

Anguish

By Cynthia McNamara

His auntie caresses his protuberant abdomen as he lies motionless, staring at the ceiling, vacant, hopeless. He is 15, born HIV positive. He had left his village in rural south Rwanda for the first time when his family had collected enough money to send him to boarding school. Away from his home, enjoying his freedom, he had stopped taking his medications. Three months later, overcome with fever, jaundice, and anorexia, he was admitted to this remote hospital.

Buildings, single level, Spartan, comprise the medical wards, each with 16 beds and their inhabitants, and literally nothing else: no machines, no equipment, no computers, no curtains separating the beds, no TV, no books, no tissues, no toilet, no sink. Atop a wire bed frame and a two-inch mattress, each patient must supply his or her own linens. His auntie dotes on him, never leaves his side. His agony is her agony.

The boy struggles to express that he is having trouble breathing. He has been here for two weeks. Our medical team, comprised of a Rwandan intern and resident, intelligent, accustomed to practicing in this setting, but inexperienced, and me, the attending, a general internist, with no formal training in HIV or tropical medicine, still don't know what is going on. What we do know: he likely has AIDS, he's malnourished with a huge abdomen encasing a massively enlarged liver and spleen, he has a fungal infection in his mouth, severe pancytopenia (hemoglobin 4), and a lung mass. We were able to get him to the military hospital, which has the only CT scanner in the whole country for a scan, but no one reviewed the study. We now have a CD disc containing images of his abdomen and pelvis that we can't read because no one has a computer into which we can insert the disc. He's tachycardic, tachypneic, febrile, jaundiced, and cachectic. He is miserable and each day he is getting worse.

I am pretty sure he is dying. But what if I'm wrong?

I know if I gave him morphine for his shortness of breath he would feel better. But he is 15, and I don't usually take care of people that young. To give morphine seems like a formal acknowledgment: You are dying. We can't save you. When do you tell a child and his family that he is dying when you have such limited information, if you don't know for certain whether he could be treated?

I bring the chaplain to see him. The boy hands me a note written on the back of a crumpled bill that his family paid for his medicine. His lips are pursed, eyes fixed, despondent, stoic. In the dimly lit medical ward that is now almost dark, I read the note with the light from my iPhone: "My name is Nange. I have problem of breathing so that our favorite is that to come our home. Happy."

What does that mean? While the chaplain prays with us, I think about what I want to say to Nange: Nange, you are dying. I am so sorry. I am sorry you were born with HIV, sorry that your parents died of this disease. I am sorry you didn't have more time at boarding school. I am sorry you can't breathe. I am sorry we can't read your CT scan and sorry we can't run other tests to make a diagnosis. I'm sorry we can't even know if you could be treated. I am sorry that if you were in the US we could probably treat your illnesses, or at least know we couldn't. I am sorry I am so uncomfortable practicing in this remote low resource setting with scant medical information that I am paralyzed as to how to help you.

I have been a board certified internist for twenty-six years. I have taken care of people and taught trainees in hospitals and offices of three different US academic institutions. I have taken care of people in a remote area of The Navajo Reservation, also with no CT scanner, in urban and rural Uganda, Honduras, Dominican Republic, and Haiti. But being an internist is arduous, and I feel alone and uncertain. Sometimes it is hard to know the right

thing to do, and sometimes it is hard to do what you think is right. A few years ago a stroke left my own mother paralyzed, with a tracheostomy for breathing and a PEG tube for feeding. I never instituted palliative care. I thought I could get her well enough to bring her home and take care of her there. This, even though in the few months before she died she was in the ICU more frequently than she was out of it, and bleeding from her gastrointestinal tract infected in her urinary tract and in her lungs. She died alone in an institution. I will always regret that I didn't, or wouldn't, recognize she was dying and make her comfortable.

In Rwanda where there is no one trained in palliative care I know the decision to accept our limitations and ease Nange's suffering will be with our medical team.

We will talk with Nange. We will ask him and his auntie what they understand. We will tell them that while we hope for improvement we are worried he is getting worse, that he is very, very sick. We will explain that we can't take away his sickness, but we can help him feel better.

After all my training and experience maybe I had to go to rural Rwanda, where death is so palpable, such a part of life, to truly understand (again) that sometimes death is palpable, a part of life; to remember (again) that just because I am an internist doesn't mean I can fix people, and just because I am not a palliative care specialist doesn't mean I can't help the people I can't fix.

Cynthia Frary McNamara is on faculty at Yale University School of Medicine and is an internist in the Veterans Administration Hospital Connecticut. She is honored to provide primary care for our country's veterans and to teach medical trainees in clinical medicine, global health, and cross-cultural issues. The mother of four biological children, she has also been a guardian and mentor for two refugee boys from Burundi who were displaced after the Rwandan genocide and came to the US with their family as adolescents. She has received two Yale/Stanford Johnson & Johnson Global Health Scholar awards to serve as a teaching physician in Uganda and Rwanda and has worked providing primary care in areas of Central America. Her essay, "Anguish," was an Honorable Mention in the Intima's 2018 Compassion in Healthcare Essay Contest in partnership with the Schwartz Center for Compassionate Healthcare - theschwartzcenter.org and judged by Haider Warraich, MD, author of *Modern Death: How Medicine Changed the End of Life*