

# Patient Perspective

## LIVING WITH HEART FAILURE

### When the Doctor Becomes the Patient



It was the holiday season of 2015, and my life was great. I had a full psychopharmacology practice, did numerous consultations in the tristate area, and had started 2 rapidly growing transcranial magnetic stimulation (TMS) centers. I had a close family, good friends, and our horses had won several world championships that fall at the Grand National and World Championship Morgan Horse Show.

I had always been healthy. I had been hospitalized only for childbirth, and I was on no medication. My only illness had been Lyme disease, treated with doxycycline during recurrences. Having spent so much of my life training clinically or in research at the Yale School of Medicine, like many physicians I felt as comfortable at Yale-New Haven Hospital as I did at home.

I found that I was not spending enough time sleeping or exercising, but life was so full and I loved what I was doing. In addition, crammed into this schedule, my daughter was a young world champion equestrian, and my family had spent more than a decade traveling out of state every weekend for her to have lessons with her trainer and horses. And then, of course, there were the summer and fall horse shows. I remember one hectic summer when I flew across the country for a medical conference where I was presenting a paper, and then I flew back to Connecticut to meet my husband and my daughter, switch suitcases, and fly with them directly to a horse show in the South. Somehow, I managed, juggling with more than a handful of balls in the air.

At the age of 64, life was busier than ever. I think I believed that I would beat the odds and live like this forever. But, of course, life intervened.

On a snowy December weekend, after I had worked a hectic week made crazier by finishing up an expert witness deposition, my family and I drove down to Washington, DC, for a memorial service for my uncle. I remember noticing that my ankles seemed a little swollen, which had never happened to me before. As many physicians are prone to do, I did not become

nearly as concerned with this symptom as I would have if this had happened with a patient. I allowed myself to believe that it was the new shoes I was wearing, all the standing, anything other than edema. And that is pretty much all that I remember.

We returned home, and I apparently was having increasing trouble breathing and was turning blue. My family tells me that they tried to get me to agree to go to the hospital, but I refused. My husband, in consultation with my internist, then called an ambulance and had me taken to Yale-New Haven Hospital. I was initially thought to have pneumonia, and was sent to the medical intensive care unit (MICU) and put on a Bipap machine (bilevel positive airway pressure ventilator).

I only remember little snippets of the early days I spent at Yale-New Haven Hospital. I remember thinking that someone had told me that I was in the MICU but that this clearly looked like a friend's house, and I was going to sneak out and go back home in between dinner courses, because why in the world would I be a patient in the MICU? I remember that I felt like someone was trying to kill me by putting something over my nose and mouth—I learned later that I had destroyed 2 Bipap machines by attempting to tear them off. In retrospect, it makes sense to me that I was delirious, because I had very little oxygenated blood being pumped by my heart. But to this day I remember almost nothing of what happened during that time.

Apparently, 24 h further work-up in the MICU showed that what was thought to be just pneumonia was also severe congestive heart failure, and I was moved to the cardiac intensive care unit (CICU), where I spent the next 2 weeks.

So, I was in the Yale CICU with an ejection fraction of 12%, catastrophically low blood pressure, and constant arrhythmias, (bigeminy, trigeminy, and what they referred to as “little riffs of v tach” [ventricular tachycardia]). After a work-up including 2 cardiac catheterizations, a cardiac biopsy with no sedation or pain medications because of my compromised cardiac status, cardiac magnetic resonance, and so forth, it was determined that my heart arteries were fine, I had had no myocardial infarction, and my diagnosis was “acute idiopathic viral myocarditis.” That is, a virus of unknown etiology had come out of nowhere and had attacked my heart. There is no way of predicting this viral illness, there

are no preventative measures known to exist, and there is no treatment for it except early intervention to keep the patient alive, and then hopefully to see some recovery.

I was initially treated by one of the senior cardiologists, who followed me for the first week of my stay in the CICU. I can best describe his attitude towards me as one of irritation. He seemed to believe that because I was a Yale-trained physician, I should take my illness more seriously, and I should be more visibly agonized at my critical condition. He would come into my CICU room to discuss a downturn in my heart function, or the almost certain need for me to be put on the heart transplant list and/or get a left ventricular assist device (surgically implanted, used in end-stage heart failure). He was always very pessimistic about my chances for living a normal life in the future.

It astonishes me that physicians can know an illness well enough to be senior clinicians, but cannot or do not make any attempt to understand the human side. I might be a physician, but I spent much of my time in the CICU simply trying to survive and to wrap my mind around the horrifying turn my life had taken. I was hypoxic, disorganized, unable to focus, and frightened, and I really was not able to see the bigger picture until several months after I was out of the CICU. Unfortunately, often, particularly in large highly esteemed teaching hospitals, doing published research takes precedence over developing better clinical skills.

In fact, I was lying in that CICU bed with barely enough energy to think, to try to focus, to try to encompass the enormity of what had happened to me. I felt totally depleted, body and mind. Again, in retrospect, this makes perfect sense to me: my heart was barely functioning, my oxygenation was severely compromised, and lying in a hospital bed staying alive took all the energy that I had.

Luckily for me as it turns out, I was in the CICU over the holidays. The senior cardiologist went away for Christmas, and a wonderful, more junior cardiologist took over his CICU patients. I was very sick, and remained on the critical list, but my new attending cardiologist was always cautiously optimistic with both me and my family, allowing us to believe that there was at least a chance that I could live normally in the future.

What I think many of the cardiologists did not understand was that I WAS NOT MYSELF. Nor can I imagine that anyone else in this situation would be. It took me months before I realized how delusional/delirious I had been when my heart was barely functioning and I was severely hypoxic. My daughter, who

spent all of my nights in the CICU with me, knew. She brought in her laptop and we watched movies, but I was seeing fangs and death and hallucinating things that were not really part of anything we watched. At 1 point I apparently started screaming all sorts of horrible things at her. This is something that I have never quite been able to forgive myself for.

One of the main things I learned from my time in the CICU is the incalculably huge role of optimism in the treating physician. When you kill hope in a patient, you kill the will to live, to get better, and to thrive. It was not until my current cardiologist took over my care in the CICU that I was able to conceive of how to move forward, albeit in little steps.

I left the CICU on New Year's Day. I was deeply depressed, I had recurrent flashbacks of events that had happened in the MICU and CICU that I had not remembered, I was always fatigued, I could not sleep (I would wake up gasping, afraid I could not breathe again), and I had to wear a LifeVest (wearable defibrillator) for months to make certain that if I went into ventricular tachycardia again I would be defibrillated and emergency medical intervention would be summoned. I was on amiodarone (for acute, significant heart arrhythmias, with several deadly potential side effects), and on 2 medications for heart failure. Over that long, cold winter I went back to work, although my daughter insisted on driving me to our offices for several months. I decided that I wanted to go into cardiac rehabilitation, which was not as easy as it might appear, because I had not had a myocardial infarction or many of the regular symptoms of congestive heart failure. But they ultimately took me into the program.

In cardiac rehabilitation, I was one of the youngest people, and the only female. By that point, my arrhythmias were gone and I was off the amiodarone. My ejection fraction was in the 40s. I found myself listening to the life stories of older men who were not getting better, who were terrified of the future, and I was providing them with reasons for hope and optimism. It was rewarding and sobering.

By the late spring, I had lost 30 lbs (a very heart-healthy thing for me), and I was back to working fulltime. In the CICU I had been diagnosed as having acute idiopathic heart failure, and I had learned to dread having an echocardiogram, lying there in suspense, praying that my ejection fraction was somehow, against the odds, increasing.

At this point my ejection fraction had (miraculously) returned to normal, and I no longer needed to have those frequent echocardiograms. My N-terminal pro-B-type natriuretic peptide had gone from astronomically high to close to zero, and my heart dilation

was actually resolving. I had made two life changes requested by my new cardiologist. The first was to “Stop living like a resident and try to get a full 7 hours of sleep,” which I tried to do. The second was to cut back my hours slightly, which I managed to do for a while.

Meanwhile, starting from when I entered cardiac rehabilitation, I began having symptoms of post-traumatic stress disorder (PTSD). When I went in for my initial cardiac rehabilitation assessment, as I told the cardiac nurse about my CICU hospitalization I began having flashbacks of MICU or CICU scenes that I had not remembered previously, I became dizzy and nauseated, and when she immediately took my blood pressure the diastolic had dropped to 40.

A second major set of flashbacks (with attendant drop in blood pressure, dizziness, nausea, and almost passing out) occurred while I was flying to the west coast. My cardiologist had recommended that I read Dr. Neil Spector’s book “Gone in a Heartbeat: A Physician’s Search for True Healing,” about his experience with chronic Lyme disease, heart damage, and ultimately a heart transplant. After going through all this, Dr. Spector transformed his career, moving from being a senior research oncologist to becoming the Duke University School of Medicine Cancer Institute’s expert in translational medicine.

Unfortunately, I chose to start this book during my first long post-CICU plane trip. I believe that the probable etiology of my cardiac illness was also my chronic Lyme disease, and the more I read about Dr. Spector’s experiences, the more this triggered some of those CICU memories for me. After this episode I spoke to my Yale electrophysiologist, who told me that PTSD was quite common in cardiac patients who had had life-threatening experiences, such as being in the CICU. He routinely suggested a course of eye movement desensitization and reprocessing (EDMR) for these symptoms. I have since learned to do some basic meditation and to use EDMR strategies. And I do not read books on heart disease while in the air, or even at one sitting. A little, in measured doses, is all that I want to handle and re-experience.

Nowadays, I live life differently, according to the lessons I learned during my brush with an almost nonfunctioning heart. These lessons include the following: Be kind to yourself. Do not make yourself crazy. Be a good person to yourself and others. Treasure family/loved ones/friends. Provide optimism and hope to patients. Use what you learned as a patient in the hospital to address the fears and concerns of patients and friends. Get involved with new ideas that will make a difference in medicine.

I no longer travel all the time. As a San Franciscan transplanted to New England, I take time to enjoy the beauty of the seasons. My patients turn to me more when they are facing hospitalization, since they know I have been there. And I have decided that I can make a new and different contribution to my field by making TMS, an important but not yet well-known outpatient alternative to medications and electroconvulsive therapy, more well known, available, and accessible. We have embarked on the opening of new TMS centers and I have been on national radio explaining and discussing TMS, with the hope that the more exposure this modality of treatment has, the more patients and physicians will use it. This is my way of giving back and making a difference.

I still try to get a full night of sleep (at least on most nights), but I do admit that there are some killer weeks. For the first time in my life I allow myself to have some weekend time off, without travel or catching up on work. Life is good again, but in a very different, more realistic, and educated way. I am no longer so blithely comfortable when I enter the doors of Yale-New Haven Hospital. I will worry in the future whenever I have follow-up echocardiograms there.

I came close to death over the Christmas holidays in 2015. I credit three people with helping to save my life. First is my wonderful cardiologist. His knowledge base is exceptional, but in addition, his clinical skills and ability to see the whole picture, as well as his interpersonal sensitivity, distinguish him among the many physicians whom I have encountered. In my opinion, these qualities enable him to establish and to maintain a special relationship with his patients that is clearly linked to their recovery. This was certainly true in my case. During my stay on the Yale CICU, in contrast to the pervasively grim perspective provided to me by other cardiology attendings, who treated me as a physician who should be thinking clearly and should be expecting the worst-case scenario, my cardiologist was an empathic presence who was consistently available and continued to provide cautious optimism and a reason for us to maintain hope for my future. He did not simply treat my illness and my symptoms; he treated me as a full person embedded within a life structure of family and profession.

In addition to my cardiologist, the constant support of my husband and my daughter were key elements in my ability to survive in the CICU and to regain my health at home. I think that having a supportive and loving family is critical to recovery after life-threatening illness. My husband and my daughter provided a consistent loving and caring safety net for me and kept me anchored, reminding me who I really was, during a desolate period of catastrophically low

heart function in the relatively dehumanizing atmosphere of a city CICU. My husband provided a solid wall of comfort and caretaking. My daughter spent every night in the CICU with me, sleeping by the side of my bed, through periods of oxygen-deprived delirium that I do not quite remember, but that I know must have been agonizing for her. Both of them made sure that during the months of my recovery I was supported and aided, and they worked hard to help move me from an impaired cardiac patient back to a working physician with a full life. I love them both dearly.

I asked my cardiologist last year “What percentage of patients with acute idiopathic viral myocarditis go back to being 100%?” He said “Less than 1%.” That was shocking and humbling. Why me? Perhaps, like with Dr. Neil Spector, this was a wake-up call to alert me to think more globally and to try to make a new and different contribution to my medical field. Or, more likely, there is probably no answer to this question. The Yale Heart Failure Clinic, where I am

seen occasionally by my cardiologist, also has no answers. I remain on low-dose losartan and carvedilol. Why? For superstitious reasons. Because I was initially put on these 2 medications (often used in low doses for acute heart failure) in the CICU, and no one knows how or why I got better but they think that it is remotely possible that these 2 drugs might have had something to do with my recovery. There are worse reasons for some of the decisions that we make in medicine.

With deep appreciation, this paper is dedicated to Tariq Ahmad, MD, MPH.

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