One Doctor's Walk With Death

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Dedicated to my patients and their families
who continueo teach me so much.

The Patient's Take

> Doctors are a strange breed. They nibble at an overwhelming amount of information in medical school. They are too bright to miss the incredible distance between what they know and what there is to know. They dedicate their waking hours to memorizing droplets from a great ocean of information. They learn trivial anatomic structures and then promptly forget them. They stand with groups of more experienced physicians and are asked questions they don't know the answers to. They shake the sleep from their eyes and walk down neon-lit halls feeling inadequate and small… Inevitably, they lose their empathy for pain. The waterfall of pain they hear from countless patients wears them down to smooth rock. After all, they have had to deny themselves so much to succeed. They have endured their own painful humiliation. They have learned that pain is simply a warning mechanism; it isn't real. Is it any wonder that our painful cries empty into a vacuum when doctors are in the room? (Shapiro D. Mom's Marijuana. Nevada City, CA: Harmony Books; 2000)

When I was eleven years old, I saw my mother cry for the first time. Moms don't cry. They comfort you when you cry.

My father, a missionary doctor at the Baptist Hospital in Barranquilla, Colombia, came home from work in the middle of the day and went straight to the bedroom where my mother was sewing. He carried a telegram that I learned said my grandfather had died a few days earlier. By the time word reached us, he was already buried.

I remember my mother's tears. She kept saying, "I just wanted to see him one more time."

I felt helpless as I listened to her cry from my adjoining bedroom. I tried to explain to my four-year-old sister that, "Granddaddy has died." She was too young to remember him.

I also remember when Mr. García died. He was a deacon in our church. I remember his wife and daughter wailing at the funeral service. His widow had already donned the black mourning color that she would wear for the rest of her life. The daughter dressed in white.

I hung out the back of a vehicle packed with people from church. My mother

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drove five miles an hour for miles and miles before we reached the cemetery. Our car was surrounded by people from church who walked in procession through the tropical heat.

I was merely curious about the whole funeral and death issue, including the casket being put into a huge vault in a wall. Other buildings were full of smaller vaults with writing on the fronts.

When I asked what was in them, I was told that there wasn't room in the large walls to keep bodies for more than five years. After five years, the caskets were removed, the bones crammed into the smaller boxes and then permanently stored in smaller spaces. Maybe this was done because Barranquilla was at sea level and graves might flood. Maybe it was done because it was cheaper.

Mr. García's funeral reminded me of an earlier death, probably my first recollection of someone I knew dying. I was about seven years old. Aida was a nurse at the Baptist Hospital while my mother was head nurse. Mom was very fond of her. I think she died of cancer of some female organ. The funeral was much like Mr. García's, but Mom was sadder about Aida's death. I remember visiting her family. There were large poster size papers plastered all over the front of her house. The writing on them was similar to an obituary. It was probably cheaper than a newspaper obituary. The papers also stayed on the house for a long time, so all the neighbors knew Aida had died.

I recall some children's deaths too. I was about nine years old when my parents told me that Terry, a five-year old missionary kid, had died of leukemia. I had played with her big sisters. I was sorry Terry died, but I did not mourn or experience a sense of loss.

Then, when I was about twelve years old, Gonzalito died. I think he was about fourteen. He was very thin and completely bald. He had Hodgkin's lymphoma.

I remember making rounds with my father on a Sunday morning at the hospital. I stood outside the ward and peered through the window as my father started the IV and gave Gonzalito nitrogen mustard.

The hospital staff was very fond of Gonzalito. I remember hearing from my Dad about Gonzalito taking Jesus into his heart. Because of this, I was comforted when he died. At least he wouldn't go to hell.

I watched nurses cry when he died. I thought he was some kind of special person – holy like. He seemed so mature. He seemed so at peace despite his illness. Not like a real kid. I felt inferior to him. I could never be that perfect.

When we returned to the Unites States, I wasn't around death as much. My father finished his training as an adult pulmonologist. Occasionally when he prayed, he would pray for comfort for someone's family. I knew then that he had lost a patient.

My grandmother died when I was seventeen. She had lived with us for two years, and life had been more difficult with her there. She was not a "warm, fuzzy" kind of grandparent like my granddaddy had been. Mom handled it all – caring for us, caring for her, her illness, her death, and her funeral arrangements back in North Carolina. I went to see my grandmother in the hospital right before she died. She was comatose and very yellow with liver failure from metastatic breast cancer. In some ways I felt sorry, but mainly I felt guilty because it was going to be a relief not to have her in our house.

I started the University of Oklahoma Medical School in 1976, at the age of 21, and met my first dead person within days--my cadaver. In order to overcome my nervousness, I told myself not to think of her as a person.

By Thanksgiving, I dissected the orbit around the eyeball (with her head already severed from the rest of her dissected body) without feeling. My concentration was on finding every muscle and nerve I was supposed to find.

The third year of medical school brought me face-to-face with patients. I now wore a short white coat. I was frightened my first night on call. All of a sudden all of that book knowledge had to be interpreted in light of a human being who was sick.

Sometime after midnight, I thought I would get to lie down. Instead, the intern called my partner and me to learn how to intubate – practicing on an elderly woman who had just died. I fumbled through it. I was tired. I was stressed. I felt like the intern was punishing me. I felt like I was violating this woman’s dignity.

In December of my third year, I was still a naïve medical student on her fourth rotation – the Surgery Rotation. Theodus McDowell came into my life. He was a 63-year-old black man with a pancreatic abscess from years of drinking.

On my first Sunday on call, I stood all day holding retractors for the chief surgeon as he made sarcastic comments and drained three liters of pus out of Theodus’ belly, pronouncing that Theodus would not see the light of day again. Theodus survived the surgery. I was overwhelmed with the amount of time he was going to take from me now.

Theodus was sent to the “DICU” (the “Dirty” ICU) at the VA Hospital. The “DICU” had a reputation – few who went through those doors ever came out alive.

Theodus was now in my care. The intern would round in the morning to check on us. The chief resident would round in the evening.

If Theodus’ central venous line reading was low and his blood pressure was low, I gave him fluids. If it was high and he was not “peeing,” I gave him Lasix. Pretty simple. Now, having learned the intricacies and interplay of a human body’s normal physiology and the added complexities of the body when failing, I shudder at the notion, learned from the surgical intern, that the pathophysiology of Theodus’ body was so black and white.

For two weeks, I gave fluids and Lasix. Theodus wasn’t conscious most of the time. I tried to talk to him. I touched his face and caressed it in case he needed comforting. I was by his bedside for hours. I began to feel a tenderness for this man who had drunk himself into his health problems. I felt sorry for him. He was my pet. He was my project. He didn’t seem to have anyone who cared about him except for his wife, his only visitor.

At Christmas break, the intern took over, since medical students still got holidays and interns did not. Before the Christmas break ended, I rode a bus back to Oklahoma City. It was snowing and midnight. I saw Theodus’ wife huddled over in a corner. I knew he was dead.

I didn’t go speak to her. I didn’t know what to say. I don’t remember how she got them to me, but she sent me two little porcelain figurines of an old couple. I displayed them on my piano for years. Now they are wrapped in a box somewhere in the attic. They don’t fit with the décor any more. Maybe one day I will pull them out again. I hate to think that over twenty years later those porcelain figures are all there is to mark the lives of Theodus and his wife.

Deaths entered my life more frequently as I started my pediatric residency. I remember watching John, a three-year-old with Cystic Fibrosis (CF), die. It was gut-wrenching. All too frequently, the attending physician was out of town when his patient was dying.

John struggled for every breath for days. I was told by the senior residents that there was nothing we could do. One morning, his mother awoke at 5 a.m. and found him lifeless beside her. I was called to pronounce him dead.

Numerous children died in this primary and tertiary Children's Hospital in Oklahoma City. I was overwhelmed with the whole internship ordeal. At Christmas, I began a series of faith crises.

Why was I doing this? I wanted to help children, but I felt so helpless. Many of their parents really didn't seem to care. Children were left for days without family members.

I was furious at God.

During my second year of residency, I was on the front line in the emergency room. Children came in near death from all manner of things--drownings, near drownings, dehydration, meningitis, and battering. I was tired, but I did what I had to do.

Most of the children made it to the ICU, but a few died in the emergency room. Amid the pain, I became angry. I was angry at bad parents. I was angry at preachers who railed against abortion and yet were nowhere to be found when an unwanted child was beaten to death. I was angry at church people who lived in ivory towers and easily praised the Lord, but had no clue about the suffering I was seeing. Nowhere in any of my training was there any discussion about how to deal with dying patients, or about how a physician learns to cope. Apparently, it was something we were to work out on our own, or perhaps I was just supposed to learn not to feel.

I stayed a fourth year in residency to serve as chief resident. We had no real intensivist, so supervision of the ICU frequently fell to the two chief residents. We both had an interest in ICU medicine – I was planning to go into pulmonary, and he was thinking of being an intensivist.

In the winter of 1983-84, Oklahoma Children's Memorial Hospital (OCMH) saw four children with Reye's syndrome. These were perfectly normal children a couple of days before they were admitted to our hospital. Only one survived. The CDC (Center for Disease Control) even visited OCMH because of our high incidence of Reye's Syndrome. This was before we knew not to give aspirin to kids with viral illnesses.

During the acute phase of Reye's Syndrome, the lot fell to the chief residents to sit at the bedside of these children. We alternated twenty-four-hour shifts at the bedside of the patient but worked for thirty-six hours at a time to deal with our other duties. Every other night we dozed in a chair at the bedside of these children – watching the monitors of the intracranial catheter and the Swan-Ganz catheter. I felt a gnawing in the pit of my stomach as I watched the intracranial pressure rise above the blood pressure that would keep blood flowing into the brain. Frantically I would try manipulations to lower the intracranial blood pressure. Three of these children were declared brain dead within three days.

I remember the families of Sheila, Jimmy, and Lance. The families brought pictures of their normal children and hung them over the bed in an attempt to remind us that this was a child – not just a body with tubes and catheters.

As each child was declared dead, I cried bitterly in the bathroom across from the "Reye's Room." I cried for the injustice of it all. I cried for Sheila's parents who lost their only child and only hope of having a child. The Sunday morning Lance died, I was exhausted after being up all night. I was driving home crying, "WHY?" I can't say that I heard a verbal response, but something inside of me said, "You will not understand, but I am here." It was a start for me – a start down a new road, a road toward the Giver of Eternal Life.

Following my pediatric residency, I moved to San Antonio for a pulmonary fellowship. As part of the training I was once again working in the intensive care unit. I faced more deaths. I became more proficient in dealing with death, or so I thought.

Two years later, in 1987, I began private practice in what is now the Methodist Children's Hospital. The first patient I saw in consultation died. I ran the ICU by myself for four and a half years and still took "call" in it for another four years. I averaged sixteen deaths a year--most of them in the ICU. At least half were previously normal children who became ill with a life threatening illness – meningitis, hepatitis, sepsis, and cardiac arrhythmias. Some died from drowning and other accidents. Some children died after open-heart surgery or from cancer. Some were abused children who were just killed.

I cried in my bathtub.

Social workers would tell me they were glad I was there when a patient died, so I must have gotten "good" at handling parents. Sometimes, some of my "special needs" or technologically dependent patients would die. These children might have been disabled for most of their lives. Although there was grief, there was sometimes major relief, not just on my part, but also on the part of the family. After the death of these children, I missed the families, as we had been a part of each other's lives for a long time.

ICU deaths were hard, but CF deaths were the worst. I dreaded the death of a CF patient more than anything. Perhaps it was the memory of little three-year old John's death. He suffered, and I didn't know how to relieve it. His CF doctor wasn't there – maybe he couldn't take it either. I had done my best but felt so inadequate.

I developed a vision that I would work very hard to get all my CF patients to eighteen and then promote them to the adult doctors. They wouldn't die under my care. I was reluctant to take older patients who were in bad shape. I said, "I'll just get attached and then they will die, and it will hurt. I don't need that".

Abel died at thirteen – one month after contracting an infection with Burkolderia cepacia, a particularly resistant organism. He was the oldest of a family of six and had two other siblings with CF. I called the transplant center, but it was too late. He died in the ICU on a morphine drip.

His mother couldn't bear to be there, but his father sat at his bedside, held his hand and wept. I was torn. I had to go to the American Thoracic Society meeting in Miami the day before he died. His father understood and made it easier for me to go. When I got the call in my hotel room at 5 a.m. about his death, I wept. I had not been there either, just like John's attending physician; and I had to admit that I didn’t want to be there.

In 1998, I began a walk with death unlike any I had experienced in the past. Julie, my golden-hearted, former oncology nurse, asked me to consider accepting a nine-year-old child with moderately severe CF. The child was being cared for at another CF center but her mother wanted to change to me. The other center claimed that the mother was non-compliant with the child’s care. In fact, the child had spent several earlier years in foster care because Child Protective Services had taken custody. One of my other CF families knew this family and begged me to take the child as a patient, saying that the mom was getting a bad rap. I kept protesting to Julie, “She’ll just come to me and die”.

Julie simply and gently said, “You will be good for her”.

I agreed, finally, to take Vanessa. The first time I met her, I popped her in the hospital, where she stayed for a month. Her oxygen saturations were in the 80s, and she was coughing non-stop. Vanessa had one older sister and two younger half-siblings. There were problems. The family lived on the southwest side of San Antonio 18 miles away from the hospital. The mother spoke an uneducated, slang Spanish, and she didn’t drive. The step-dad worked all the time, so Vanessa spent most of her days in the hospital without her family.

When Vanessa was ready for discharge, I asked the parents to come in for a conference. I had the whole CF team there. I spoke carefully in Spanish and explained as best as I could about CF, what was happening to Vanessa, and what I wanted them to do. They thanked me profusely, stating that they had never understood her disease. I never had a problem with adherence after that. Sometimes the mother got confused or didn’t understand something, but she tried to follow my orders.

Vanessa did not do well in school – she had missed a lot. I worked with her on math; the nurses worked on reading. For months she was in and out of the hospital. We withdrew her from her own school district when she was in the hospital and enrolled her in Northside School District. The hospital tutor worked hard with her and tried to work with her own school district to ease the transition when she went back home.

Being away from her family was hard for Vanessa. One day, in protest, she took a bar of soap and spread it over the walls, furniture and floor, as though it were a piece of chalk on a chalkboard. The nurses fussed at her but helped her clean it up. She hoarded black olives off her trays because her step-dad and sister loved them. She loved her home and her family, and she hated being in the hospital. She loved playing with her brothers and sisters and was overjoyed with her new brother, a ‘99 New Years baby.

Until October of 2000, I was always able to return her lung functions to her baseline with aggressive hospital care. Then she began to skid. I couldn’t stop the decline. I tried everything. She was in the hospital even more.

On a Saturday just before Christmas, on an impulse, I asked Vanessa if she wanted to go with me to my son’s basketball game. Her eyes lit up. We couldn’t find her parents for permission. They were Christmas shopping at Wal-Mart. The nurses declared themselves her “other mother” and gave permission. We didn’t tell the administration.

Vanessa had no shoes with her in the hospital, so she attended the game in slippers. The nurses had French-braided her hair. She screamed at the top of her voice for my son, Andrew, and his team. She couldn't quit smiling. Outside in the cold wind, I held her against me as the coach debriefed the team. As she coughed, people commented on her terrible "chest cold".

We went to McDonald's for lunch, knowing we were going to be late for her medications. She even ate a McFlurry as I called the nurses to get the insulin ready. We went "flying" back to the hospital. Glucose well over 200! Oh, well. We both thought it had been worth it.

After that Saturday, Vanessa would roam the halls waiting for me to show up on rounds. She would put her arm around my waist and her head on my shoulder, as we would walk back to her room. In January, I knew she was dying. I laid it all out for her parents. They did not think a transplant was in anyone's best interest. They said she was in God's hands; they had been told she wouldn't live to be two and she was now almost eleven. They just wanted to be able to take her home.

The day before I was to talk to her parents, I went in to see Vanessa with no intention of bringing the subject of death up with her yet. She was alone and the room was dark. She was pensive. I don't remember how the subject came up, but we began talking about her death. She told me she was scared she was dying. I told her I was scared, too.

She sat in my arms and cried. When, we talked about what she was afraid of, I learned she didn't want to leave her family. We talked about what she believed would happen after she died. Her very simple and candid answer at the age of almost eleven was, "I will go to heaven to be with Jesus and that will be a good thing".

By the next day, actually the day I spoke with her parents, there was a peace in Vanessa. She wasn't scared as her parents and I talked to her about her dying--she just wanted to know if she would hurt. This time, with the help of Dr. Javier Kane and Cynthia Beckwith from the Palliative Medicine Service, I was able to say, "No".

Vanessa's last wish was to be home for her birthday, which was about ten days hence, but by now she needed about 40% oxygen. I felt that if I stopped her IV antibiotics, I would crack the dam. Her mother had never done IV antibiotics at home, but she agreed to do it this time. Fortunately, I was able to get nursing help.

We had a birthday party at the hospital for her four days before her birthday. A hairdresser and mother herself of a CF patient--the woman who had interceded for Vanessa's mother when I didn't want to take her – did Vanessa's hair. Vanessa had a new dress, and the staff got pizza, a cake, and a white limousine to take her home. I remember thinking, with a lump in my throat that her next limousine ride would be in a black one. Vanessa's family came to the party at the hospital. Members of the staff--those working and those off work – came, showing their love for Vanessa. The party was a celebration of her life. Tears flowed, as many felt it would be the last time they would see her. I prayed for strength to go through her death with her and her family. I didn't know if I would make it.

Three days later, my husband, my son, and I went to Vanessa's home birthday party on the southwest side of San Antonio. My husband had helped me pick out a big, soft stuffed lion as a gift. Vanessa was decked out in a frilly, white dress, but her eyes told me of her discomfort. Her breathing seemed labored.

Two days after Vanessa's party, her mother called me worrying that she was hallucinating. Her mother reported that although she seemed clear in her head, Vanessa did not understand why her family could not see the beautiful woman in her room. This was not the only vision Vanessa had in her last days. She saw children in heaven that at first she mistook for her siblings at play. One vision was of the children crying because she was so sick; in another, the children asked her to come to them.

She saw Jesus on the other side of a green river. She asked him if she could stay with her family awhile longer, and he gave her permission. In a recurring vision, Vanessa sat in a room "waiting for the second door to open." One day, I was kneeling by her bed when she described a dark tunnel with a distant light and Jesus beckoning her.

Between visions, Vanessa slept a lot, but when she would wake she was happy to be with her family. We worked out some problems with pain medication, and she was kept comfortable and lucid. She made decisions about stopping her own gastrostomy tube (G-tube) feeds and IV antibiotics. She talked about not having a port-a-cath (the catheter implanted under her skin years before to facilitate giving her IV antibiotics) or a G-tube in heaven. She spoke of being able to run and play.

As Vanessa's mother bathed her the night before she died, Vanessa said her last words: "The second door opened." She died peacefully, at home, in her mother's arms. Her siblings were asleep in the next room.

I went to the family. There was obvious grief in all of them, but the reality and the finality of her death had not sunk in yet. Each family member was so grateful that she had been home the last few weeks. Maybe this is what is meant by the term: a Good Death.

The highpoint of Vanessa's funeral was the song her step-dad sang over her casket: "What a Day That Will Be". The words seemed so appropriate.

> There is coming a day when no heartaches shall come,
> No more clouds in the sky, no more tears to dim the eye;
> All is peace forevermore on that happy golden shore,
> What a day, glorious day that will be.
>
> There'll be no sorrow there, no more burdens to bear,
> No more sickness, no pain, no more parting over there;
> And forever I will be with the One who died for me.
> What a day, glorious day that will be.
>
> What a day that will be when my Jesus I shall see,
> And I look upon His face, the One who saved me by His grace;
> When He takes me by the hand, and leads me through the Promised Land,
> What a day, glorious day that will be.

Now, two years after Vanessa's death, I still visit and speak periodically to her mother. We reminisce about Vanessa, but we also talk about the other kids and life in general. Her mom always asks me about my other CF patients. A picture of Vanessa, taken three weeks before her death, still sits beside the computer in my office. But snapshots of her birthday parties are still in their original envelope. I can't put them in an album yet.

Vanessa's death changed my life. I miss her. I hurt terribly during the last few months of her life, but in some ways she made it the easiest death I had ever experienced. I know now that I can love a patient and lose a patient and survive – and be better for it.

Dealing with death in my professional life is different for me now. I don't scream out, "WHY?????" as much. Vanessa helped me to accept the words I had heard years before: "You will not understand, but I am here".

Yet, I wonder how I will fare when death comes knocking on my door. I have watched a great uncle die without dignity in the same VA hospital in Oklahoma City that Theodus died in. I struggled through a memorial service, instead of a funeral service, for my great aunt as her body was not there. She had willed it to the Medical School to be used as a cadaver. My mother's brother died suddenly of an aortic aneurysm while I was still in fellowship. I couldn't go, but I couldn't have dealt with his death. I was of no comfort to my mother or my beloved cousins.

I have yet to suffer the loss of my parents, my spouse, a close friend, or certainly the loss of my own child to death. If and when I am confronted with such a loss or tragedy, I pray that I will have the strength and the courage I have seen in the lives of my patients and their parents. I pray that I will draw comfort from the Voice that says: "You will not understand, but I am here".