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CASE REPORT

As Long As I Work I Will Live

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Abstract

Life altering situations can come at the most unexpected time. This abstract addresses a real-life unfolding scenario case study of a 57 female who is the main financial and health care support of her family. The case study presented here in real-time will help health care workers understand the dynamics of a family unit being torn apart as they are grasping the gravity of the diagnosis of Triple Negative metastatic breast cancer. This revealing case study will also show the good and bad experiences that a family and patient experience as they traverse the health care system in attempt to find the right medical team that is willing to work together for the best possible outcomes. Additionally, this case study will shed light on the situation whereby the female who is the primary support of the family income as well as health care insurance accepts that she may have to work up until the end of life to ensure her family is cared for.

Unfolding Case Study

It was approximately fourteen months ago, (to be exact December 28, 2016). I was a healthy; energetic nursing faculty member eagerly excited to become one of The University of Texas Medical Branch Medical School (UTMB) newest members. On December 29, 2016, I felt a small mass on my right breast. The mass was not present on December 28, 2016. I did not worry too much about this as ten years previous I had been found to have benign fibroids on my left breast. I was actually a Nursing Professor at UT Health San Antonio School of Nursing and had just been hired to begin January 2, 2017 at UTMB. My clinical background is as a Medical Intensive Care Nurse for approximately 25 years before going into academia. Knowing I would be coming to Galveston, I elected to be seen by the UTMB Clinic System. I was promptly notified that I had an appointment January 10 at 8am (the same day that I was supposed to be introduced as new faculty to the students that I would be teaching in one of the courses that I was assigned to teach).

The detailed nurse that I was, I typed up a thorough medical history of my life which included: Appendicitis 6 weeks prior to delivery of my first and only child – of which as the dedicated nurse that I was, I had just come off of a 16 hour shift; Birch procedure; hip replacement (2014) resulting in a blood clot from my femur area to my petala a trapped tendon as a result of the cup of the artificial hip insertion along with over usage with a cane due to the pain from the trapped tendon, I developed rotator cuff damage which required surgery in December of 2016 as well as being diagnosed with peripheral vascular disease to my lower extremities (the plight of a Nurse who has worked the 12 to 16 hour shifts in an Intensive care unit). I also as the detailed nurse included all medications that I was on to include: anti-hypertensive drugs, ASA, etc.

The 3rd year Resident was quite pleased to receive such a detailed record of my health. I provided him this copy but then said, “Now, let me show you why I am here.” I palpated in his presence the mass (which was a small triangular shape, no more than 2-3 cm in width). The 3rd year Resident then palpated where I had shown him and his response was “revealing” as he said to me, “Aaah, I will be right back!” The 3rd year Resident came back with his Attending Physician who proceeded to palpate the area, and immediately told me that she was sending me to the Breast Imaging Center for a mammogram. One only has to imagine, I have just started a new job, and I am being told that I needed to have an urgent mammogram and Doppler studies. The radiologist, extremely bright and very thorough and he immediately knew what he was seeing on the mammogram and then with exceeding diligence, performed the Doppler going deep into my right axillary area where he found a single lymph node that looked highly suspicious. The Radiologist next tells me that you are coming back here tomorrow at 0800 am (January 11. 2017) and he was going to perform biopsies on my right breast and right axilla region. Needless to say, I never was able to meet my student class that day.

My husband had not moved from San Antonio as it was mid in the school year and he was a School Crossing Guard and thus, he would come on the weekends or every other weekend to be with me. You see the reality was and still is that I am the partner who brings in the income as well as the benefits. My husband (having only a high school education, but tons of common sense) did not quite understand what I was telling him. I told him not to worry as when he came on the weekend I would share with him the findings.

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I, myself, being a MICU bedside nurse had not been exposed to many oncology experiences except for those unfortunate individuals who were on ventilators and septic and still the oncology nurses would come up to the MICU and perform the required chemo treatments. I was on a real learning curve. I was diagnosed with Triple Negative Cancer with a high rate of growth - in other words, the health care team would have to work at break-neck speed to get me enrolled in treatment. Meanwhile I am attempting to teach at my new position (full-time). I succumb after the first treatment of chemo therapy which caused all of my hair to fall out within a week; but too, developing throughout my entire body the most severe muscle cramping and then the worse of it, I developed all over my body golf-ball sized nodules that were extremely painful and hard like rocks.

I had just filed the paperwork for Family Medical Leave which was immediately approved. I had always taken vacation time for any other health care need in the past. The paperwork involved with both the Family Medical Leave was daunting. By the time my husband arrived in Galveston, he found me in my bed, nearly unconscious, dehydrated and on the verge of crisis. He spoon fed me juice, pudding, anything that he could get me to swallow.

The nodules that had erupted all over my body were so painful but yet I was being told by my first Oncologist that these were just a "skin rash." I knew that this was no skin rash and I finally got my nurse's voice and spoke in my behalf (being my own patient's advocate). The first Oncologist had provided me with his personal cell phone number as he stated, "I never receive my patient's calls through the 24 hour nurse line." It was a Saturday night that suddenly about eight nodules suddenly appeared around the lower border of the breast mass and this was extremely frightening and thus I texted the Oncologist as he had told me if I ever had any concerns that I could call or text him on his personal cell phone. It was a Sunday (February 26, 2017 at 10:30 am) The first Oncologist returned my call and the first words out of his mouth were, "Don't you ever text or call me unless you are in a 911 situation and then he basically told me that I was welcome to go find another Oncologist, basically he was firing me as his patient. I got my Nurse Voice and spoke up in my behalf (being my own "Patient Advocate").

My husband decided to take me back to San Antonio that very same day (Sunday), still not knowing what we were going to do as we had no experience with cancer, I decided to called the only person that I truly trusted and who I knew would be able to assist me, my private cardiologist. My cardiologist promptly called me back on that same day, Sunday evening and instructed me to come to his office the next morning (Monday February 27, 2017). He immediately connected me with the UT Health San Antonio Oncology Group who listened to my experience.

My husband and I were frightened as to what was happening to my body with these large nodules erupting all over my body to include around the mass that was at the right breast. The second Oncologist (I can only say great things about his whole team) immediately told us that this was not another form of cancer but rather it was a result of when an individual receives an overdose of chemotherapy products at one time.

The term (which the first Oncologist could not even express) was that the nodules were called Hemorrhagic Vacuities and he said unfortunately my body would have to absorb these gradually which over time did occur, though some leaving their scars (skin discolorations) permanently now to my body. I was lucky that when I had signed up for my benefits when I taught at UT Health San Antonio School of Nursing that I had taken out both short and long term disability insurance.

I had the support of not only all of the Faculty and Leadership at UTMB but also the Faculty and Leadership at UT Health San Antonio Schools of Nursing as I was and am still going through this experience. Fast forward to May, 2017, I had completed the first phase of the chemotherapy (which had taken a toll on me causing me to be essentially bed-ridden).

Throughout those first 5 months (January-May), I would receive encouragement from my faculty from both schools plus a mobile-phone sent message of encouragement from my Dean, Dr. Watson, simply saying. . . . "Linda, how are you doing?" Too, Dr. Watson had sent me a letter saying that she hoped to see me back to work here in Galveston June 1st which gave me a time table that I could get the surgery completed in San Antonio as I had finished the final chemotherapy treatment the second week in April, 2017 (which was just on the borderline of acceptance to go ahead with the surgery).

I had the surgery for the removal of the mass on May 2, 2017 with the additional removal of nine lymph nodes and went home the next day with Jackson Pratt Drains in my axillary area. Of these nine lymph nodes, eight were positive for cancer meaning that the cancer had traveled.

Greatly appreciating my second Oncologist and his team, still I asked him to transition me to MD Anderson, located in Houston, Texas as I needed to get back to work. The first thing that the MD Anderson Oncologist did was to restage me with a multitude of diagnostic tests: CAT scan, Bone Scan and a variety of blood tests. The results from this staging were astounding: The Cancer had traveled into my Liver and extensively throughout my skeletal system to include: spine, both legs, and bilateral ribs. My third Oncologist (the MD Anderson Oncologist) was out-front with this information as he knew I was a nurse, and then he said "you are not even going to make it to retirement!" which just about caused my husband to faint.

The treatment plan was agreed upon that on the Friday evening of every week for 12 weeks, I would receive the second phase of chemotherapy and then I would be restaged again. Keep in mind, I am back to work full time while the second phase of chemotherapy was occurring. The second phase of the chemotherapy treatment caused me to have permanent neuropathology in both my hands and feet (which I kept expressing to the staff at MD Anderson) until finally one Nurse who was caring for me listened and allowed me to express that I believe I am experiencing a severe reaction to this particular chemotherapy and she listed this particular drug as an allergy due to the severity of the neuropathology. With the nurse listening to me and then embedding the various serious reactions that I was experiencing with the second phase of the IV Chemotherapy, the MD Anderson (third Oncologist) finally listened and agreed that in fact I was experiencing a severe reaction.

Thus, I was started on a 3rd chemotherapy drug known as Xelado. Friday, December 15, 2017, I went to UT MD Anderson for the second staging (again a full CAT scan, Bone Scan and Blood work). I was dismissed from the CT Table and was discharged, not knowing that I was walking around with clot in part of my celiac vein and one partial occluding clot in my pulmonary tree (that could break lose at any time).

It was Monday December 18th after 5pm that I received a frantic call from a Nurse at UT MD Anderson saying, “Get yourself to the nearest hospital, you have a Pulmonary Embolus!” I was still in my office working on my preparations for the next semester and as she spoke, I pulled up My MD Anderson Patient Chart and the only test that had been released was the Bone Scan that revealed that the cancer was now in my left scapula region, but surprising the CAT scan result had not been released.

I told the Nurse who had made the frantic call, that I was not exhibiting any signs of a Pulmonary Embolus, after all I should know being a Medical Intensive Care Nurse - I knew what the symptoms were. I explained to her that I had this wonderful UTMB Family Physician who I can say is the best Family Physician that I had ever encountered in my entire nursing career and I would ask him to review the tests since I was not allowed to review my own CAT scan. I sent a message to my UTMB Family Physician. As I was so busy Tuesday, I had totally forgotten about the frantic call from the MD Anderson Nurse or perhaps it was a result of the new Cancer Medication that I had been started on in the fall of 2017 (Xelado) - which I believe creates short-term memory loss (or at least in my case it causes short term memory issues). At the end of my work day on Tuesday, I remembered and looked at my UTMB My Patient’s Chart and sure enough there was a message from my Family Physician (who by the way knew a back way entrance into being able to see tests from MD Anderson) and he cut and pasted the results of the CAT scan that was performed on Friday and recommended me to go to the hospital. I had to call my husband and tell him of these findings and he just about came apart - actually going to a mortuary to plan my cremation as we had already discussed such final plans as he did not understand what I was trying to explain to him.

First I had to drive home, and then my husband and I went to the Jeannie Sealy Hospital and there I received excellent care and treatment under the watchful hands of the Head Internal Medicine Group. The Lead Physician understood very well that I was an experienced nurse and based upon my abilities to provide my treatment, discharged me Thursday with providing me with my treatment plan that of being placed on a regimen of Lovenox BID which at the time of this writing, I have already completed a huge case of injections and am now on my second case. Evidence-based practice revealed that research had found that Lovenox was the recommended treatment with the various cancers that I had invaded my body. Having the appropriate physician’s release to allow me to return to work, I came back to work that very Friday (missing only 2 days of work). Currently, based upon the poor or lack of communication that UT MD Anderson had with my UTMB Family Physician, I have made a decision to come back to UTMB to a new Oncologist (this is my fourth and final Oncologist that I will see), thereby ensuring that communication will be fluid between the various physicians that are providing my care. Currently I have developed a small ulceration on my left heel and with my already diagnosed PVD, my family physician was unable to obtain pulses to my feet but I joked with him that it is probably due to the coldness of the building that I work in. The saga continues, but the one thing I can say is I have worked throughout this unbelievable journey. I do not know how long I will survive but I believe that as long as I continue working, I will continue living.

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