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Airiel



By David Gunn, MS III

The first patient who died in my care.

Thirteen-year-old Airiel came to the ED in the late afternoon with a fever, rash, shortness of breath, worsening weakness and muscle pains. She was a dark-skinned girl with a Latina mother, white adoptive father and African-American biological father.

The family was concerned this could be a flare-up of her juvenile rheumatoid arthritis, diagnosed a few years ago. “What can we do to help her pain?” they asked. The entire family was warm, welcoming and helpful, fully attentive and active in her care. “What do you recommend?” They looked to us with an open trust that is the celebration and burden of a caregiver.

We began to treat her pain with naproxen and her rash with steroids. A chest X-ray would be taken to assess for possible pneumonia. She would rest while we consulted the imaging and devised a plan to keep these flare-ups better controlled in the future.

There are always other patients to see, and today was no different. Hours passed with gunshot wounds, vomiting, delirium and dementia. As I caught my breath it was time to reassess. Was the gunshot victim in Bed 6 stabilized and prepped for the OR? Was Ben, the vomiting patient in Bed 4, receiving adequate hydration?

What about that X-ray for Airiel? I pulled up the imaging, and immediately saw the mass in her chest. This was not arthritis. This was cancer.

How It All Began

I first heard about Airiel on the first day of my Hematology/Oncology pediatrics clerkship. Monday had given me a lot of adjustments and it was all I could do to keep absorbing what those around me were discussing in fragmented speech. Connecting the dots was a demanding job, let alone decoding how to proceed; I couldn't bother to help Airiel until I could keep up with the current state of flux.

But one thing stayed constant. Her name was uttered on morning rounds with such consistency of affection by our normally harried senior resident that I began to follow her story after I had seen my regular patients. It was a natural inclination, to be curious in her story; in her. Crawling my way through the weeks of progress and consult notes I began to piece together the events that brought Airiel to us.

She had just transferred onto the Hem/Onc service from the pediatric ICU. Airiel had a 3 year history of systemic JRA that was well controlled until 10 days prior to admission. A rash, myalgias and fever consistent with a flare up had brought her to our ED. Her symptoms were successfully treated with naproxen, and she was being set up for Medi-Cal and a rheumatology clinic for follow up.

We did some perfunctory blood and urine cultures to rule out an occult infection, and a chest X-ray and EKG to rule out pneumonia and pericarditis. Things were looking up until the X-ray came back. It showed a mediastinal mass that was determined to be Hodgkin's lymphoma. Despite the huge shock, the family remained positive and optimistic for Airiel's future. The family consented to chemotherapy.

Chemotherapy is never a problem until it's a problem. Sure, nausea and alopecia can be real problems, but when compared to the cancer or a disseminated infection, they are comparatively minor in consequence.

After starting her chemotherapy, Airiel began to have difficulty breathing, and her blood pressure began to drop, and did so quickly. Her immune system was being shut down to attack the Hodgkin's lymphoma and now it looked as though she'd caught a bacterial infection.

She was transferred to the pediatric intensive care unit for more intensive support. Even after being given aggressive antibiotic therapy and respiratory and circulatory support, her heart stopped working and she had to be put on ECLS, extra-corporeal life support. Fortunately, the intervention worked and she remained in the PICU for several weeks before recovering enough to breathe on her own and begin to rehabilitate on our Hem/Onc service.

Recovery and Eye Problems

I met her family when they returned to the ward. All three parents were staying in her room, reading, using the computer, talking with Airiel. Her mom was positive, attentive and involved in her daughter's care. Her two fathers were equally positive, they were easy friends with each other, despite what might have been a complex family dynamic.

It seemed as though they had come so close to losing their daughter that every day with her was a blessing to be celebrated. That seemed to me to be living life the way that we all try to do when we become inspired.

Ariel was the same way — happy, goofy, had a crush on John, the intern, and was a fun patient to visit. When asked to smile for her cranial nerve exam, she grinned from ear to ear, and then just as quickly pretended to regain her composure as a smaller smile crept back out. Later in the exam, she emphatically stuck her tongue out at our gruff and dour attending to prove cranial nerve 12 was still intact.

For a week after Airiel was taken off of ECLS she was intubated, which prohibited her from talking to her mother about the changes she was experiencing. We were giving her anti-hypertensives to correct her high systemic blood pressure. The internal carotid had been sacrificed for ECLS and left her ophthalmic artery with a decreased blood flow. The combination of the two was lowering blood pressure to her eye to the point where her optic nerve began to atrophy.

Only after we removed the tube was she able to speak. She had noticed she wasn't able to see out of her right eye while intubated, but thought the eye had been taped shut as it had been earlier. Now that her strength had

returned and she could move her arms, she knew the blackness in her right eye was not due to a bandage.

She had lost the vision in her right eye. Was it from the ECLS? Was it from the hypertensive medicine? Was it from the JRA? We couldn't tell. I thought that was a pretty lame answer. How could we protect the vision in her other eye if we didn't know what had caused her to lose vision in the first place?

"There aren't answers to all the questions," my attending said. "We have to care for her with the information we do have, incomplete information, but all that is known. That is medicine," she explained, "making decisions on incomplete sets of information. You do the best with what you have."

A lot of people think that doctors know everything, but we don't. We have seen a lot of patients, and use this experience to guide our judgment in the face of incomplete information. It might not always be the right choice, but it is the best choice we can make at the time given the information we have.

I went to see Airiel to examine her for myself, before ophthalmology arrived, so that I could compare my observations with theirs. If I was going to help people, I needed to be able to observe finer details. The best clinical reasoning is worthless if the physical exam overlooks a key clinical finding.

I explained to the family that I was the 3rd year medical student on the Hem/Onc service and that I would like to examine her eyes, to help make sure she didn't lose her remaining vision. Her family was very happy to have me there. Airiel was cooperative and engaging, yet uncharacteristically quiet. I gave my examination and noted my observations, thanked the family and left. Ophtho came and went. They thought the other eye was good and would remain so. And so began Airiel's rehabilitation. Each day that week our team would visit each of the patients on our service and see how they were progressing along the treatment plan we had devised with the family. Continued antibiotics, physical therapy, chemotherapy or pain medicine — each patient was different.

Every day Airiel would be there with her family, smiling at us and goofing around with the attending. She was receiving daily chemo to make sure the lymphoma didn't return, and was tolerating the treatments very well. She began to breathe better, and walk around. Her family was so happy that she had made it through, and we were all happy for her.

Unexpected Seizures

That Friday of the first week I came home and relaxed for a bit. After a while, I checked the EMR system to see how my patients were doing. I saved Airiel for last; she had been doing so well there really wasn't too much going on with her. There was a flurry of progress notes from Stacy, the R2, the nurses and even the attending physician. This couldn't be good.

Just about the time I had been enjoying a pizza and cola, Airiel began to have a seizure out of the blue. Stacy did an emergency physical exam to ascertain the origin of the seizures. Were they from an electrolyte imbalance? Undiagnosed epilepsy? The chemo? A febrile seizure? Had Airiel caught a bug? I quickly scanned the progress notes for answers.

Within two minutes she had stopped seizing. There must have been a moment of tense calming for the team that was attempting to manage the unknown. I imagined what was going through their minds: What to do? What caused this in the first place?

In my mind I put myself there in the tension and anxiety of making decisions on incomplete information, and the relief I felt knowing that as a medical student I would not have to. As much as my faith in the “all-knowing” physician has been shattered, I realized I still wanted to let myself have faith in my superiors.

Just as quickly, two minutes later she seized again. She was given antiepileptics to stop her muscles from contracting, and she relaxed, but was unresponsive. They transferred her back to the PICU where she had been for over a week, where she received ECLS. Back where she lost her vision. That was the last progress note on EMR. I would have to wait until the morning to find out what her course would be. I came back the next morning, and the first thing I looked at was the EMR for Airiel. Some hours after I had gone to sleep, while she was in the PICU, she had an EEG measuring her brain activity for seizures.

The EEG was totally flat. There was no activity in Airiel’s brain — she was brain-dead. Airiel had been in septic shock from bacteria, and blood flow to her brain had been cut off from the massive swelling that was a consequence of the bacteria’s exotoxin. Her head and neck swelled and the pressure had occluded her remaining carotid artery.

I was stunned. Our attending physician came up to our team and told us what the course over the past day had been. That didn’t make it any easier. I felt myself start to cry, and turned away towards my computer. He would have to go tell the family what the EEG showed.

As he walked away I looked after him, wanting to be there for the family when they heard the news. Halfway down the hall he turned and saw me still looking, “Did you want to come; were you following this patient?” “Yes, I was, I’d love to come.” As soon as the words left my mouth I was struck by the contradiction — I was experiencing eagerness in the presence of such great loss and tragedy. Was this okay to feel?

I followed him into the family conference room where our attending, the PICU attending, and a fellow medical student and I waited for the family to enter. As we were waiting, the PICU attending told us three things.

The first was we would tell them what we knew and what their options were. The second was that we should be seated; there was evidence to show that families thought their doctors spent more time with them when they were sitting, even if standing doctors actually spent more time than sitting doctors. And third, we would be seated between them and the door, in case they became violent.

The family filed in, and a somber hush fell over the room and the PICU attending asked the family what they already knew. He filled in the gaps, and danced around the word brain-dead. The mother started to cry horribly, and her grief filled the room and pushed the words out of his mouth. He started speaking again before I would have, and told them about the course of the near future.

“But she was a perfect little girl,” the mother cried, “she was perfect. You know that,” she said to my attending. “Yes, she was,” he replied, “I knew her and she was a wonderful girl.”

The mother asked if there was any hope left at all, any at all. Although the neurology fellow had not read the EEG yet to say 100 percent that Airiel was brain-dead, the PICU attending could tell that there was no activity whatsoever on any of the brainwaves. If there were any family members who wanted to say goodbye, now was

the time to call them. We could arrange religious services for them, and a social worker to help them with anything they needed. We would return to follow up after they had time to be together and talk about the situation.

As my attending and I silently walked down the hall, I asked him if there was anything he wanted to teach me about that experience. He said it's a horrible thing to have to do and it never gets any easier: "You tell them what you know and what you can do."

We came back to our team, and had a moment together, just being together. After a minute or so, we each looked up and knew that there were other patients who needed our help. And so we went on and did what needed to be done. There was a new 11-year-old boy here with a long history of sickle-cell disease who was in a pain crisis, Christopher. Did I want to take him? Yes, of course I did.

The Funeral Services

I went to the funeral. The rest of the physicians thanked me for coming. I was surprised by that. I kept getting the feeling that they felt I was coming to the funeral on behalf of UC Davis. Why else would they be thanking me? To encourage that positive quality in me that drove me to want to visit? Can you encourage that in someone else, or is the quality innate?

Honestly, I came to the funeral because Airiel was such an amazing person, who filled me with so much positive energy I couldn't help but want to go. In fact, that was what I wrote for the family when they asked for a memory of Airiel to be written down for their scrapbook.

But the surprising part of the service was that everyone shared that same feeling — Airiel made them feel that same way. It was really awesome, impressive, that everyone would get the same feeling from this person. Her personality was so strong and positive.

I was sad that Airiel died, because she had such an amazing spirit. We need more people like her in the world. Of course, if we had more people like Airiel, would I be as impressed with her?

Is the rare and beautiful still beautiful when it is common? Is a beauty proportional to its rarity? Or is there something more fundamental to beauty that isn't reliant upon scarcity?

At the end of the service I said goodbye to her aunt. I told her I had planned to speak at the funeral and share my impression of Airiel's tremendous spirit with others, but the more I listened the more I heard people say the same things that I would have shared.

She asked if it was common for a physician to come to a patient's funeral. I got the impression that she was asking if her niece's personality was common. I told her it was very rare for physicians to attend their patients' funerals. Airiel was very special and would be missed terribly. We shared an embrace and I left.

In the parking lot one of the attendings made it a point to thank me again for coming to the funeral; she said it really showed a lot about my commitment to my patients. I think it showed less about me and more about Airiel.

David Gunn is a medical student at UC Davis and the Class of 2011's co-president. He is currently searching for an opportunity to practice international rural medicine with a primary care physician. He holds an M.F.A. from Mills College, and a B.S. from The University of Oregon, both in electronic music. He previously worked for Leapfrog Toys designing the HHS's Interactive Afghan Family Health Book.