making on end-of-life issues even during curative-intent treatment. This allows patients the time during treatment to consider the many options and be supported in the decisions that they make. In this way, they can more appropriately decide when enough has been done. It may thus be possible to guide some patients toward more conservative measures earlier than expected by the treatment team. However, should patients decide that they wish to pursue invasive or costly medical treatments despite the possibility of minimal to no clinical benefit, it is up to the care team to help them in feasible ways or provide them with the resources to pursue care at other centers. Ethics consultation may be useful to aid in these discussions when there is significant disagreement between the treatment team and the patient. Even in these cases, though, there is a significant cohort of patients who will still wish for “full code” status, and they must be respected within the capabilities of modern medicine.

It is difficult to determine what inappropriate life-extending care consists of, as our technology and surgical techniques continue to evolve. This was demonstrated by a recent study of surgical palliation where the majority of patients had palliative surgical procedures for bleeding as a result of their advanced tumors. Surgical procedures included carotid artery ligation as well as tumor debulking, and the studied population survived >5 months on average following surgical palliation. Advancing technology permitted us in this case to accomplish full-length carotid repair through an endovascular approach without cutting off blood flow to the brain, which allowed our patient to prolong life with only a short hospital stay. It may also have given him and his family members the time to come to
terms with his death. While going through this process, our patient was able to come to terms with his status, and he elected to pursue hospice treatment of his own accord. He then spent 2 more weeks with his family, gaining peace with his decisions and with all parties and knowing that he was not forced into the situation without consideration for the importance of his autonomy.

It is nevertheless imperative that physicians recognize what constitutes inappropriate treatment and that they be willing to state this opinion explicitly to patients or families. Early discussions and communication among the physician, patient, family, and remaining care partners are critical. Patients who are not ready to end their commitment to life-sustaining treatments, however, must be helped to come to this decision of their own accord and not be forced to withdrawal of care due to concerns about health care costs or the beliefs of the physician regarding the futility of the procedures.

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Jason Talmadge, design of the work, drafting, final approval, accountability for all aspects of the work; Paul Judge, substantial contributions to the conception of the work, drafting of the paper, revising for important intellectual content, final approval of the paper, and accountability for all aspects of the work; Zafar Sayed, conception/design of the paper, drafting, revising, final approval of the paper, and accountability for all aspects of the work.

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