PALLIATIVE CARE
CASE OF THE MONTH

"Conservative Management of Advanced Chronic Kidney Disease"

by

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Case: Mr. N is a 73-year-old African-American man with a medical history notable for chronic kidney disease (CKD) stage 5 presumed to be from hypertension related nephrosclerosis. He also has a history of hyperlipidemia, coronary artery disease for which he underwent percutaneous intervention, prior stroke with a residual foot drop on the right side, and a history of pulmonary embolus for which he is on coumadin. He has seen a nephrologist for many years and preparations were being made for hemodialysis. An arteriovenous fistula (AVF) was created by a vascular surgeon in 2012 when he had an estimated GFR of 20 mL/min per 1.72m2. At that time his creatinine was about 3.5 mg/dL.

By late 2017, he began telling his primary care physician and nephrologist that he may not be interested in pursuing dialysis. He was referred to renal supportive care clinic for further care. His nephrologist cited two main reasons for referral: 1) she was not sure if his decision made sense because she felt dialysis was the appropriate next step and 2) if he decided to withhold dialysis, she felt unsure about how to manage him. By the spring of 2018 his creatinine was 6.5 mg/dL and he had moderate anorexia and fatigue. He did not report nausea.

Discussion: In the United States, adults older than 75 have the highest rates for dialysis initiation. More than half of all prevalent dialysis patients are older than 65. Due to these trends, a substantial percentage of patients have a combination of multiple comorbidities, frailty, and functional impairment. The current delivery of kidney care (and singular focus on dialysis) for these patients leads to underutilization of basic palliative care interventions.

First, patients with kidney disease have a high symptom burden that is often under-recognized and undertreated by providers. There is a lack of adequate advance care planning reflected by low rates of completion of advance directives compared to other seriously ill populations. These factors lead to high rates of dying in the hospital and infrequent hospice utilization.

In addition, for frail, elderly patients, dialysis may not be the treatment that best fits their goals. In elderly patients with cardiovascular comorbidities, dialysis may not prolong their expectancy. A NEJM study of patients who were 80 years and older demonstrated the profound functional decline associated with dialysis initiation. At the time of initiation, about 75% of the patients lived at home and were independent with activities of daily living. Within 6 months of starting dialysis, over 30% of the patients had functional decline (i.e., they needed an arrangement like assisted living or a nursing home).

Lastly, patients receiving dialysis spend more time in the hospital (and ICU's), receive more cardiopulmonary resuscitation, and more invasive procedures at the end of life compared to patients with cancer or heart failure.

Conservative care (CC) is a way of providing comprehensive kidney care to patients whose values are not consistent with dialysis initiation or who may not benefit from dialysis. Patients who start dialysis are often unaware that CC is a viable pathway for managing their kidney disease. There are likely a variety of reasons for this including 1) system-level barriers, 2) lack of comfort in discussing and providing CC among nephrology providers, and 3) inadequate training to have conversations related to advance care planning and serious illness.

Conservative care is based on the fundamentals of general CKD care with some important differences. In general CKD care, there is a focus on biochemical optimization and preparation for dialysis (and kidney transplant for some). Nephrology providers typically optimize blood pressure, anemia, vitamin D metabolism, and bone-mineral health with input from professional society clinical practice guidelines. In CC, the focus shifts away from biochemical optimization and pivots towards symptom management and quality of life. For example, in general CKD care, the goal for blood pressure management is often to achieve a reading below a patient-specific goal (e.g., 140/80 mmHg). In CC, providers often liberalize these goals and instead may focus more on preventing symptoms that arise from volume expansion and severe hypertension.

In addition to CKD related issues, CC incorporates an added emphasis on advance care planning and symptom management. Advance care planning (ACP) in a CC setting is similar to ACP in a general outpatient palliative care setting with an added focus on how kidney disease and dialysis affect quality of life. Building consensus with a patient's outpatient care team is an important way to address goals of care, especially if some are less familiar with CC.

Most patients with CKD have a high symptom burden and a majority will experience fatigue, pain, nausea, itching, shortness of breath, or anorexia. Psychological symptoms like depression and anxiety are also prevalent in the CKD population. Clinics that provide CC tend to use a validated symptom assessment tool to assess patient's symptoms and provide focused therapies. For example at the UPMC Renal Supportive Care Clinic, we use the palliative care outcome scale for renal patients (IPOS-Renal).

(Discussion continued)

Data suggests that patients who are part of CC are more likely to receive symptom management and hospice care. In a CC pathway, it is common for patients to survive months to years beyond the point when dialysis would have otherwise been initiated. Part of this phenomenon is explained by the slow progression of kidney disease that elderly patients experience. Among elderly patients, slower progression of kidney disease leads to an essential observation: with advancing age, the risk of death begins to outweigh, and eventually exceeds the risk of developing kidney failure that requires dialysis.

Resolution of the Case:

As of this writing, Mr. N has remained interested in avoiding dialysis. After transitioning to the renal supportive care clinic, it became clearer that his preferences to avoid dialysis were driven by his fear that it would become a barrier for frequent travel to Virginia, where his son lives. Mr. N has also known other individuals on dialysis and is worried about a decline in quality of life. Mr. N has mentioned he feels safe knowing that a kidney doctor is still helping with medication management even though he has opted not to pursue dialysis. Through coordination with his PCP and renal supportive care clinic, he is now supported by a home palliative care team. His last creatinine was 8.5 mg/dL with an estimated GFR of < 10 mL/min. He continues to travel between Pittsburgh and Virginia.

For referral to the UPMC Renal Supportive Care clinic, please call 412-802-3043.

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