Notes from Africa #9: Juliet and Francoise

I could tell by his fallen look that something had broken Charles' heart. She is Juliet, orphaned today from the death of her mother from AIDS. While she was one of thousands of children orphaned this week she is the one touching our lives. She had our attention.

In the last desperate weeks of Juliet's mother's life she had done the best she could for her girls. She "gave" the oldest one, Susanna, 17, away to a man…to a man that sells milk on the corner. Susanna would be his "wife", in other words, she would submit in his bed and be able to live in his shanty. The second daughter, Rosy, 14, was sent to a distant village to be the "house girl" for a relative. There was no plan for Juliet. On the night of her mother's death, Juliet stayed with a community health worker who had helped with her mother's care. This child was a breath away from becoming homeless on the street. That's when we decided to do something for her.

I met Juliet yesterday when Esther, the community health worker, and I went to the slum where she now lives. The milkman gave his consent for Juliet to move in with him, Susanna, his sister in law and her infant son. Their home is typical: a room of mud and sticks about 10' X 10', with no windows, no electricity or water. It is roughly divided into two parts by a piece of fabric hung on a string. On the walls are peeling HIV posters and tattered newspaper pictures of the pope. They own practically nothing. Really, imagine. Nothing. No toys, books, shoes, or underclothes. No nightgown. No food in the cupboard. No cupboard. The contents of the room include three cooking pots, a few jerry cans for water, some cutlery and dishes, a few clothes and one bed.

Juliet's name, Musabelman Birungi means "Pray for God Oh Beautiful One." And she is a beauty. She has very large expressive eyes that hold my gaze shyly. Her long arms and fingers are folded in her lap as she listens quietly to the adults talking about her future. Where shall we send her to school? What supplies will she need? She must have a uniform and shoes, underpants, and a sports outfit of shorts and top. And she will need a book bag for her exercise books and her pencils. We decide that she should go to the better, and somewhat more expensive, ($50 per term) private primary school in the neighborhood. This is a huge step up from the government school. Does she understand this odd world where one moment she had nothing but the love of her sisters and now she will be going to school and have some of the necessities that she has always gone without? I look around the house and add to our list: a mattress, sheets, and a toothbrush. Susanna, herself a girl with nothing, is lovely in her demeanor, soft, and innocent. I ask Esther, to inquire as to how Susanna is doing with her situation. Esther gazes at me for a moment and then says, "She has no choice. It must work for her. Otherwise she will not be eating." I determine to get Susanna a few necessities also when we get Juliet ready to go to school. She will have a nightgown too. Would Susanna like to go learn how to plait hair? Could there be something in her future besides babies, poverty, and the work to stay alive?

I sometimes ask myself, "Does it make any difference to the world to be helping people one at a time?" It makes a difference to me. I believe that alleviating suffering is one of the deepest impulses of the human heart. It is a way for me to experience my essential self. It is a blessing for those of us, who have the opportunities given to us by our North American birth, to be generous in the material world. We get to receive the gifts of friendship and connection and of working together. It teaches that giving is getting. The Running River School, in Boulder, Colorado, is now sponsoring Juliet for her education and living expenses. All of those children at Running River are lucky that they are getting to know Juliet. They get to have the gift of giving. Everyone wins. Love wins.

Francoise After a year as an AIDS doctor in Uganda I can just begin to see the complexity of the problem of providing AIDS care in resource limited settings like Uganda. Here is one patient's experience in our clinic. Francoise Mirembe, a 30 year old Rwandan refugee and a widow since her husband died five years ago from AIDS, first came to our clinic in May of 2003 for an HIV test. She came for testing because in Rwanda, during the holocaust of killing ten years ago, she got multiple wounds and was covered in blood from others who were injured or dying. She was thrown into a mass grave and had to claw her way out.

At our clinic she tested positive. She had three children to care for, ages 6 to 16, no living relatives, and was working as a house girl. When her employer learned of her diagnosis, she was fired. She attended clinic regularly and had various fungal infections, skin rashes, malaria, and dysentery, all of which responded to episodic care. She suffered from a chronic cough that made her chest hurt. She received food and social support, lived with another AIDS patient, and got by, barely.

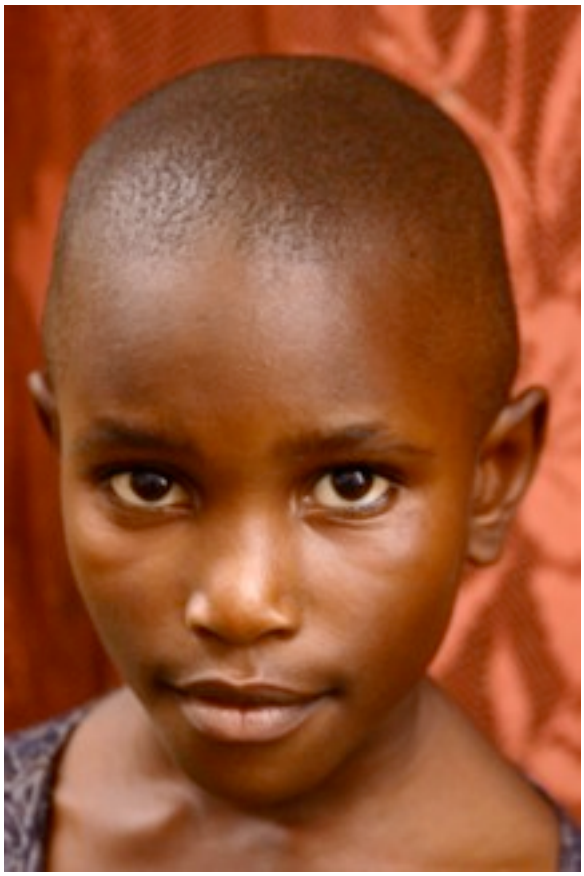
Her cough "work up" kept being delayed. I read in her chart that once there was no money for transport to take the sputum sample to the lab. Another time she went to the village and missed a month at the clinic. One time the lab power was off and the test was ruined and discarded. One set of results got lost. By January of 2004, after 7 months and a 10 kilogram weight loss, her chest x-ray looked suspicious for T.B. Finally she began an 8 month course of 4 TB meds daily, The next month she was tested for her CD4 cell count, which was reported as 517, reflecting a still healthy immune system. This was a surprise. She looked so ill. It meant all her ill health was from TB and drinking, not HIV. Her weight hovered around 43 kgs. (95 lbs.) and she continued to have rashes, fevers, oral thrush and diarrhea. She was faithful to her TB regimen and her cough began to improve. But she didn't.

The file is full of social notes through this time. "She shares rent with a friend who also has children. They are all squeezed into a single room and I wonder where they lie down at night." As we reviewed her file in clinic we asked, "Why isn't she getting better, gaining weight, clearing her cough? Was poverty all to blame?" Her CD4 count was repeated as a 6-month routine late in August. We were shocked to see the result: 54. She had a severely suppressed immune system. She needed anti-retrovirals (ARV's). She probably had needed them for years. Or was it a mistake? Repeat the test: 58. She looked like a patient with a CD4 of 50, so we believed it.

While waiting for the repeat CD4 we did all the counseling, education and screening tests necessary to begin ARV's. Since adherence is crucial, this is a painstakingly thorough, step-by-step educational process. She did her part well and by mid September she began the lifesaving ARV's, which would halt HIV replication and let her immune system recover. These four pills a day, plus her TB therapy (the last month of 8) plus vitamins, prophylactic antibiotics, an antifungal and various skin creams meant she was on more than ten medicines a day. And as her cough wasn't improving, treatment for the AIDS pneumonia PCP was added…9 more pills. But a 4 kg. weight gain in 2 weeks began to look hopeful.

October saw the end of TB treatment but another bout of malaria. More weight loss. Weekly visits in November were frustrating as repeat TB tests, meningitis tests and malaria tests all came back negative. She was slipping again. I was asked to see Francoise at her home. It was Thanksgiving in the US. I had been to the American Ambassador's for turkey and stuffing. Francoise had no appetite and wasn't eating. Her pulse was too fast. She was nauseated but keeping down liquids. She hurt all over. I gave her some meds to comfort her and drew blood for liver function tests.

Two hours later the problem was clear. All the medicines, especially the ARV's and TB drugs had been too much for her liver. It was failing. Francoise died at 4:00 am 2 days later. As I reviewed the file, I struggled to understand her death. Our clinic has 12 practitioners and we all had shared in her care. Would one practitioner have provided better continuity? Were all the medicines necessary? I could not understand her CD4 drop. When I asked the lab to review the initial 517, they discovered that it had been mistyped into the computer. It had been 51. I wondered if we lost Francoise because we lost 7 months in diagnosing her TB. Or because we lost 8 months before knowing she needed ARV's. Or, ironically, by delaying her ARV's 8 months did we actually delay her fatal liver reaction? The complexities of medical care remain challenging, sometimes insurmountable. Françoise left behind three orphans. The youngest is Juliet.



We love and miss you, Torkin and Charles