

IN A FEW WORDS

Feeding the Hungry Ghosts

He sat very straight, but not out of nervousness or fear. His was the calming presence of the very old. He clearly prepared himself with care for these visits: the faded blue tweed jacket was pressed, the white shirt was crisp, the shoes polished. He was over 95 years old, his exact year of birth lost somewhere in Qing-era China. If he had any opinions about being tended to by a physician young enough to be his granddaughter, he did not reveal them in his bearing.

His remaining kidney function was just barely enough to keep him alive. He was rail-thin and fatigued. We were meeting to discuss the possibility of dialysis.

The three-way exchange I had become accustomed to with Chinese patients—me, the patient, and the interpreter, each with our separate understanding—was extended, for this patient was profoundly deaf and spoke an uncommon dialect of Cantonese. I spoke, the interpreter translated, and his 70-year-old daughter shouted words into his ear. His slow, measured phrases were returned to me through two filters, as if our conversation were taking place under water.

He never looked at the interpreter when she spoke, nor even at his daughter. He looked straight at me, intent. His responses were short and firm.

Back came the translation: "He does not want the treatment."

"Does he understand that he will not live very long without it?"

"He knows. He is ready to die," the interpreter said. "With grace," she added.

Were those his words, or hers? What Chinese word, translated twice over, came back to me this way? I looked at the old man, who was looking at me. He nodded.

We repeated this exchange almost weekly, as he kept coming to the clinic. The translators changed, the nuances changed, but the conversation was the same. No treatment. We arranged visiting nurses, adjusted his diuretics, and monitored his symptoms.

Then one day we received a call: his family had brought him into the emergency room. He was sick, very sick, and they were frantic with worry. Several generations of family members were gathered at the hospital. He needed urgent treatment, they said. Of course, laboratory studies had been drawn, and frightening numbers were rattled off in rapid-fire sequence.

His visiting nurse was Chinese. I called her to find out what had happened. Had we missed some aspect of palliation? Had we misunderstood the family?

"Nothing is too different. He has been sick, not eating. They are afraid, they say he needs the treatment now," she told me.

I was frustrated. I saw a painful future, unwanted treatments, infections, and an undignified death for this dignified man.

"We tried to explain that he would die, and they seemed to understand. What has made them change their minds?"

"They are afraid of having a hungry ghost in the house, of course," the nurse explained, as if I should understand.

"A hungry ghost?" I asked, bewildered.

"The worst kind of ghost. He dies with an empty stomach; he will not have what he needs in the afterlife. He will keep coming back to the house. He must die with food in his belly."

I was young when my grandmother became ill, when, at age 60, metastatic cancer reduced her from Hepburn-like elegance to skeletal emaciation. The last-ditch brutality of the final

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rounds of treatment left her with profound anorexia. Her frantic children filled the kitchen with food; her sister rearranged the countertop to accommodate a juicer intended to make strengthening potions; her friends came by and packed the cabinets with anything that might tempt her. Back home after a visit, I baked her sugar cookies. Soft and easy to eat, I thought. I packed them in a tin and mailed them off in brown paper. At her bedside a few days later, I found my tin with the note I had written close by. I heard the mourners gathering in the rooms below. The untouched cookies were still soft, still easy to eat.

I had known a hungry ghost.

We prescribed anti-nausea medication and megestrol, soup and mandarin oranges. A Chinese-speaking hospice program was arranged. There were no more trips to the emergency room, no more blood tests, no more anorexia. A few days later, the visiting nurse called to tell me he had died quietly, with food in his belly. And with grace, I silently added.

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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 will accept for review nonfiction, narrative submissions up to 1,600 words, regarding 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). Footnotes or references are discouraged.

Any submission which refers to real patients must be either unidentifiable or approved by the patient(s) described. Submissions from physicians, allied health professionals, patients, or family members are welcome.

Items for consideration should be submitted via e-mail at AJKD@tuftsmedicalcenter.org. Questions or requests for assistance may also be directed to the editorial office staff at this address.