The Role and Use Of Diagnostic Tests and Invasive Procedures

Several questions should be considered in determining the appropriateness of aggressive medical or palliative interventions near the end of life: What is the goal or expected outcome of the proposed intervention? What is the probable efficacy of the intervention? What is the patient's baseline level of function and life expectancy? What are the potential side effects and burdens of the intervention? What are the patient's and family's wishes, values, and preferences?

The range of medical and palliative options available is huge, so the challenge is to determine what makes sense to enhance the well-being of this patient at this particular stage of illness. Palliative interventions range from pure symptom management and support to invasive options, such as chemotherapy, radiotherapy, surgical/endoscopic interventions, stenting procedures, thoracentisis, paracentesis, pericardiocentesis, home inotropic therapy, non-invasive ventilation, antibiotics, or transfusions. The challenge is to individualize discussions, so that patients can take full advantage of treatments that will help them meet their goals without having their experience dominated by near futile invasive interventions.

The Role of Hospice

Hospice care is a specialized form of palliative care aimed at those patients and families in the terminal stages of illness. In 2011, 1.65 million patients were served by hospice programs in the United States. Median length of stay on hospice is less than 3 weeks. In order to qualify for the Medicare Hospice Benefit, two physicians must sign a statement certifying that the patient's prognosis for survival, if the disease runs its natural course, is likely to be 6 months or less. Hospice criteria exist to assist in making these determinations for common medical conditions. Hospice care can be delivered in hospitals, patient's homes, nursing homes, or dedicated "hospice houses." The Medicare Hospice Benefit covers most costs related to terminal care without a deductible, which includes palliative medications, nursing oversight, supplies, and bereavement care. Hospice also covers up to 4 hours of custodial caregiver services per day; however, family and/or friends must provide the remaining care if the patient is to stay at home. Hospice it does not cover custodial caregiver serives if the patient is admitted to a nursing facility.

Cancer continues to be the most common diagnosis for patients dying in hospice programs. However, the prevalence of non-cancer diagnoses is increasing and now represents more than 50% of all hospice admissions. Discussing hospice with patients and families can be challenging. First, it is often initially viewed as a "bad news" discussion given that patients and families need to confront the fact that disease-directed treatment is no longer effective and that prognosis is likely to be 6 months or less. Second, given the reimbursement restrictions, patients may also need to forgo particular types of treatment that are important to them (e.g., acute hospital or ICU-level care, dialysis, chemotherapy, milrinone for heart failure).

Request for Hastened Death and Last Resort Options

The prevalence of suicidal ideation and suicide attempts is higher in patients with advanced life-limiting illness compared to those without serious disease. In Oregon where physician-assisted suicide is legally permitted (subject to safeguards), the prevalence of a patient's wanting to explore a health care professional's willingness to help hasten death is about 1/50, whereas only about 1/500 die using physician-assisted suicide. The motivation behind such initial explorations may relate to relentless physical suffering, disfigurement, hopelessness, loss of dignity, fear of being a burden, or a "cry for help." Most enduring requests from patients with progressive medical illnesses, however, arise not from inadequate symptom control, but from a patient's belief about dignity, meaning, and control over the circumstances of death. Although some providers might be uncomfortable with exploring such requests, they need to be approached systematically with a diligent search to understand the root causes before responding.

A careful evaluation includes a precise clarification and exploration as to exactly what the patient is asking and why. Is the request based on transient thoughts about ending life (common) or a serious appeal for assistance (relatively rare)? Does the request occur in the context of intense physical suffering, psychological despair, an existential crisis, or a combination of factors? Does the patient have full decision-making capacity? Is the request proportionate to the level of suffering? Evaluating such requests can be emotionally fatiguing and conflicting, and clinicians need self-awareness in distinguishing their emotions from the patient's, including tending to one's own support by sharing the burden of such requests with trusted colleagues.

Responding to such a request should first include intensification of a search for potentially reversible contributions to suffering. This will often include treating physical and psychological symptoms, aggressive attempts to foster hope, consulting psychiatrists or spiritual counselors, and creative brainstorming with trusted colleagues and team members. Some requests for hastened death persist, despite optimal palliative care. In such circumstances, the clinician should seek out a second opinion and confront the possibilities. These possibilities include withdrawal of life-sustaining interventions, palliative sedation, voluntary cessation of oral intake, and assisted suicide (illegal in the United States except for the states of Oregon, Washington, Vermont, and Montana). While it is important to support the patient, the clinician must balance integrity and non-abandonment. This may include drawing specific boundaries of what the clinician can and cannot do, while still searching in earnest for a mutually acceptable solution.

COMMON ETHICAL CHALLENGES IN PALLIATIVE CARE

Inadequate Treatment of Pain and the Myth that Pain Medication Hastens Death

Evidence abounds that pain is under-treated in many medical settings, including those patients who are severely and even terminally ill (especially women, the elderly, minorities and those