



The heart that beats

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Abstract

An intern narrates her encounter with a 19 year old girl recently diagnosed with giant cell myocarditis and shortlisted for a heart transplant. Inspired by the young girl's eagerness to live despite the looming difficulties inherent in the future of a transplant recipient, she reflects on her own life and comes to an understanding of why heart transplant surgery, despite making people dependent on life-long medication, also, more importantly, gives them another chance at life.

Keywords: Heart; Narrative medicine; Transplantation

One week prior to her hospitalization, a healthy young woman was teaching children at an art summer camp when she first noticed a slight stomachache and nausea. Over the next two days the ache worsened, she spiked a fever with chills, and became short of breath. Worse, she had the uneasy feeling that her heart was about to beat right out of her chest. Indeed, when she presented to the emergency department, her heart rate was in the 130s and the blood pressure was dangerously low. No sooner was she diagnosed with cardiogenic shock and diffuse ST segment changes, when a ventricular arrhythmia overtook her heart and she became unconscious.

I had begun my clinical rotation in the cardiology critical care unit as a final year medical student. My resident had assigned two patients to me and the first on my list was the young woman in cardiogenic shock. She had been diagnosed with idiopathic giant cell myocarditis which is a rare, rapidly fatal disease that occurs in otherwise healthy young adults. I am going to call the young woman Lia – this is the story of Lia's heart.

Lia woke up a day after admission

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unaware of her surroundings, and with soreness in her chest from the chest compressions. We had started her on intravenous amiodarone, a rhythm stabilizer, and were moving towards converting it to an oral dose which had fewer side effects. In the mornings every time I examined her fragile heart, I would ask if she slept well the previous night. She'd tell me she was scared that when the lights went off and she shut her eyes, her heart would do that funny thing again. This prevented her from sleeping and so she was always tired during the day. The doctors prescribed pills that would help her sleep and asked her to stay calm, but she would retort, "Why don't you try sleeping on a bed chained to an intravenous drip?" and her gaze would drift to the monitor of the electrocardiogram machine.

Lia was being worked up for a heart transplant. She was eager to get the transplant and inquired everyday about her progress on the transplant list. She was on top priority at her initial presentation, but after a week, since we were able to stabilize her on an oral dose of amiodarone, we were reconsidering her position on the list.

I asked my Attending why we were working her up for a heart transplant at all. A heart transplant is serious business. Idiopathic giant cell myocarditis has the potential to recur in both the native and in the transplanted heart making it a lifelong gamble. Transplant surgeries make sick people sicker, I said, and she is just too young to be handling the burden of the surgery. My Attending did not give me a direct answer; instead, she asked me to go around the cardiology critical care unit and talk with patients who had received transplants.

The next morning I ventured back into the critical care unit determined to talk to some of the post-transplant patients.

One of them, a youngish man, was getting his temporary pacemaker wires removed by the nurse and I volunteered to help. After the nurse scrubbed, she asked me to grab and drop a few things for her so she could maintain a sterile field. As she started to clean the man's wounds and slowly pull out the lines, I asked him if it burned or if he felt any pain. He did not respond; instead, he had his eyes glued to an iPhone screen and all I could hear was basketball commentary in response to my questions. Apparently, he felt no pain - nothing.

Curious, I asked if he was watching recaps of an old game. He took his eyes off the iPhone long enough to say - no, his wife was FaceTiming his 10-year-old daughter's basketball game from camp. We had to request several times that he keep his iPhone away from his body or we would have to take it away. He was determined to watch the game, so he sat in an awkward position, holding the screen away from where we worked. As I looked around the room I noticed a card on the windowsill that read, "Dear Papa, the best gift this year was you getting a heart." In that moment I felt a shift in what I imagined I understood about heart transplants, but it was a tiny shift.

Later that day, one of the psychiatrists who was working with Lia for the transplant wanted her to meet with another young lady. This one was in her 20s and had a left ventricular assistive device in place, while she waited to be listed for a heart transplant. She was a daughter, wife, and mother of three, and had postpartum cardiomyopathy.

The conversation started and they spoke about their lives before and after their diagnosis. I was particularly struck by their keenness to carry on with their lives despite their obvious physical limitations. Just as we were winding up, I asked them a question. What did they expect

out of their lives from here on; what were their goals? The young mother said she only wanted to spend time with her children at home - they'd only ever seen her in and out of the hospital ever since they'd been born. Lia said that she wanted to feel the water on her body when she took a shower; and she wanted to apply to college.

I ran back to the resident's room right after that conversation. Hiding my face in my hands, I cried. I couldn't stop myself - the other residents kept asking me what was wrong, but it took me a few minutes before I could speak coherently.

I narrated the incidents that had brought this on, then cried some more. I thought about my father. He had passed away suddenly due to a massive heart attack. If only he had survived long enough to need another heart, I would have made sure he got one. I would get him a new heart just so that he could enjoy the simple things in life; he could watch with mom as I graduated from college, and he could watch my basketball games on FaceTime. Yes, I would have given him another heart. I moped that whole day and then the whole week.

Another two weeks passed by. Lia was on oral amiodarone and still waiting for a donor. The prolonged hospitalization was beginning to wear her out. The team was considering placing an automatic implantable cardioverter-defibrillator and then discharging her from the hospital.

One night I was at the cafeteria right before my shift when her boyfriend walked up to me and exclaimed, "Lia got a donor heart!"

Was this really happening? I immediately contacted the operating team and requested permission to observe the surgery. I was unable to sleep that night

out of anticipation. At 6 am I jumped out of bed, put on my brand new scrub hat and made my way to the preoperative area. I watched as Lia said goodbye to her family and then was rolled into the operating room. Her mother squeezed me briefly in her arms; I tried reassuring her, but I didn't know how. I was just as nervous as she was.

I expressed my jitters to the case manager, who had coordinated and observed about 50 heart transplant surgeries. She said, "Girl, we do not need that mojo in there." As that thought sunk in, I straightened my back and with confident steps entered the operating room.

The operating surgeon allowed me to scrub and stand beside him for the duration of the surgery. In awe I observed the intricacy with which he resized the donor heart and sewed it into Lia's chest. I held Lia's native heart in my hands and knew I'd remember that quintessential moment forever. By around 5 pm, we had closed the incision. The surgery was successful for now and Lia was transferred to the cardiology critical care unit. When the anesthesia wore off, I got a chance to meet Lia. She told me that it had not been easy, but knowing that she had helped another person, her donor, realize a wish made it better.

Those six weeks were transformational for me. Every time I think of Lia and my father, and of all the people who donate their organs, and of others who receive them, my eyes water up, my ears turn red, and I feel a pounding in my chest. A voice roars in my head - I want to be a heart surgeon - dear God give me strength. I wasted so many heartbeats taking my body and family for granted, now I want to give those who recognize the importance of every beat, another chance, another life.