She was late for her first appointment and there was much to discuss—the progression of her kidney disease, dialysis planning, transplant evaluation, blood pressure management, and the likely cause of it all: diabetes mellitus. Her problem list reflected the complications of her diabetes: neuropathy, retinopathy, nephropathy, and cardiomyopathy. I wondered what social and environmental factors had contributed to her disease progression.

She sat at the edge of the chair with anticipation. Her arms were folded, and eyebrows raised. I provided an overview of diabetic kidney disease, reviewed laboratory data, answered questions, and explained the next steps. With additional patient education, telephone reminders, frequent appointments, and the assistance of a community health worker, she could thrive.

But she never returned.

“No show” or “cancelled” commonly appeared in her electronic health record. We had several conversations over the telephone after missed appointments. She expressed her feelings of fear and frustration about chronic kidney disease and the possibility of dialysis. Mounting responsibilities at home, work, and an overall sense of gloom barred her from stepping back into the examination room. Coordinated efforts with her primary care physician were largely unsuccessful. We collaborated on laboratory tests and echoed the same sentiment: we were concerned about her.

Several months later, she presented with fatigue and shortness of breath. Learning of my patient’s hospitalization and the urgent initiation of kidney replacement therapy, I thought about what I could have done differently. As a nephrology fellow, I have been fortunate to witness the smooth transition to dialysis for many of my patients. I felt as though I had failed her, as she was not prepared emotionally for what she feared the most.

Reflecting on this experience I thought more about my patient. She was a middle-aged Black woman attempting to navigate our complex medical system while receiving multiple new diagnoses over the course of several months. At the same time the world that she once knew was rapidly changing. She would be working from home. Telephone and video conferences replaced in-person clinic visits. Even though we could review labs and discuss her active problems on the telephone, there was more that needed to be conveyed. The moments of silence that felt so natural in the office seemed awkward over the telephone.

I was afraid of what would happen next. Our nephrology team would be replaced by an outpatient dialysis team.

I wondered:

- How would her interactions be with this new team?
- Would she be treated with empathy and respect?
- Would she be another “dialysis patient” sitting in a chair 3 times a week or another data point in a national registry of dialysis patients?
- Would she feel seen?
- I pondered her future.

Would her kidney failure lead to an untimely demise? Would she ever receive a kidney transplant or would the phrase “no show” be etched in the minds of the transplant team when they reviewed her file?

These questions pervaded my mind as I walked through the clinic doors. As a Black woman nephrologist-in-training with family members with kidney disease, I try to demonstrate patience, compassion, and respect to all of my patients. Even before matriculation into medical school, I studied the uniqueness of the doctor-patient relationship. I chose to become a nephrologist because I desired to have longitudinal relationships with patients.

But, this experience was different from what I imagined.

Although it was difficult to accept that she would never return to clinic, it was even harder to accept that a carefully designed plan would not be enough to change her disease trajectory.

Still, I have hope.

I have hope that she will feel empowered to express her concerns.

I have hope that each concern will be acknowledged and addressed by her medical team.

I have hope that she will receive important health information to aid in decision making.

I have hope that her values and preferences will be clearly identified and prioritized.

I have hope that she will receive equitable care and a kidney transplant.
I have hope that she will not experience alienation, abandonment, and medical mistrust. Finally, I hope she will have a chance to live an abundant life filled with joy and laughter.

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CALL FOR SUBMISSIONS

“A doctor, like a writer, must have a voice of his own, something that conveys the timbre, the rhythm, the diction, and the music of his humanity, that compensates us for all the speechless machines.” —Anatole Broyard, Intoxicated by My Illness

In this space, we hope to give voice to the personal experiences and stories that define kidney disease. We welcome nonfiction, narrative submissions focusing on the personal, ethical, or policy implications of any aspect of kidney disease in adults and children (acute kidney injury, chronic kidney disease, dialysis, transplantation, ethics, health policy, genetics, etc). Submissions from physicians, allied health professionals, patients, or family members are encouraged.

Types of submissions for this feature include essays of up to 1,000 words; short poems; or original visual art accompanied by 1-2 paragraphs of text. In submissions that refer to real patients, the patients must either be unidentifiable or approved by the patient(s) described.

Items for consideration should be submitted online at www.editorialmanager.com/ajkd.