# Palliative Care of Urologic Patients at End of Life



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#### **KEYWORDS**

- Palliative care End-of-life care Urinary symptoms Urology Geriatrics
- Chronic illness Hospice Death

#### **KEY POINTS**

- For patients and families facing serious illness, they and their providers need to have a good
  understanding of how that patient's illness trajectory is likely to manifest itself; with this information, patients and providers can work together to formulate treatment plans that fit
  with what is most important to the patient and family as the illness changes over time.
- Palliative care integrated along the trajectory of illness improves patient care, family coping, and professional satisfaction with work.
- Excellent management of urologic symptoms (pain, spasm, bladder outlet obstruction, spinal cord compression, hematuria, delirium) is paramount to the palliative approach in advanced illness.
- There are common urologic issues that may be faced by all patients in the late terminal stage of illness, known as the active dying process; excellent management of these symptoms is important to ensure quality of care at the end of life.
- An understanding of caregiver burden for loved ones of those with advanced urologic illness is important; physical care burdens, emotional issues, spiritual needs, intimacy, and practical issues of the health care system all weigh heavily on patients and their families.

#### INTRODUCTION

This article focuses on the issues facing patients with advanced and ultimately terminal urologic illness, including a framework of care planning based on defining patient and family goals of care, as well as palliative management strategies for common symptoms and syndromes that these patients and their families experience. It also focuses on the management of common urologic issues that may arise in the course of care for all patients at the end of life, as well as the impact on caregivers.

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#### **EPIDEMIOLOGY**

For patients who will die of urologic illnesses, prostate, bladder, and renal cell cancer are the most common causes, with these cancers accounting for 10.1% of all cancer deaths annually. However, people can live with these conditions for an extended period of time, and can experience related symptoms. In addition, these patients may be dealing with progression of comorbid conditions. Such factors should be considered when considering the risks and benefits of possible treatment options.

In general, people do not die of noncancer urologic issues. However urologic symptoms can play a prominent role in several illnesses as they approach the terminal stage, including multiple sclerosis, amyotrophic lateral sclerosis, Alzheimer disease, tuberculosis, and stroke. Many patients facing the end of life, regardless of the terminal diagnosis, may experience urologic symptoms that need to be recognized and appropriately addressed.

#### TREATMENT PLANNING IN ADVANCED ILLNESS: PROGNOSTICATION

It is hard to know exactly who is dying. Doctors tend to overestimate how long a patient has, even by as much as 5 times the prognosis. However, an understanding of time frame is often one of the most important pieces of information that patients and families want to know. Although median survival data for patients with a particular type and stage of cancer can be helpful to provide a general understanding, no individual prognosis should be derived from those data. Studies to identify factors that clarify individual prognosis have found that markers of core functional status, including the ability for self-care, ambulation, nutritional intake, and level of consciousness, play pivotal roles in determining treatment candidacy as well as survival. Even more simply, a study in which providers were asked "Would it surprise you if your patient were to die in the next year?" found that a provider's answer of "No" had a positive predictive value of 83.8% for who would die in the following 12 months. Clinical recommendations for estimating prognosis in patients with advanced cancer ultimately conclude that a combination of clinical prediction of survival and prognostic scores such as the Palliative Prognostic Score (PPS) are best.

### TREATMENT PLANNING IN ADVANCED ILLNESS: UNDERSTANDING ILLNESS TRAJECTORIES

Lunney and colleagues<sup>6</sup> sought to better understand the patterns of functional decline at the end of life. They studied markers of core functional decline over time and found that there are 4 fairly predictable patterns: the cancer, organ failure, frailty, and sudden illness trajectories (Fig. 1).<sup>6</sup> The cancer trajectory is characterized by a more predictable, steady loss in function, likely as tumor burden not responsive to interventions increases. Approximately 30% of patients have this pattern of functional decline. The organ failure trajectory is characterized by recurrent, sudden episodes of decline and partial recovery in function, in an unpredictable fashion. On the frailty trajectory, patients may live for an extended period of time, even years, with a low level of functional independence, with the organ failure trajectory pattern becoming more prominent in the end. Together the organ failure and frailty patterns account for about 60% of deaths in the United States.

### TREATMENT PLANNING IN ADVANCED ILLNESS: DEFINING AND DISCUSSING GOALS OF CARE

Where a patient is along the illness trajectory is an important facet in answering the question noted earlier about prognostication, and should factor into discussions of

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