In a Few Words

The Whole Picture

When my father, whom I called Appa in Tamil, turned 56, he told me he had end-stage kidney disease (ESKD) and needed to begin dialysis. When he was dying at 70, he still had ESKD. “How can one be ‘ending’ for fourteen years?” I often asked myself before I entered medical training.

As with many patients with ESKD, dialysis sustained yet restrained Appa’s life. His schedule came to include nothing but dialysis sessions and doctors’ appointments. The dialysis was too tiring to allow for anything else. He was able to exist at this “end stage” for 14 years, thanks to thrice-weekly dialysis, countless medications, a host of appointments with specialists, transportation by members of our local South Asian community, and the tireless care of my mother, Amma. Despite Appa’s daily struggles to overcome the many symptoms of his multisystem pathologies—nausea, dyspnea, pruritis, digit deformity, insomnia, nerve pain, and fluid accumulation—“he is managing quite well,” his nephrologist often said. He praised Appa’s ability to ambulate with a walker, manage finances, bathe himself (albeit sometimes standing over a bathroom sink), and even maintain his full head of hair.

But Appa’s nephrologist did not see the whole picture. He did not witness each of the changes Appa and Amma had to make in order to help Appa “manage well.” Having struggled to make it to dialysis appointments on time with publicly funded medical transportation options, Appa had enlisted the services of a South Asian refugee-owned taxi service, costing him nearly $50 per dialysis session. He carefully instructed each driver on how to fold his walker and stow it in the nook next to the front door of our house, in case a different driver brought him home from dialysis. They obliged him out of their sense of duty to care for the infirmed in our community.

His nephrologist did not know that Amma stashed meals in the microwave before she left for work, so that when Appa came home from dialysis depleted of energy, he could heat up a bowl of food without dropping it on his 10-foot walk to the lunch table. This walk was the hypotenuse of the triangle of his daily motions: from his bed, to the microwave, to the table, and back to his bed. His nephrologist did not know that when Appa howled in pain in the middle of the night, or writhed in discomfort from diffuse pruritis, Amma was there to rub ointments on his limbs and keep him company.

His nephrologist did not know that the only gifts Appa asked for were short-sleeved buttoned shirts—ones that made for easy dialysis fistula access but needed frequent replacing after weekly bouts of fistula bleeds. He could never clean them in time to prevent stains.

The sicker Appa became due to his multiple comorbidities, the less he was able to communicate with those who were not accustomed to his peculiar cadence, his words spilling out like the last spurts of ketchup from an old bottle. Amma and I watched as Appa’s doctors, nurses, and medical assistants, his primary sources of social interaction by that point aside from our family, grew more impatient with him. They mostly spoke with us rather than trying to work through his speech with him. It felt to us like his “end-stage” disease portended the end of his medical team’s ability to think through his needs and goals in partnership with him.

As I progress in my medical training, I have become more aware every day that my parents needed more than merely dialysis and routine monthly follow-up visits. They needed a team who saw this whole picture, a team who saw that every time Appa went to doctors’ appointments, he put his best shirts on—not the ones that were stained from daily food spills, blood, and vomit.

Perhaps this is the true promise of patient-centered care: that a patient be seen not as the small constituent parts of their disease or diagnosis, but for the whole family portrait depicting the full scope of their needs: symptoms, stains, suffering, and all.

Ramya Sampath, BA
Rochester, New York

Ramya Sampath is a medical student at the University of Rochester School of Medicine and Dentistry.

Address for Correspondence: ramya_sampath@urmc.rochester.edu

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