



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.

His nephrologist did not know that when *Appa*’s persistent, dry cough triggered vomiting, *Amma*, at 63 years of age, leapt to his bedside to hold a plastic bag open and then cleaned up the spills afterward. She told me a year before *Appa* died that despite California’s ban on plastic bags, which required her to pay 10 cents per bag, she still bought them at every grocery store visit because they were large enough and sturdy enough to contain emesis.

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.

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