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Fantastic Delusions, Futility and a Family's Love

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It is two weeks into my critical illness, a bell rings—is that one more patient entered into the embarrassing, unethical research trial I'm leading, or is it my monitor's heart rate alarm? Is it day or night? Why is that white light so bright with my eyes closed? These thoughts cloud my brain. Am I still alive?

This story began more than 30 years ago while I was transfusing a shotgun victim in San Antonio. My needle stick didn't seem like much—we had lots of them while we perfected our resuscitations. Ten years have passed since that stick. Running makes me feel good and keeps me fit. My arthroscopy should get me back to it. The scope goes well despite the bad news that my ACL is gone. More surprising is that my liver function tests are elevated.

Hepatitis C. Was I ever jaundiced? Did I use IV drugs, or have a blood transfusion? The questions come rapidly; my internist knows me well. My hepatitis C is genotype 1—a variety that's difficult to treat. But maybe I'll be one who never gets sick from this virus. I need to protect my liver now. I'll swear off alcohol; I'll sure miss a cold beer.

The VA Hospital physician's assistant shares the news: "you are service connected." Veterans have a four to six-fold higher rate of infection than the general population. Being a baby boomer, I know that one out of thirty of us are infected with hepatitis C and 15,000 of us die each year. The liver biopsy doesn't hurt much, just a little when I breathe deeply.

So am I back in the ICU? Time is hard to gauge; sure seems like the middle of the night. My shoulders and hips feel as if they are being yanked out of

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their sockets. Hepatitis C chemotherapy is brutal. My son comforts me: “Pops, it’s OK they’re just cleaning you”. I roll to the other side with a push from the nurses; my joints cry out in pain. The protective muscles around my hips and shoulders have melted away along with fifty pounds. My delusions continue; are they really trying to torture me? My daughter brings our grandchildren to see Papa one last time. She’s a physician and understands; patients don’t survive with these labs. I smiled widely at my two grandbaby boys.

My doctor and friend shares the news, “Epstein Barr virus sepsis is an unusual illness. We didn’t think about it at first, we just kept you alive. The hepatitis C chemotherapy immunosuppressed you. The dialysis is needed—your kidneys quit with contrast and hypotension. The node biopsy looks like B-cell lymphoma, the virus can transform, and rituximab may help. You’ve been a handful and you’re giving me a bad name, hang in there.”

Six organ systems are out, my platelets and white cells are gone, the DIC is wild, the norepinephrine continues, my heart rate is 145, the pancreatitis is painful—my liver quits making albumin; draining my ascites helps. ARDS plus renal failure carries a poor prognosis. The intensivist later tells me my mortality prediction approached 100%. I close my eyes and the delusional trial continues, another subject enters the study, there is that bell again.

I never thought I’d know the time of my death. How odd. My family seems like they’ve been here. That mask sure seems tight, it is hard to breath. My son asks: “Pops what do you want us to do?” I say; “Do the next thing,” and I am back into my delusion. The ICU team wonders if I’m suffering so much that life support should be withdrawn with comfort the goal. My course statistically appears futile to many of the team. Would the Affordable Care Act support more care for me if it were 2014? What are the assumptions for that critical illness algorithm? My wife shares with the intensivists after a discussion with the kids, “he’s always been a fighter, let’s give him a chance.”

It’s three weeks into my ICU stay, the endotracheal tube is uncomfortable; I cough a lot when it’s moved. The suction catheter really gets me going; do the nurses enjoy doing that? The delusions continue. Wait that’s no delusion; it’s my recurring dream—I take control of the aircraft; it’s near the high wires, I pull on the stick and we miss them. The hills are too close, I bank right and we skim past. The runway looks reachable; I add flaps, ease back on the power and the gear touch down with a squeak. I’ve always landed well.

My eyes open quickly; the colors are so vivid. Is it heaven or is it my ICU room? I’m really weak. There is great peace. The nurse brings me the alphabet board; the endotracheal tube still really hurts, I cough. I point out on the board to my nurse, “I’ve never been more alive”. His eyes are wide.

In one heart beat I have become myself. “What time is it? What date is it? What happened to me?” The questions are many. “It’s Saturday morning and you’ve been unconscious for almost a month.” Get my wife, I am wide awake. Those alarms are my monitors, not the ringing bell of another subject entering the study!

Kathy comes to my bedside, I look into her eyes and tell her I love her through the alphabet board, she cries a lot. She still looks scared. I can tell after forty years. Her hug feels good. My son kisses my forehead and shares his love. Taking stock of my condition, I market my tracheal extubation to anyone passing my bed. That tube is really uncomfortable. I type on the alphabet board to my intensivist, "I have a big heart, you get a big heart, pull the tube." My extubation campaign lasts thirty-six hours. The first breath with an open airway was like crossing the finish line, and winning the race. My wide-eyed and clear headed state continues after extubation; boy did getting rid of the tube feel good. The lines in my chest allow dialysis and intravenous access; each set is hovered over by their owners and treated as life-lines.

Dialysis is comforting, lots of warm blankets, and the TV lets me catch up on March Madness. I still like college basketball. The walker at my bedside allows me to get up. I talk a lot; it is so great to be alive. I did think I was dead and that white light seemed so close and bright and calming. Maybe I won't say too much about that right now.

The drive home three weeks after leaving the ICU is wonderful. The green grass is much more vivid than I remembered. It was winter when my sepsis started. My family stood by my side, they prayed a lot for my recovery, as did my friends and medical center teammates. I now know I can return to lead our team. Those ICU physicians are my guys and gals. Boy, did they do a great job. I made my primary physician look good too. I recovered for both him and for the opportunity to get back in the game of life, family and medicine. A few miracles occurred along the way. This experience really wasn't futile and the algorithm was wrong; my wife was right, I am a fighter.