

comorbidities (e.g., arthritis, visual impairment, past mild strokes, diabetes with neuropathy). Gradual decline in function, weight loss, fatigue, and low levels of activity are core features. Caregiver burden is usually immense. Prognosticating survival is difficult and complications, such as pneumonia and fractures, may be terminal events. The benefits and burdens of artificial nutrition and hydration must be balanced in the late stages.

Trajectory 4: Sudden, Severe Neurological Injury

Sudden impairment trajectories are those that stem from sudden neurological injury that can lead to profound cognitive and functional impairment. These include stroke, hypoxic ischemic encephalopathy, and traumatic brain injury. The vast majority of deaths occur either early after the event when treatments are withheld or withdrawn, or in the chronic stage in survivors who have accumulating debility (these events represent the leading cause of adult disability). At the extremes of impairment are persistent vegetative states, minimally conscious states, and locked-in syndrome. But there is a vast spectrum of severe impairments short of these extremes that raise questions about how to manage potentially severe debility with little or uncertain chances of improvement. This trajectory requires a health care system responsive to negotiating goals of treatment with patients and surrogates who may consider these future health states to be “worse than death.”

COMMUNICATION SKILLS AND NEGOTIATING GOALS OF TREATMENT

Excellent communication skills are central to palliative care: communication with patients, family, other physicians, nurses, and other members of the health care team. The overarching aim is to assist the patient and family in establishing the goals of current and future treatment in a process of shared decision making. When negotiating goals of treatment in palliative care, the focus is often to assist with the following decisions: to help decide types and aggressiveness of disease-directed therapies; to ensure optimum palliation of symptoms; to assist in hospice determinations; to discuss initiating, withholding or withdrawing therapies; to facilitate advance care planning; and to initiate surrogate decision-making if the patient lacks capacity. These discussions occur at various time points in the course of advancing illness when new and important information is learned and needs to be communicated to the patient and family. The need to renegotiate goals should also be anticipated when triggers of advancing disease suggest limited life expectancy or excessive suffering. These discussions are almost always variants of “bad news” discussions.

The overall approach to communication and negotiating goals of care in each of these scenarios is similar (Table 125-1). This includes running an effective family meeting with or without the patient present. Initial elements include establishing the proper setting, identifying key stakeholders, and “doing your homework” (i.e., discussing potential plans with all relevant subspecialties who may have communicated with the patient and families). When the meeting begins, find out what the patient and family understand about the medical condition and ask about what added information they want. Keeping an open mind and trying

to hold back on a fixed agenda (e.g., to “get the DNR” or to “stop futile care”) helps clinicians allow patients and families sufficient time to “tell their stories” and provides the context within which effective decision making can occur. In general, the more patients and families speak in the early parts of such meetings, the better.

The provider then needs to share prognostic information and discuss the benefits and burdens of the available treatment options. Alerting the patient or family of impending bad news (e.g., “I am afraid I have some difficult news to share with you”) is a useful initial communication strategy. The amount of information should be paced with frequent pauses to allow time for emotional responses. Comprehension should be frequently checked, and questions should be encouraged using an “ask-tell-ask” strategy. The skilled clinician can flexibly assess, probe, and pace the content and depth of the discussion in an emotionally responsive (acknowledge, explore, empathize, and legitimize) and culturally competent manner. This includes the ability to understand and respect diverse religious practices and differing preferences about degree of truth telling. When appropriate, the clinician should make recommendations based on scientific knowledge as well as awareness of a patient’s values and preferences, and be prepared to help resolve conflicts among patient, family members, and providers. Finally, providers need to develop strategies to preserve and potentially reframe hope, including ways to “hope for the best” and simultaneously “prepare for the worst.” Commitments to minimize suffering and to not abandon the patient and family are essential. At the end of the discussions, the provider should summarize key aspects of what was reviewed and establish a follow-up plan for future communications and treatments.

Estimating and Communicating Prognosis

A core component of information shared in the palliative care setting is prognosis. Understanding prognosis is central to making decisions (e.g., treatment, comfort measures, hospice). Prognosis is a prediction of possible future outcomes of a disease (e.g.,

TABLE 125-1 GENERAL STRATEGY FOR COMMUNICATING AND NEGOTIATING GOALS OF CARE IN COMMON PALLIATIVE CARE SETTINGS

Step 1	Prepare and establish setting Do not have a rigid preset agenda
Step 2	Ask patient and family what they know and understand Provide sufficient time for patients and families to “tell their story” Active listening skills
Step 3	Find out how much patient and family want to know Acknowledge and explore emotions
Step 4	Give information in small amounts, and frequently check understanding Discuss prognosis and benefits and burdens of treatment options Be mindful of overly optimistic and pessimistic predictions Be prepared to make recommendations
Step 5	Respond to emotions and empathetic response Convey honesty and reframe hope Use “I wish” statements
Step 6	Summarize, establish and implement plan, follow-up Possible time-limited trial

