The Terrorism of Caring

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My left lung collapsed on December 6, 2001. It just dropped. I developed crushing chest pain and intensive shortness of breath. The chest pain went away and my pulse was steady so I allowed my ever-present coping mechanism of denial to take over. I did nothing about it for 2 days.

Then I went to see my primary care nurse practitioner. I told her she was going to earn her money at this visit. Breath sounds could not be heard on my left side. The X-ray confirmed my worse fears: pneumothorax.

So I am whisked off to the emergency room where boredom and potential are the sisters that haunt the dwelling. After much fanfare, I am placed on a stretcher and the poking begins. Blood gases. Big bore IV. Foley catheter. The nurses performed these with remarkable skill and ease. Then walks in the surgeon. Let's call him Dr. Skippy. If I were a bartender I would have carded him. He was cute, goofy, and young.

I finally asked him had he ever put in a chest tube before. "Yup," he giggled as a reply. I looked over at my nurse and searched her eyes for an answer. "I won't leave you for a moment," she said as she slipped some morphine in my IV. The pain relief was joyous.

She then asked Dr. Skippy how much Versed he wanted me to have. I picked up my head and informed them—once again—that I was on Sustiva and Versed was contraindicated. I was trying to formulate the words to explain induction of the CYP3A4 pathway as the Versed was pushed into my line. So the end result is I remember everything about the chest tube insertion since the Versed effect was reduced in the presence of Sustiva.

This was my first encounter with the fact that few clinicians really listen to us dumb patients. I felt like I was there to satisfy their adrenaline needs.

Twelve hours later, I hear a hissing noise in my room. I suddenly feel my left lung deflate like a balloon set free. My chest tube is half way out! I grab it and place pressure on my chest and scream for a nurse. I quickly tell her what is wrong and she urgently pages a surgeon. I tell her, as I do my best Smurf imitation, that I want someone older this time. Experience does count.

When I saw a man my age run into the room, I actually felt relief. He promised me his chest tube would not fall out. The pain was incredible. I had to begin begging for pain medicine. As the second surgeon sliced my chest, I thought . . . this is insane! Why do I have to beg and scream? Does anyone really think I am trying to con drugs by having chest tubes inserted?

Okay, all is calm and I am back home on Cape Cod. I am getting back to my regular routine and feeling pretty good. The phone rings and my sister tells me my mother is on life support in the ICU. She is dying. My family and I were anticipating a quiet at-home death for my mother due to breast and lung cancer. All the paperwork and the DNRs were in order. However, some overzealous EMT has intubated my mother and she is hooked up to a ventilator. By the time I can rush home, I find her in four-point restraints and bucking her ventilator.

As I walk into her cubical, my father, brothers, and sister are all there and fear has gripped their faces. It

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was not supposed to be like this! The physician turns around and smiles when he sees me.

"Don't worry," he says. "We are going to take care of your mother's high blood pressure and rapid heart rate with a Cardizem drip."

"No, you are not," I calmly reply.

I explain that she needs pain and anxiety relief. She is a "no code" and we do not want any interventions except for comfort measures.

"I don't know if I can do that," he stammered back.

"I want the administrator on call in here now," I countered.

Magically, 10 minutes later a nurse walks in with a morphine drip and syringe full of Valium. The drugs do what they are supposed to do, and my mother calms down and looks peaceful. I spend the night suctioning out her mouth, cleaning her, and turning her. I was so grateful to be a nurse and to be able to care for her.

In the morning, with the help of a nursing supervisor, I petition the hospital's ethic committee to have my mother extubated. It was a surreal meeting. Let my mother die, please.

Nine hours later with her family at her bedside, my mother moved into eternity.

Six days later, the other woman who raised us died. My aunt just could not go on without her sister. So I am back home and knocking on the funeral director's door once again. He is stunned. I have come to the conclusion you know you are really having a bad time when you make a funeral director cry.

Two weeks after my aunt's funeral, I distinctly heard my left lung pop again and felt my chest turn into a clot of pain. I got to experience my first ambulance ride from the patient's point of view. Needles and tubes got stuck in me, and I was stripped naked. So far, no one had mentioned anything for pain, so I decided to bring it up.

"You bet as soon as we get to a town where the cell phones work."

I did not even bother to quibble. Technology had sabotaged me once again. Oh well.

The younger of the EMTs is still in training. He announces—again, like I am not in the same van—that he does not like the way I look. Well, I thought to myself, I have had my better moments. He thought I was having some runs of PVCs. I quickly scanned the EKG and informed him that it was artifact, and not ventricular ectopy. I began to do my EKG 101 lecture just to distract myself. Never let a teachable moment pass.

Another ER, another chest tube insertion, and another nightmare. Once I was stable in the ICU, I finally got some pain relief and I started to cry. Everything just came crashing down on me. The deaths of my mother and aunt, the chest tubes, the fear, and just the whole damn thing.

A nurse walked in and looked at me crying and called me a wimp. Look at you and all your muscles and you cryin' like that?

It is one of the few times in my life that I ever wanted to hit someone. I told her to get out and leave me alone. I was angry that a nurse could even mouth those words. I felt violated by my own profession.

Three days later, I am back at home once again and go for a follow-up X-ray. I was feeling fine. My breathing was great. I planned to go out to lunch after the X-ray, with friends. As the doctor threw the film up on the light box my eyes widened in horror. My left lung was nowhere to be seen. He gently turned to me. I started to cry. He hugged me, and rescue was called.

This time I got a helicopter ride to a big-time hospital in Boston. I was rushed to the airport and greeted by police and firefighters. "Why all this?" I asked out loud.

It was a really windy day, and they feared the chopper might crash I was told. Oh, this is just great. I secretly began to hope I could get upgraded to first-class and get a stiff drink before takeoff.

In the chopper, a medic and nurse stripped me naked with the sophisticated skills of a highly experienced streetwalker. The frenzied dance of tubes began once again. There must be a rule that once an orifice is found a tube must go in. Marionettes had less strings than I did by the time we took off.

Then they debated paralyzing and intubating me in midflight as the medic jammed an 18-gauge needle between my ribs. It felt like my foley was being used to play jump rope. I mentioned that I was still alive and in the same chopper with them. The ride became very bumpy, and all they could do was hang on. For the first time in my life I thanked God for turbulence.

We landed with a great thud and with painful rapidity I was once again jabbed, poked, and tussled without regard. Okay, this was my fourth chest tube, and I am a pro. Still, no one listened.

Shipped up to the ICU, I asked for pain medicine and the physician told me he did not "believe" in pain medicine. I informed him that pain management does not require a belief system like a religion. It is clinical medicine.

He asked me if I would like a Tylenol. No, I wanted his boss.

The surgeon who placed the chest tube walked in, and I explained the situation to her. I got what I needed, and she told me that she had some real concerns about this guy. Of course, this doctor in question would still be my doctor. I did not feel good about this. I remained hypervigilant my entire time in ICU monitoring everything. I rarely slept out of sheer fear. Forget about eating live bugs on national television. If you want to understand real fear, all you have to do is lay in a critical care unit with tubes flowing out of you and questionable clinicians.

Now it is time for me to have a thoracotomy and still more chest tubes. I woke up from surgery as I felt the nurse anesthetist extubate me. She was gentle and wonderful. And, oh, I was alive.

My post-op pain was horrible, and a little "ICU psychosis" settled in. No one thinks that a patient in a bed with tubes is a real person. They yak and yank at you without any regard. I decided to kick the next person who tugged at my foley. Respect for sleep is not even on the radar screen. Because I was one of the sickest patients, I was near the nurse's station, and I was embarrassed to have heard what I did. One nurse spent hours on the phone, and I knew everything about her from her sex life to the house she wanted to buy. She chatted, and I laid across the hall in pain. A drink of water would have been nice.

So here is what I have learned from all of this—something has to be done. No more lip service.

The stress on both the staff and the patients in an ICU is beyond anyone's measure. It needs to be identified and dealt with immediately. It is a time bomb exploding on a regular basis.

Experience and certification do matter in quality of care. I can honestly state that any time I had a certified nurse take care of me—AIDS, critical care, you name it—I received much better care. This only makes sense. Certification in your specialty requires professionalism, extra study, and extra commitment. Believe me, it showed at the bedside.

Pain and symptom management are afterthoughts. Do not get me wrong. People ask you all the time about your pain because the Joint Commission mandates it. The only thing is, most did nothing about it, except chart. I can only assume my chart was doing a lot better than I was.

I think if I heard one more cheesy, "So Doctor Ferri, on a scale of 1 to 10, how would you rate your pain?" I would scream. It did not matter what number I gave, since almost nothing changed unless I demanded it.

Pain and symptom management need to be in every nursing program in the country. Nurses have to reclaim their leadership role in this area. Every nursing dean needs to make sure pain and symptom management is in their curricula.

As AIDS nurses, we have a tremendous gift to give to our profession and the health care community. We are the leaders in pain and symptom management. It is time for us to lead others down the path we once had to trod. It is time for a revolution in health care. Pain and suffering need to be dealt with appropriately. I think it is going to be up to us.