

Key Points

1. Patients with end-stage renal disease often suffer extensively despite maximum disease-modifying therapies.

Some patients decline or discontinue dialysis therapy; others are inappropriate because of co-morbid diseases or Quality-of-Life issues.

2. Evaluate patients with end-stage renal disease for suffering in the physical, emotional, social and spiritual realms.

Evaluate for uncontrolled physical symptoms such as dyspnea, asthenia and delirium; emotional distress in the face of physical decline; social distress from increased debility and need for additional services; and spiritual distress in the form of existential angst and hopelessness.

3. The palliative response to end-stage renal disease includes symptom management and advanced planning:

Symptom management includes developing a plan to palliate symptoms unrelieved by disease-modifying treatment. Advance directive planning includes discussions with the patient to choose surrogate decision-maker(s) and determine treatment preferences.

4. Truth-telling assists with symptom management, enables accessing community resources, fosters preparing and planning care, and helps the patient and family avoid lurching from crisis to crisis.

5. There are key clinical markers for end-stage renal disease.

Clinical markers include weight loss greater than 10% of body weight over the previous six months, and resting tachycardia of heartbeat greater than 100/minute unrelated to recent breathing treatment, atrial fibrillation, or MAT. Important laboratory markers indicating poor prognosis for patients not to be dialyzed are serum creatinine >8mg/dl and creatinine clearance <10cc/minute.

6. Functional markers of poor prognosis include multiple Emergency Room visits and hospital admissions and declining functional status based on assessment of ADL and ability to live independently.

7. Any combination of markers for poor prognosis might prompt evaluation by palliative care for unrelieved suffering or for hospice referral.

Renal Disease

The Palliative Response



Suffering in End-Stage Renal Disease

Patients with end-stage renal disease often suffer extensively despite maximum disease-modifying therapies.

Dialysis Therapy

- Some patients decline
- Some patients inappropriate
 - Co-morbid diseases*
 - Quality-of-Life issues*
- Some patients decide to discontinue
 - Progressive decline*
 - Co-morbid illness*
 - Appropriate for hospice referral*

Palliative Evaluation

- Physical
 - Uncontrolled symptoms (e.g., Dyspnea, Asthenia, Delirium)*
- Emotional
 - Distress in the face of physical decline*

Palliative Evaluation

- Social
 - Distress from increased debility and need for additional services*
- Spiritual
 - Existential angst and hopelessness*

The Palliative Response

- Symptom management
 - Develop plan of care to palliate symptoms not relieved by disease-modifying treatment*
- Advance directive discussion
 - Discuss surrogate decision maker(s)*
 - Discuss treatment preferences*
 - Document result of discussion*
- Hospice referral for advanced patients
- Truth-telling

Value of Truth-Telling and Prognostication

- Assists with symptom management
- Enables accessing community resources
- Fosters preparing and planning care
- Helps avoid lurching from crisis to crisis

Establishing Prognosis

"Would you be surprised if this patient died in next six months?"

Yields more accurate prognosis than...

"Will this patient die in the next six months?"

If you would not be surprised, assess for palliative care needs.

Sharing Prognosis

Important for people to know that prognosis is limited

"Because of the severity of your kidney disease, you and your family are eligible for the assistance of hospice at home"

is preferable to...

"You have a prognosis of less than six months; therefore, I am referring you to hospice"

Language Is Important

- "While no one knows how long anyone will live, there are certain signs that your kidney disease is very severe and that time could be limited"
- "People are eligible for hospice when their illness is so severe that they might die in the next six months to a year"

Markers for Poor Prognosis Co-Morbid Illnesses

- Strokes
- Advanced dementia
- Congestive heart failure despite control of fluid overload

Markers for Poor Prognosis Co-Morbid Illnesses

- Chronic lung disease
Oxygen dependence
- Diabetes mellitus
Manifestations of long-term complications

Poor Prognosis

Key Clinical Markers

- Unintentional weight loss
Greater than 10% of body weight over six months
- Resting tachycardia
Resting heartbeat greater than 100/minute
Unrelated to recent breathing treatment, atrial fibrillation, or MAT

Poor Prognosis

Key Clinical Markers

Poor prognostic markers for patient who will not be receiving dialysis

- Serum Creatinine >8mg/dl
- Creatinine Clearance <10cc/minute

Poor Prognosis

Functional Markers

- Multiple Emergency Room visits
- Multiple hospital admissions
- Declining functional status based on assessment of activities of daily living
- Need to move from living independently to living with family or in a residential-care facility

Palliative Response to Markers for Poor Prognosis

- Any combination of markers for poor prognosis might prompt evaluation by palliative care for unrelieved suffering or for hospice referral
- It is not necessary or appropriate for a patient to exhibit all of the markers before being evaluated by palliative care

Palliative Care Consult

- Symptom control
- Treatment plan
Assist to develop plan that melds symptom management with disease-modifying treatment
- Goals of Care
- Advance care planning
- Assess for hospice care

Palliative Care End-Stage Renal Disease

Consult often and early.

Selected Readings

Withdrawing Dialysis

Choen, L. M., M. J. Germain, D. M. Poppel, A. L. Woods, P. S. Pekow, and C. M. Kjellstrand. "Dying Well after Discontinuing the Life-support Treatment of Dialysis." *Archives of Internal Medicine* 160 (2000): 2513–2518.

Neely, K. J. and D. M. Roxe. "Palliative Care/Hospice and the Withdrawal of Dialysis." *Journal of Palliative Medicine* 3 (2000): 57–67.

Quality of Dying

Cohen, L. M., D. M. Poppel, G. M. Cohn, and G. S. Reiter. "A Very Good Death: Measuring Quality of Dying in End-stage Renal Disease." *Journal of Palliative Medicine* 4 (2001): 167–172.

Association with Myocardial Infarction

Shlipak, M. G., P. A. Heidenreich, H. Noguchi, G. M. Chertow et al. "Association of Renal Insufficiency with Treatment and Outcomes after Myocardial Infarction in Elderly Patients." *Annals of Internal Medicine* 137 (2002): 555–562.