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Disclaimer

I want to start with a few disclaimers.

Due to the spiritual and, at times, religious nature of this talk, I would first like to say that it is not my intention to exclude any types of believers or non believers in this discussion. It is my belief that all care providers are capable of impacting a patient's spiritual healing, regardless of his or her faith background and personal beliefs.

I would also like to disclose that I am a member of St. John the Evangelist Catholic Church.

However, this talk is not exclusively Catholic in nature—in fact, sometimes it isn't very catholic at all.

Finally, I would like to thank all of the people in my life who taught me the meaning of true love, especially my family, and first and foremost, my mother. Without her love, I doubt I would be alive to tell my story. And without her love, I am sure that my story would not be an inspiring one.

This speech is dedicated to my Mama.

Introduction

I have been asked to share with all of you today the story of a certain chapter in my life. It is a story that has become an important component of my personal identity. It is a story that includes the development of my passion for writing as well as the solidification of my future career as a physician. It is a story that is both horrible and beautiful; both filled with darkness and streaked with light; both depressing and uplifting. It is a story about doubt and faith; about dreams being broken and hope being created. It is a story about how spiritual healing impacts physical healing. And most importantly, it is a story about what it means to be a hero—for the hero in my story is not me, the cancer survivor; rather, the heroes in my story are the family members, the friends, the fellow patients, and the healthcare professionals who held my hand and guided me down the path of healing.

Diagnosis

It all started 7 years ago, during the summer of 2010, near the end of my freshman year at Rhodes College, a liberal arts school in Memphis, TN. I had just had the best year of my 19 years of life. I had finally found a place where I felt like I belonged, and I had cultivated the deepest friendships I'd ever had. I was a pre-med student, and I loved all of my classes, the sorority I joined, the school clubs I was a part of, and most of all, my newfound confidence and independence. To top it all off, I had just been selected for a competitive fellowship at the nearby St. Jude Children's Research Hospital, which meant I had the opportunity to complete my own research project on childhood cancer. I was on top of the world—until something very unexpected brought me crashing down.

As soon as the semester ended, I went home to see an orthopedist about a recurrent pain in my right leg that had been bothering me for several months. What happened next is best explained by a passage I wrote soon after:

I knew that something was wrong the moment the doctor came into the examining room. He wasn't smiling, and he didn't greet me with a hug as he had previously. He avoided eye contact and pulled up a stool. He sat down very slowly. You could've heard a pin drop. I stared out the window and waited.

The doctor tried to find the courage to speak, the courage to know what to say. Finally, *I* spoke up. "What's wrong with my leg?" I said.

He looked down at the papers on his lap. "It looks like there is some abnormal tissue in your leg."

Too many things went through my head. The words "abnormal" and "tissue" seemed like nothing to worry about when separate from each other. Together, though, especially in conjunction with me, they made my heart fall into my stomach. I looked back outside, at the small forest of pine trees, at the gray roof of the floors below us, at the cars driving by, and I asked, "Is it cancer?"

"That --- is--- a possibility," he said, one word falling out of his mouth at a time, ripping the sentence into pieces. I knew by the way he looked at me when his eyes met mine that it was more than a possibility. It was a diagnosis. He already knew that there was cancer in my body. He just didn't know how much. Death was a very real possibility.

How did I get to that point? How did my normal, seemingly perfect life turn into something else? How did my biggest worry go from making good grades to surviving? Had I done something wrong? How had God let this happen to me? These were questions for which I had no answers. All I knew for certain was that none of it was fair.

One week later, in the middle of May, on the day I was scheduled to begin my research position at St. Jude, I walked through the doors of that very hospital as a childhood cancer patient. I had been diagnosed with Ewing sarcoma, a rare childhood bone cancer that occurs most often in young children and preteen boys. My disease was not common, predictable, hereditary, or even explainable. I was one in two million with a spontaneous gene mutation, and at the time I equated this to being very *unlucky*.

The Bad Year

I took a leave of absence from college and spent what would have been my sophomore year, from May of 2010 to May of 2011, being treated for cancer at St. Jude. Mama, my 14-year-old little sister, Flynn, and I, moved into an apartment at the Target House, a St. Jude housing facility for long-term patients.

It is easy to remember the parts of that year that were agonizing. The fifteen cycles of chemotherapy, each of which I spent inpatient for five days at a time because of my intractable vomiting and how it felt like ants were crawling down my throat for days after each session. The limb-sparing surgery that removed my tibia and knee bones and replaced them with titanium prosthetics and the daily painstaking physical therapy that followed just so I could learn to walk again. The multiple infections to my leg wound that occurred after surgery, causing delays in my

chemotherapy schedule and, at one point, sepsis. Being told I would always have a limp and never be able to wear high heels. The way my friends in college just down the road moved on with their lives while mine was put on pause. The realization that my dreams of returning to college and getting into to medical school might never become a reality because even if I did survive I might never regain my strength or mental capacity.

The side effects from chemo were so difficult for my body that I sometimes wondered whether surviving was worth it. And everywhere around me, there were innocent children of all ages with the same awful disease receiving the same awful medications. The shaky amount of faith that I'd previously maintained was shattered. I did not understand how any God could permit such suffering among innocent children who had yet to even experience many of life's greatest joys. If there was a God, I concluded, I was no longer interested in paying him or her my respects.

A few months into my treatment, my optimism and passion for life had been replaced with fear, anger, and doubt. My mother was worried about me and feared that this would impact the outcome of my treatment, so she asked me to meet with a chaplain at St. Jude.

Meeting Lisa

Her name was Lisa. I told her everything—how wonderful life had been before my illness, how it had all been taken away, how I felt surrounded by suffering children who were even more unworthy of their suffering than I. I told her how frustrated I became when people told me that this was “all part of God's plan for me.” I told her I refused to believe or respect a God who *planned* for cancer to happen to anyone.

I was amazed at how well Lisa listened. Never once did she attempt to interrupt my rant or correct my thoughts or beliefs. When I had finally finished, she smiled. “Wow,” she said, “you're really angry with God. That's okay, though; you're allowed to be.” This shocked me. I had never been given that kind of permission before, especially by a preacher. Somehow, it was liberating.

When I asked Lisa how she could believe in a God when she so frequently witnessed the suffering of childhood cancer patients, she told me that she saw much more than suffering around her. Much of the time, she saw love and hope and joy. “But where in this place do you see God?” I asked her. “That *is* where I see God,” she said.

Finding God in Strange Places

After our meeting, I slowly began to grow in my understanding of what Lisa meant. I began carrying a small video camera around to take video clips when I found something that I thought somehow indicated the presence of God. It started with simple things that gave me small amounts of joy. The autumn leaves blowing in the wind outside. My little sister's way of pushing me extra fast in my wheelchair to give me a thrill. The therapy dogs that came on Tuesdays. The huge squirrels living in the oak trees outside of Target House that came to us in groups when we threw shelled peanuts into the grass and waited for them. And the way wearing strange hats around brought laughter—or a look of embarrassment—to random people.

But then I started finding *it* in more complicated places. Playing with sick kids in the waiting room and discovering that my mood had improved by the time I left. The friend group we made at Target House, which we met with once a week to watch—and make fun of—the TV show the bachelorette. The inside jokes that my little sister and I had come to share since spending so much time together, and the understanding that she was sacrificing a year at home with her friends to be

with me. All of the times my older sister left college to come and spend time with me in the hospital. The loving way in which my mother helped me vomit for hours on end during chemotherapy sessions and bathed me afterwards because I was too weak to bathe myself. The ability of the sickest children at St. Jude to keep playing and laughing most of the time, to keep living life to the fullest.

Many of them with metastatic disease, many of them enrolled on early phase clinical trials as a “last-resort”, and many of them with drug toxicities far more morbid than my own; in the midst of great suffering, often in the face of death, the children remained resilient. Not bitter about their unfair disease or afraid of their unknowable futures (like me), they were able to be fully present in each moment, continuing to smile and laugh and play. They kept living, even as they were dying. The more time I spent in the waiting rooms, befriending the children or babysitting them while their parents took much-needed breaks, the more I realized that I wasn’t helping them; they were helping me.

My Caregivers

Most of all, I began to notice God, and to feel God’s love, in my caregivers. It was obvious that their mission was not merely to save lives; it was also make each moment left in a patient’s life count, based on an understanding that life is too short and fragile and delicate and full of chance to waste a second. This applied to every patient, whether his or her prognosis was promising or grave. Let me give you some examples.

Dr. Pappo was not what I’d pictured for an oncologist to be like. Instead of serious, he was humorous. Instead of cynical, he was optimistic. Instead of building walls between himself and his patients, he built relationships with us. When I walked into the room, though, my blood counts were not the first thing Dr. Pappo addressed. He always asked me if I’d seen any funny movies lately. His recommendation for me when my spirits were low was always a trip to the movie theatre and a large bucket of popcorn mixed with chocolate candy. If I told him I had gained weight, which was a positive thing during treatment that I often viewed as a negative thing, he would simply reply, “me too,” while patting his stomach. He believed that laughter, not just chemo, was the best medicine.

Dr. Pappo’s children were grown, but he and his wife had 3 large dogs. He talked about them frequently, bringing pictures for his patients to look at and telling funny stories about them. He was quite an entertainer, dressing up as Mr. Potato Head from toy story on Halloween. Whenever I was inpatient for something, he would stop by unannounced, not just on morning rounds, and sit down on the couch with my mother. He sometimes even asked if we had any snacks to share with him that day.

But Dr. Pappo was more than just funny. After my 13th cycle of chemotherapy, when my side effects had been worse than ever before, I felt depleted. I did not feel that I could physically or emotionally handle another treatment. I decided to tell Dr. Pappo that I was finished. I think I expected him to laugh at me or tell me how terrible my request was. Instead, he said, “Ok. If you still feel like that when it’s time for the next treatment, then we won’t do it.” For whatever reason, I felt so empowered by his response. I felt like my opinion and my quality of life mattered just as much to him as me finishing the chemo I needed. By the next week, I had changed my mind; I would finish my treatment.

My other doctor, Beth, was in her first year of pediatric oncology fellowship training that year. Because of our relative closeness in age, she could relate to me. Now that I understand what

residency and fellowship entail, I realize that Beth must have had a very busy schedule. Somehow, whenever I ended up in the hospital, she would make time to stop by and visit me.

The week before Christmas, I was put in the hospital with shingles. To make matters worse, I had to be in an isolation room because many of the immunocompromised children were susceptible. This meant that I wasn't allowed to leave one tiny room for the entire week leading up to Christmas. I was devastated. I had been looking forward to spending Christmas with my family in our decorated apartment at Target House.

The next day, Beth showed up in my hospital room, wearing a yellow contact precautions gown and gloves, and carrying a very large box. Inside the box were all of Beth's Christmas decorations—she hadn't had time to decorate her apartment and knew how much Christmas meant to me. We spent hours over the next few days adding more and more decorations to my room. I have never seen a hospital room look so festive before. When we ran out of decorations to add, Beth started bringing me Christmas crafts to make and hang up on the walls. I ended up being released from the hospital on Christmas Eve, but Beth had turned a potentially awful Christmas week into one of my all time favorite memories.

I do not remember many of the details of my chemotherapy sessions, because the only anti nausea drug that was helpful for me was a benzodiazepine. My family has since told me that I spent these days in and out of sleep, vomiting nearly every moment that I was awake. I was required to empty my bladder every 2 hours to prevent toxicity from the chemotherapy drugs, but I was unable to walk due to the condition of my leg, so I used a bedside commode. I kept Taylor Swift songs playing on repeat and asked for warm blankets every 15 minutes. I wept frequently, often telling my family goodbye because I believed I was dying.

Beth stopped by to visit me during every one of these chemotherapy sessions. She wasn't required to, and she knew that I might not remember it, but she kept coming. She would use window paint to write the number of treatments I had left—all of us were counting down.

I do remember my last chemo. I didn't start taking the anti nausea drugs as early as I usually did because I wanted to remember it. Beth brought lots of window paint and we decorated all of the windows inside and outside of my hospital room to broadcast the celebration that it was my last chemo. It is one of the happiest memories I have.

Throughout that year and into the following years as I returned for follow up visits, I became extremely close to both Dr. Pappo and Beth. They became family. My physicians were not afraid to become close to their patients; because for some of us, that was exactly what we needed most.

Odie

I want to tell you more about a particular patient now, because although I became close to many of the children I met that year, my bond with this child was unique. It was not a romantic connection—though that might have made for a better movie. Far apart in age, we were an unlikely pair of friends.

I noticed something different about him from the moment we first met, in the waiting room before we were called for our morning labs. He was wearing a hat and staring at the iPad in his lap. I immediately felt the desire to talk to him, despite the angry look on his face that signified he did not want to be bothered.

His name was Odie, and he was twelve years old. He told me that he had liver cancer and that several doctors had told him he was going to die from it within the year. He was at St. Jude for a clinical trial because he wanted to try to fight for his life anyway.

I knew that befriending this little boy would end in heartache, but on that day I felt drawn to him. He needed a distraction, another angry teenager to relate to. He needed a friend. So I talked to him, making silly comments and jokes until he finally cracked a smile. Seeing him smile transformed my mood.

I knew I couldn't take away Odie's cancer or his pain. I knew I couldn't save his life. But from that day forward, I had a new goal: I was going to keep making Odie smile. I began seeking him out in the hospital. I wore ridiculous hats to my appointments to make him laugh. I brought him his favorite candy—bite sized twix, not regular size. I convinced him to go without a hat and expose his bald head with pride. When I checked into the hospital, a nurse told me that the little boy down the hall was asking about me, so I visited him before starting my chemo.

In the hallway, his mother began to cry. "He's only himself when you're around," she said. And that's when I realized that I wasn't just helping Odie; Odie was helping me too. This child was teaching me to be fully present in the moment, to laugh through the pain, and to give of myself in order to receive. He wasn't just a surrogate little brother; he was also a gift from God.

As time went by and my cancer continued to shrink, Odie's cancer continued to spread. He chose to return home for his hospice care, and I didn't see him for two months. When Odie returned to St. Jude, he was admitted to the hospital with a liver bleed, and he was placed in an isolation room because of an infection.

According to hospital policy, immunocompromised patients were not allowed to visit patients in isolation rooms. But I begged Dr. Pappo to let me visit Odie. I knew it would be my last chance to talk to him. Dr. Pappo must have known how important this was for me, so he made put on the precautions gown and gloves, and I entered Odie's room to say goodbye.

I remember every word of that last conversation, but one sentence stands out the most. As he lay in bed, fully aware that he was dying, he said, "Maggie, having cancer was worth it because I got to meet you."

I know that one day I will be reunited with Odie in some way, whether it's in heaven, in another life, or when I see his smile in the smile of one of my future patients. Though, at the time of his death, I promised Odie that I would dedicate my life to fighting cancer, I have since realized that cancer is not the real enemy.

The real enemy is found in hopelessness, in weakness, and in hardening the heart. The real enemy is failing to notice the life that is in and around us. The real enemy is forgetting how far we have come and from who it is that we come. The enemy is forgetting to look for life—forgetting to look for God.

After Therapy

In May of 2011, after completing all of my chemotherapy and a little extra time in the hospital due to sepsis from a prosthetic leg infection, I was finally finished with my cancer treatment. After a karaoke-themed "no mo chemo party" and a trip to Hawaii, I spent the summer at home, resting and writing down everything I could remember about what I had experienced that year.

It was undeniable that my year of cancer treatment had taken many things away from me. It took away all of my hair, my physical stamina, my fertility, half of my renal function, and much of the enamel on my teeth. It took away my sophomore year of college, many friends who lost track of me, the bones in my right leg, and my youthful naivety.

But it was even clearer to me that my cancer journey had given me much in return. I gained courage, hope, inspiration, and optimism. I gained countless new role models and many dear friends; some of them I got to see recover, and a few who I had to see leave this world behind. I gained a new career goal and a new passion for living life to the fullest. I gained a new type of faith, a new definition of God, and a new willingness to look harder for God when it is difficult to find him—or her.

I gained all of this, not because I “fought” or “survived,” but because of the people who fought alongside me. Not because I was a “hero,” but because my caregivers and loved ones were “heroes.” Not because I deserved it, but because it was given to me.

And now that it is over, it seems most clear to me now that this is the way love works. This is the way grace works. This is the basis of what Christ and many other religious leaders have taught—that things can be given to us without rhyme, reason, or merit—out of love and love alone.

Light in Darkness

When I returned to college, I was surprised to find that my life did not feel “normal.” It was difficult to live in a world with priorities so different from the ones I had focused on for my entire illness. I channeled my frustration into the research project at St. Jude that had been waiting for me and into raising money for St. Jude by speaking at fundraisers, and I began a second degree in religious studies. I didn’t want to stop searching for God and for meaning.

During my last religious studies class at Rhodes College, I read a book by the author Edward Edinger, who writes in the terminology of Carl Jung. The ego, he describes, must be in a humbled state of darkness and need before it can perceive the dim light of the transpersonal psyche. In less confusing psychological terms, we are unable to see the true nature of reality or our inner selves until we are exposed to darkness, because the truth is so dim that we often miss it. Meister Eckhardt, a German mystic and very controversial figure in the history of the Catholic Church, put this in words that relate back to God:

“God is bound to act, to pour himself out as soon as ever he shall find thee ready...finding thee ready he is obliged to act, to overflow into thee; just as the sun must needs burst forth when the air is bright and clear, and is unable to contain itself.”

I love this analogy of the sun, and it reminds me of the mindset that many Holocaust survivors described. It is said that the walls of Auschwitz bear the following inscription, scratched into the wall by a Jewish victim of the camp: “I believe in the sun even when it’s not shining. I believe in love even when I don’t feel it. I believe in God even when He is silent.”

I think all of these words illustrate the concept that darkness or suffering serves as a connection to the spiritual world, as a place for God to enter. I have no doubt that God also exists in the light, I just think we are often too blind to notice it.

As I read the words that I wrote about my cancer years ago, I am reminded that the light can sometimes only be seen in the darkness.

The ending of my story

This story would not be complete without its actual ending. I completed my cancer therapy almost 6 years ago and have remained cancer free. Soon after I returned to college from being sick, I met a boy named Drew who saw past my short hair, scarred leg, and risk for relapse and became my boyfriend. My caregivers attended our joint graduation party. They also attended our wedding last May. Beth was a bridesmaid. Dr. Pappo a guest of honor, and he and I shared a dance right after my father daughter dance.

My career

I know that my experience will shape me as a developing physician. I know that every patient experience with illness is unique and that not all of them will be the same as mine. However, I do believe that human suffering is universal; my experience with suffering will likely resonate with that of many of my patients’.

I am now very aware of the spiritual struggle that accompanies suffering. Although many people may be too embarrassed or ashamed to admit it, I know that it is often present. Many patients feel the need to ask “why?” when their life is taken over by illness, especially illness with no defined trigger. Many patients feel anger towards God. Many patients lose their faith, their hope, and their ability to find joy in the world when they are chronically or critically ill.

I hope that I will be helpful to these patients in relaying to them the most important lesson that I learned the year of my suffering: God is present in many forms. For me, God was most apparent in the people who surrounded me. God was most apparent in love.

The implications of this are huge when I think about my future patients. As caregivers, we are given opportunities, not only to tend to patient’s medical needs, but also to tend to their spiritual needs. I believe that these needs are often intertwined, and by allowing spiritual healing, we can only accelerate and strengthen physical healing.

Closing

I would like to close with a quote by an anonymous author. Though it was written about cancer, the same struggles and triumphs apply to all forms of suffering.

Cancer is so limited...It cannot cripple love. It cannot shatter hope. It cannot corrode faith. It cannot eat away peace. It cannot destroy confidence. It cannot kill friendship, It cannot shut out memories. It cannot silence courage. It cannot reduce eternal life. It cannot quench the Spirit.

No, suffering from illness cannot quench the spirit—not when we as healthcare providers give ourselves in love to our patients.