

# Beating the Odds in Uganda

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Mable was 24 years old when I first met her 5 years ago. A petite young woman, with dark brown skin, her hair tightly braided, she did not look well. She had a chronically ill appearance to her, her thinness disguised by edema. Edema was pretty ubiquitous on the Nephrology Ward at Mulago Hospital. Mable was lying in bed on the thin hospital-issued mattress, head propped up by a few pillows, her body covered by a nice, heavy, gently used blanket. Mable smiled nervously as I approached her bedside with my team and greeted us quietly, tenderly, in perfect Ugandan-accented English.

The cavernous ward to which Mable was admitted is shared with the pulmonology and cardiology services. Men in one room, women in the other, and between them a hall that fills with the more acutely ill; a large oxygen tank stands in the center of a network of beds, sending tubing outward in all directions, each tube ending in a cannula, adorning a patient in need. Suffering partially alleviated by shared oxygen in a shared space. Mable was in the back corner of the women's ward, next to the windows that are always open, letting in fresh air and the constant din of the city below. The rains were still around and, usually once a day, the urban sounds were overtaken by the ruckus of rain pelting at the windows, cleaning off the red Ugandan dirt, and splattering those, like Mable, who lie beneath.

Why Mable's kidneys failed is unknown. She was last well many months ago, although whatever was progressing inside her likely started years before, manifesting recently, around the time she graduated Uganda's top university. Since then, she gradually became more fatigued, frail, and less able to lead her normal life. Many of the patients around her were in similar straits, presenting in the late stages of kidney disease—far later than most patients come to medical attention in developed countries. They are frequently oliguric, hyperkalemic, acidotic, and anemic at presentation. Fluid accumulates in the face, legs, peritoneal cavity and, ultimately the lungs. I was quickly becoming very familiar with uremic

encephalopathy, pericarditis, platelet dysfunction, and the granular white dust of uremic frost.

For the first 2 weeks, our team managed Mable with medications. Her mother, who was by her side all the time, slept at night on a woven banana-leaf mat on the floor next to the bed, Bible in hand. She kept saying that she was collecting the money for dialysis—that her church was holding collections. So we waited. My confidence was lacking, having already seen this scenario play out multiple times. Family members and friends are asked to mobilize any available money, sometimes a wealthy relative pledges to pay, sometimes land or other assets are sold off. But all too often the outcome is insufficient to cover the immense costs. And although Mable's mother was certainly better off than the large majority of Ugandans, she was going to require external largesse to realize this dream.

With time, Mable's condition deteriorated. By the middle of the second week she was hardly producing urine. She became lethargic and confused. The accumulating pulmonary edema kept her from restful sleep. She was no longer responding to diuretics. She was having nosebleeds. Still her mother insisted that she was gathering funds through her church.

I arrived on the unit a few days later and saw my two interns standing at her bedside. Mable was in severe distress, sitting erect in bed. She had so much fluid in her lungs that it was coming out of her mouth, frothing around the angles of her lips. Her mother was notably absent. "She is on the dialysis unit—she got the funds," my interns said. I was shocked that the funds had come through, that her mother had managed to pull this off. But I simultaneously found myself gripped by the feeling that this would not be a sustainable endeavor. They would never afford a transplant, I thought to myself. Wouldn't it be unethical to start dialysis given that Mable likely would only be able to afford a few sessions before running out of funds? Would she not be better served getting medications to make her comfortable, thereby allowing her to go peacefully? How could we all have been so blinded to this reality that we allowed her mother to misdirect her time and energy at the end of her daughter's life? Why we were all so uncomfortable with telling our patients the truth, with preparing their families for the inevitable? This suddenly seemed like a very bad idea.

My interns and I ran up the three flights of stairs to the dialysis unit on the top floor of the hospital building. Unlike the main wards, where the concentration of

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patients, beds, family members, odors, and interns are always palpable, the top floor feels empty. A private ward is on one side, the dialysis unit on the other. Between them a set of doors opens onto an outdoor terrace where one finds oneself at the level of the treetops, sharing the air rights with nesting marabou storks. Along with those giant birds, there finally is a sense of open space. It was there we found Mable's mother. She was staring out, with one hand on her cheek and the other gripping an empty manila envelope from which she had just emptied a few million Ugandan shilling to pay for initiating dialysis. She was a wreck—clearly emotionally overwhelmed. Feeling pressured by time, I asked her whether this was the right thing to do. She crouched down against the wall and began to wail. It was not the wail of a lost loved one that was all too frequent at Mulago and to which I had grown uncomfortably accustomed. This was just shy of that intensity; the sobbing of a mother overcome by the anguish of a decision no parent should ever have to make. This conversation was happening way too late—it should have happened weeks if not months ago. Not now when Mable was downstairs dying, when she was going to need a dialysis catheter emergently placed in her neck. Through her tears Mable's mother managed to speak. "I have just now paid for the first week and for the catheter. The nurse told me the catheter will be placed as soon as the doctor arrives," referring to the Ugandan nephrologist. She said the church had not only gathered the funds, but that they were hoping to get Mable to South Africa for a transplant next month. I was amazed; skeptical, but relieved that her mother seemed to have a robust plan. So we agreed that it made sense to go ahead. Over the next few hours, the team mobilized, the catheter was placed,

and by the end of the morning Mable was in the unit getting her first session.

The next morning her bed on the ward was empty. I feared the worst; that she was too sick to have made it through that first session. But one of the interns came over and told me she was upstairs again. I went up and saw her lying flat in bed, comfortably sleeping. Her mom sat in a chair by the bed, praying. The dialysis machine whirred as it detoxified Mable's blood and removed excess fluid before returning it to her body. Mable opened her eyes, smiled at me, and went back to sleep.

A year later I returned to Kampala. I have been going for 10 years now—as a medical student, resident, chief resident, and now an attending. My visit happened to coincide with the first Kampala Renal Conference. Noncommunicable diseases are a concern of massive proportions but attention to them has been lacking. This conference was one sign that the tide is beginning to change. At the end of the morning session, I made my way to the front of the room to greet my Ugandan colleagues but was intercepted by a petite, young, vibrant woman with a big smile. During my last visit I had seen Mable in the hospital a few times after starting dialysis, admitted with pneumonia and then with a catheter-associated bloodstream infection. Her status had been tenuous; she had lost the weight of excess edema and had not looked well. But now it was clear to me that she had done what I doubted was possible. "I'm doing well," she told me, the smile never leaving her face. "I get dialyzed twice a week. I have a match for a kidney," she said. "We are trying to raise the funds for transplant." She pointed across the room to her mother who sat, grinning, contentedly watching us.