INTRODUCTION

Many older adults will die from complications of chronic diseases such as congestive heart failure (CHF), dementia, and chronic obstructive pulmonary disease (COPD). In 2001, heart disease was the leading cause of death in the United States, with chronic lower respiratory tract illnesses, dementia, and renal disease ranked in the top ten, according to the Centers for Disease Control and Prevention statistics. Rather than dying suddenly, patients with these diseases often experience a gradual decline in health punctuated by exacerbations of their disease. These patients may live for years with multiple serious illnesses.

On one hand, this illness trajectory can help clinicians to initiate end-of-life discussions because a slow period of decline with multiple intercurrent events offers numerous prompts and opportunities. However, this extended illness course also makes prognosis very difficult to predict. Moreover, this uncertainty in estimating prognosis can be particularly difficult to explain to patients and families.

These complexities in prognosis estimation and communication are significant. While numerous studies have shown that patients would like to discuss prognosis and advance care planning with their health care providers, few patients have the opportunity to do so. This article will review the answers to the following questions about discussing prognosis and end-of-life plans with chronically ill patients:

- Why should clinicians discuss prognosis and end-of-life plans?
- How well do clinicians make and discuss prognostic judgments?
- When should clinicians discuss prognosis and end-of-life plans?

WHY SHOULD CLINICIANS DISCUSS PROGNOSIS AND END-OF-LIFE PLANS?

There are several compelling reasons to discuss prognosis and end-of-life care plans. For instance, patients who understand their prognosis can use...
this information to make informed health care decisions that are congruent with their preferences. Specifically, patients are able to make choices that are more consistent with their medical circumstances. Patients who are aware that they have a limited prognosis are also better prepared to make practical decisions about living arrangements, financial matters, and other common concerns. Prognostic information also allows patients to seek spiritual support, if desired, and can give patients a chance to achieve reconciliation and closure, and to say goodbye to loved ones.

There are also several ways in which discussions about prognosis can foster better care, apart from the information that the clinician presents. For instance, these conversations may provide an opportunity for advance care planning and anticipatory guidance. These conversations can also open the door to related discussions about options for palliative care, including hospice. Finally, conversations about prognosis can give patients and families an opportunity to share their own fears about death, and to seek reassurance from clinicians.

From the clinician’s perspective, these conversations allow the clarification of expectations about prognosis and illness trajectory. Most importantly, these conversations help the clinician to understand patients’ values and preferences for care at the end of life, and to guide them in identifying and communicating with surrogate decision makers.

HOW WELL DO CLINICIANS MAKE AND DISCUSS PROGNOSTIC JUDGMENTS?

It is clear that clinicians are uncomfortable making estimates about prognosis. In a survey of primary care physicians, the majority expressed that it was stressful and difficult to make prognosis estimations. Furthermore, 80% felt that patients and families wanted too much certainty with the prediction, and that this adversely affected clinicians’ comfort in communicating prognosis.

Available data indicate that this lack of comfort is justified and that clinicians are not accurate in predicting prognosis. Several studies have found that physicians have a tendency to overestimate life expectancy and are reluctant to provide information about prognosis to their patients. In one study, 343 experienced physicians were asked to give survival estimates for 468 terminally ill patients at the time of hospice referral. Although 20% gave accurate estimates within ± 33%, on average the clinicians overestimated prognosis by a factor of 5.3.

Not only do physicians overestimate prognosis, but they also consciously communicate overly optimistic prognoses to their patients. In another study, 258 physicians referred 326 patients to hospice. The physicians were asked to give survival estimates for the patients (called the formulated prognosis). They were then asked what prognosis they would communicate to the patient and family (called the communicated prognosis). The physicians reported that they consciously overstated the prognosis by a factor of 1.2. When the actual survival was compared to the communicated prognosis, the investigators found that physicians had overstated prognosis by a factor of 3.5.

WHEN SHOULD CLINICIANS DISCUSS PROGNOSIS AND END-OF-LIFE PLANS?

Ideally, clinicians should discuss these issues routinely with all of their patients. However, such blanket statements provide little useful guidance to clinicians. Instead, it is useful to consider reasonable triggers for conversations about prognosis.

One helpful strategy to use as a clinician attempting to determine prognosis is to ask yourself: “Would you be surprised if [the patient] died within the next year?” If the answer is “No,” then this should prompt the provider to begin to discuss end-of-life care with the patient. These are patients who are likely to have a limited prognosis, and for whom prognostic information is likely to be particularly relevant. Although the answer to this question offers a useful guide in identifying patients with a limited prognosis, it does not provide specific prognostic information and does not help to structure a discussion with a patient.

Models have been developed to aid in prognostication. However, even the best prognostic models perform imperfectly. For instance, the Study to Understand Prognosis and Preferences for Outcomes and
Risks of Treatment (SUPPORT) developed prognostic models and supplied patients’ prognosis estimates to their physicians. The model—which combined variables from the Acute Physiology, Age, and Chronic Health Evaluation (APACHE II), with disease-specific variables such as low ejection fraction in CHF and a low forced expiratory volume in 1 second (FEV₁) in COPD—was only able to identify 50% of the patients who died within 6 months, and performed no better than physician estimates. However, physicians who used the model made more accurate predictions, which suggests that using models in combination with clinical acumen will increase accuracy in prognostication.

In another study, researchers examined the data from the SUPPORT study to determine whether criteria developed by the National Hospice and Palliative Care Organization (NHPCO) can distinguish patients with non-cancer diagnoses who have a prognosis of 6 months or less, and are therefore hospice-eligible. Although the NHPCO criteria identified over half of the patients who died within 6 months, the criteria failed to identify a significant number of patients who died soon after hospital discharge. Therefore, when presenting prognosis estimates to a patient and his or her family, it is important to state that although it is known that large groups behave a certain way, every individual’s illness course is different. There is no perfect predictor of prognosis estimation in chronic disease, and the studies cited below are imperfect. Nevertheless, there are a variety of disease-specific signs and symptoms that can help to identify patients who have a limited prognosis.

**Cancer**

Compared to the illness trajectories of organ failure syndromes, such as renal failure and congestive heart failure, the illness trajectory of cancer has been fairly well described. Cancer survival can be considered by using two major categories: performance (functional) status, and signs and symptoms. Performance status is a measure of a patient’s functional status.

Two commonly used scales are the Karnofsky Performance Status Scale and the Eastern Cooperative Oncology Group Performance Status (ECOG PS). Both scales have been validated for the evaluation of survival in patients with cancer. A Karnofsky score of < 50 indicates that a patient requires considerable assistance and frequent medical care, and has a survival that is likely to be less than 6 months. Similarly, an ECOG PS score of > 2 identifies a patient who spends more than 50% of waking hours in bed, and has a similar prognostic outlook.

Although investigators have improved on these models by incorporating additional data, they continue to offer substantial predictive value by themselves.

Large studies of patients with cancer who have died have identified easily-recognizable symptoms that predict a survival of 30 days or less. These symptoms include anorexia, dysphagia, confusion, and dyspnea. It is important to note, however, that symptoms like anorexia may be very common in patients with advanced cancer at all stages. Therefore, although they may be associated with mortality, these common symptoms offer limited specificity. Hypercalcemia, when found in cancers other than multiple myeloma or breast cancer, is also a predictor of end-stage disease. Malignant pericardial effusions and carcinomatous meningitis, although less common than the signs listed above, also indicate that the disease is in its last stages.

Taken together, these data provide substantial information to clinicians. Performance status should be used as a routine screening tool for all patients with cancer. The clinician should be alert for the presence of end-stage findings, such as carcinomatous meningitis and pericardial effusions.

**Chronic Obstructive Pulmonary Disease**

Patients who die from COPD often experience an unrelenting decline in pulmonary function over several years. Declines in the FEV₁ have been shown to be inversely associated with survival in hospitalized patients. An FEV₁ of < 1.0 or a decline in the FEV₁ of ≥ 40 cc in 1 year predicts prognosis of less than 1 year in the majority of patients.

Other characteristics may be helpful as well. In a retrospective study of elderly patients with COPD with an FEV₁ of < 1.0 who were admitted to an intensive care unit, 30% died while in the hospital, and almost 60% died within the next year. Studies of ambulatory patients have found that the FEV₁ is less predictive...
of mortality than a poor functional status, as measured by the Manchester Respiratory Activities of Daily Living scale and peak VO₂. An elevated carbon dioxide (CO₂) level, cardiovascular comorbidities, as well as steroid and oxygen dependency, also predict poor survival. A recent study found that a multidimensional index of four patient factors, including body mass index, FEV₁, dyspnea, and exercise capacity, was more accurate a prognostication than FEV₁ alone.

Congestive Heart Failure

Like other chronic diseases such as renal and hepatic failure, patients with CHF experience an illness trajectory that is marked with exacerbations resulting in hospitalization followed by either stabilization or death. In addition, many patients with CHF die suddenly of arrhythmias. This makes prognostication particularly challenging. One common approach is to consider the patient’s New York Heart Association (NYHA) classification, which is a scale ranging from 1-4 describing the presence or absence of symptoms with varying degrees of exertion. A score of 4 (NYHA IV) describes a patient who develops symptoms with minimal exertion and at rest. In several large studies, these patients had an average 4-year survival of less then 35%. Functional status, as measured by oxygen consumption during exercise testing, is also used to identify patients with poor prognosis; however, this is not currently widely available outside of research.

Physiologic measures may be equally useful. An ejection fraction of < 30% has been found to be predictive of poor survival in some, but not all, studies. Other predictors of poor prognosis in heart failure include tachycardia, a serum sodium of < 134 and a creatinine of > 1.8. Brain natriuretic peptide has been identified as a potentially useful serum marker for prognosis in CHF; however, further study is needed to identify useful thresholds for prognostication. Additionally, the use of implantable ventricular devices may considerably improve the prognosis of some patients.

Although physiologic measures have been identified as useful guides, the clearest indicator of limited prognosis is the NYHA IV classification, identifying a patient who has symptoms of heart failure at rest. Future research is needed to identify clinically accurate prognostic indicators in CHF.

Nursing Home

Residents of nursing homes represent a heterogeneous, frail population of patients whose multiple illnesses pose a particular challenge to clinicians attempting to estimate prognosis. Several retrospective studies are helpful in providing signs and symptoms that identify patients who have poor prognoses. These include a drop in serum albumin by ≥ 1.0 mg/dL in 1 year, new agitation in a patient without dementia, and new decubitus ulcers. Decline in functional status is also an important predictor of poor prognosis, particularly the decline of two or more activities of daily living (ADLs) in 1 year. Two recent studies used data from the Minimum Data Set (MDS) to create mortality prediction models. One of the prediction models—which consisted of patient factors, including functional status, weight loss, age over 88 years, low body mass index (BMI), swallowing dysfunction, male sex, and the presence of CHF and/or dyspnea—predicted 1-year mortality.

Four predictors may be used to identify nursing home residents who may die in the next 12 months: decline in albumin by > 1.0 mg/dL in 1 year, the development of new agitation, the development of a new decubitus ulcer, and decline of two ADLs in 1 year.

Dementia

The most widely studied guidelines for prognosis in dementia focus on functional decline. The Functional Assessment Staging Tool (FAST) is a staging system that describes the progression of functional decline in patients with dementia in a series of seven stages. In validation studies of the FAST staging system, patients at stage 7 (language limited to several words and dependent in all ADLs) have a prognosis of less than 1 year. This is generally the functional level at which patients become eligible for hospice. Earlier in the illness course, loss of ability to ambulate further identifies a population with poor prognosis.

Hospitalization of patients with dementia may also predict poor prognosis. In a study of patients with dementia who were admitted to the hospital with a
diagnosis of a hip fracture or pneumonia, over half died within the 6 months postdischarge. A recently published study of nursing home residents with advanced dementia used data routinely collected in the MDS to create a mortality prediction model. The presence of cancer or CHF, dependence in ADLs, age over 83 years, and male sex were important predictors of 6-month mortality. Although acute illnesses such as hip fractures and pneumonia predict poor prognosis, assessment of performance status remains the most accurate tool used to predict the prognosis of individuals with dementia.

LAST DAYS OF LIFE: SYNDROME OF IMMINENT DEATH

It is impossible to definitively determine when a patient is actively dying; however, there are signs and symptoms that indicate that a patient may be imminently dying. Once the signs and symptoms of imminent death are observed, the family can be notified so that they can prepare for the impending loss. There are obvious practical benefits to knowing when a patient’s death may be imminent (ie, allows travel from a distance), as well as psychological benefits, including a chance for closure and an opportunity to say goodbye.

Signs that suggest imminent death include: decreased responsiveness with environment and decreased consciousness; decreased food and water intake, with resultant diminished urinary output; significant changes in skin color and temperature (including cooling of the extremities and the appearance of livedo reticularis); and dwindling pulse and blood pressure. Dying patients often develop swallowing dysfunction resulting in retained secretions and “rattles” in the chest, relaxation of facial muscles, and breathing changes, including Cheyne-Stokes respiration and periodic apnea. In one study examining the most common signs and symptoms during the last 48 hours of life per the family’s recall, the most frequently reported were noisy breathing, urinary incontinence and retention, and pain and restlessness. Clinicians can use these known signs and symptoms to predict imminent death and identify symptoms in need of palliation. In addition, many families benefit from having some basic understanding of what to expect in the last hours of their loved one’s life. In fact, many hospices and long-term care facilities routinely provide this information to families.

SUMMARY

Many patients and their families value conversations about prognosis and end-of-life care. Both clinicians and patients clearly benefit from timely and effective communication. However, few conversations occur before the patient is in the end stages of disease. Asking ourselves the question, “Would I be surprised if this patient died within the next year?” can prompt providers to initiate these conversations about prognosis and treatment goals. In addition to disease-specific characteristics (ie, decline in FEV, COPD), performance (functional) status has proven to be an accurate guide for predicting prognosis, particularly for patients with congestive heart failure, cancer, or dementia. Use of known prognosis predictors may help health care providers to improve their prognostication skills and decrease the level of discomfort clinicians experience when faced with discussing prognoses with their patients.

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References


