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ELDER CARE

A Resource for Interprofessional Providers

Recognition of Advanced Illness and Impending Death

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Recognition of approaching death is a critical skill required of all clinicians who provide care for patients at risk of dying. This skill enables the clinicians to consider a number of important issues. They include whether palliative care and hospice care are needed; whether to hospitalize the patient; or whether to perform cardiopulmonary resuscitation vs. allowing natural death.

Identification of impending death also enables the clinician to inform the patient and family about the prognosis when this information is desired, allowing them to identify goals, priorities, and expectations for their future. It also allows individuals to address existential and spiritual issues as well as to prepare for the end-of-life.

While there is no precise method for determining prognosis, most healthcare workers tend to be overly optimistic about prognosis. This over-optimism can generate false hope and deprive patients and families of the opportunity to use their remaining time in ways that would be most meaningful to them. The online tool ePrognosis (<http://eprognosis.ucsf.edu>) can facilitate the clinical application of prognostic indices and improve decision-making.”

Disease Trajectories

Many chronic illnesses follow a specific pattern of decline which, when recognized, can assist with assigning a prognosis and warn of approaching death. For example, organ failure from chronic heart, lung, kidney and liver disease usually results in a gradual decline, punctuated by acute crises that are followed by partial recovery until a more serious acute episode that results in the patient's death. Degenerative neurologic illnesses and geriatric frailty, on the other hand, usually cause a decline without exacerbations, gradually leading to death. Most fatal cancers initially produce a gradual decline and then a second phase of a more rapid, accelerated decline over a period of weeks or months. Awareness of these general patterns can prove helpful when caring for an individual with a particular disease.

General Concepts Suggesting a Prognosis of Months

Most advanced non-cancer illnesses associated with a survival of less than 6 months often present at an advanced age and with changes that include poor functional status, poor nutritional status, organ dysfunction, co-morbid illnesses, and hospitalizations for acute decompensation.

Solid-organ cancers with a less-than 6-month prognosis generally follow a final common pathway that often includes anorexia, weight loss, declining functional status, brain, spine, or liver metastases, and systemic inflammation.

Hematologic malignancies including leukemia, lymphoma, and myeloma generally have a less-than 6-month prognosis in the setting of advanced age, treatment-refractory disease, disease recurrence after treatment, poor functional status, >50% blasts for the chronic leukemias, marked cytopenias, and central nervous system involvement.

Validated performance tools for cancer patients can help establish <6-month survival. These include a Karnofsky Performance Status score ≤ 50 (patient requires considerable assistance and frequent medical care) and an Eastern Cooperative Oncology Group score ≥ 3 (capable of only limited self care, confined to bed or chair more than 50% of waking hours).

Imminent Death

The final phase of illness, in which death is imminent, is usually manifest by progressive weakness with increased time spent sleeping and in bed, delirium, loss of interest in food and fluids, and dysphagia (see table on next page). Patients also may demonstrate noisy breathing caused by aspiration of oral secretions, apnea or irregular breathing, mottled extremities (livedo reticularis) and/or coma. While not all patients demonstrate all of these signs and symptoms, this description covers much of what may occur.

TIPS

- Be realistic about prognosis. Most healthcare workers overestimate the time until death and doing so may not allow patients and families the opportunity to spend time doing things that match their priorities.
- Communication about prognosis should always be in the form of time ranges without use of specific numbers.
- Imminent death is heralded by declining functional status, alertness, and oral intake, rather than disease-specific signs.

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Continued from front page

Attempts to increase the patient's activity or force food/fluid intake only serve to increase patient discomfort and do not reverse the dying process at this point. Recognition of this final phase with careful attention to the patient and family's needs is a central part of end-of-life care.

During the final hours and days of life, most patients have continuous care needs that can be met in the home, care home, nursing facility, prison, a hospice facility or a hospital with palliative care. Most patients wish to die at home." Specific medical and nursing interventions to palliate the symptoms described above as death approaches are listed in the references/resources at the bottom of this page.

Wherever the final days of life occur, the care environment should allow continuous access to the patient by the family, assuring privacy, and regular support from caregivers. Support to the family and caregivers should include reassurance that what is occurring is a normal part of the death process, along with education about the care that is being provided.

Patients and families may have emotional needs, financial concerns, or questions about mortuary arrangements that can be addressed by a social worker. Asking about spiritual or religious needs can identify opportunities for chaplaincy. Additionally, inquiring about religious affiliation may identify particular rituals before or after death that the patient and family may desire. Finally, keep in mind that in some cultures, it is inappropriate to directly discuss death, even if it is rapidly approaching. The key is communication and the recognition that this experience is unique and emotional for every patient and family.

Signs of Imminent Death	
Increasing weakness	Noisy breathing
Increasing time in bed	Aspiration of secretions
Increasing time sleeping	Apnea
Delirium	Irregular breathing
Loss of interest in food	Mottled extremities
Loss of interest in fluids	Coma

References and Resources

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Salpeter SR, Luo EJ, Malter DS, Stuart B. Systematic review of noncancer presentations with a median survival of 6 months or less. *Am. J. Med.* 2012; 125(5): 512.e1-512.e16.

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Communication About The Dying Process

Communication is important for all involved to ease the distress that centers around a patient's approaching death. Prognosis should always be communicated as a range of time (hours-to-days, days-to-weeks, weeks-to-months.) without specific numbers being mentioned. Be careful to be realistic, and not provide over-optimistic time frames.

Families often ask if the patient is suffering or starving to death once eating has stopped. They may ask if they should stay at the bedside, or if their loved one can hear them. Usually what a family observes seems worse than what a patient experiences. Aggressive palliative care can relieve the symptoms that families perceive as distress.

With regards to the starvation question, decreased intake can be described to the family as the normal way the body shuts down in preparation for death. Artificial hydration and nutrition have not been demonstrated to increase comfort or delay death at the end of life and, in fact they are thought to cause discomfort because of invasive intravenous catheters and/or feeding tubes. In addition, providing fluids at the end of life can cause fluid overload and worsen the respiratory secretions.

Families should be encouraged to care for themselves and be reassured some patients seem to wait until they are alone before dying. While it is not known exactly when or if hearing ceases during the dying process, families should be encouraged to speak to the dying loved one as if they do hear. This can provide an opportunity for pre-bereavement closure and may also comfort the patient.

End-of-Life Care

Ideally, hospice care has been initiated well before impending death. The hospice benefit is available to all Medicare and most insurance recipients whose expected survival is less than 6 months at the time of assessment or reassessment. Unfortunately, most patients receive hospice care only for days or weeks before death, even though many would benefit from having that specialized interdisciplinary approach to their care for a longer period. More accurate identification of terminal illness and approaching death would make this resource available to more who would benefit from it.

Interprofessional care improves the outcomes of older adults with complex health problems

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