

Desperate Needs for Compassion from Oncologists

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Commentary

Late in August 2011, my wife and I joined a group tour to Alaska. It was a one-week tour from Fairbanks to Anchorage. During the trip, my wife complained about leg cramps and had to slow down quite often when we walked at the Denali National Park.

After we came back from the trip, we were checking our calendar for the next appointment date with our family physician. It was still several days away. My wife then casually mentioned that she lost a lot of weight lately. I asked how many pounds. She said around 25. Upon hearing that, I did something I had never done before in our 40-year marriage. I made an appointment with our reliable family doctor, Lisa Burch, for next day. My wife made all the doctors' appointments for both of us until that time.

Life Saving Efficiency of Our Physicians

Dr. Burch had my wife blood-tested the next day and she called us immediately and ordered us to come to her office right away when the results came out. She told us that lab results were all jumbled and she suspected a cancer somewhere near bile duct. She told us to check into the hospital right away through the emergency entrance. It was the middle of October, 2011.

All afternoon that day, several doctors checked her stomach through a variety of tests, and their conclusion was that my wife had the beginning stage of pancreatic cancer. Doctors told us that the cancer was so small that it was barely visible. One of the doctors who examined my wife, made an appointment for us with a cancer surgeon at Mobile Infirmary, considered by many to be the best in the area. Actually, all doctors who examined my wife that day were the best doctors to us.

On November 9, my wife had a successful Whipple surgery. The surgery was followed by Gemzar chemo from December 11 to April 2012 at a well-known cancer center in Mobile, Alabama, where we lived.

Why Tell the Story

You may wonder why I am telling my story. There are many studies exploring benefit-cost aspects of hospice care. Some deal with cost of hospice care based on its demand and supply, while others show negligible savings from substituting home care visits for hospital stays [1,2]. Still others warn that additional cuts to Medicare and Medicaid budget "would have a devastating effect on the quality, compassionate care that hospice provides to individuals who are terminally ill and their families" [3].

Hospice care is defined as "quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain

management, and emotional and spiritual support expressly tailored to the patient's needs and wishes" [4]. My interests in the definition are compassion and pain.

There is no shortage of documents that stress the quality of hospice care. The Patient Protection and Affordable Care Act of 2010 even mandated that a hospice quality reporting program begin by fiscal year 2014. In 2014, the Centers for Medicare & Medicaid Services (CMS) adopted seven quality measures, four of which relate to pain and dyspnea (i.e., difficulty in breathing).

In 2014, the Institute of Medicine recommended public reporting on quality measures of care near the end of life for federally funded health care programs. In 2015, CMS implemented experience-of-care survey for bereaved family members. In January 2017, I completed and mailed one. When I received the same questionnaire again in February, I was not sure how accurate the survey results would be and threw away the questionnaire.

There is a need to develop a way to effectively measure the quality of end of life provider services. Measuring the quality of these services is difficult, however, because the hospice patients "have accepted that they are dying and, therefore, typical quality measures, such as patient satisfaction at the end of services and recovery time, are not appropriate" [5]. In its March 2016 report, the Medicare Payment Advisory Commission recommended advance care planning services for hospice patients and families, and in 2016, Medicare began to pay for advance care planning conversations between a beneficiary and his or her physician, advanced practice registered nurse, or physician assistant under the physician fee schedule [6].

However, measuring the quality of hospice service and advanced planning are easier said than done.

Curtis et al. do emphasize the importance of physicians "taking as much time as needed with the patient" and the accessibility to them by patients and their families [7]. A thoughtful article by Woo et al. states that "clinicians who are responsible for the treatment of patients at the end of life commonly lack adequate training to help guide end-of-life decisions," and suggests that "an understanding of the dying patient's experience should help clinicians improve their care of the terminally ill." They correctly point out that "pain, and the fear of pain, often drives the behavior of patients at the end of life" [8].

Obviously, I cannot give you an understanding of the dying patient's experience. However, I can tell you my experience as the sole caregiver of the painful death of my one and only wife.

Slow Progression

The tumor marker CA 19-9 began its gradual rise, with some fluctuations, from 19 on June 23, 2012 to 398 on July 11, 2014. As the number was creeping up, I began to worry and spent a large amount of

time on web to find out what the number really meant. I found out that, standing alone, the number did not mean much and many oncologists just ignored the number. When the number is combined with other indicators, however, the number is likely to show what is happening to cancer cells inside the body.

Explanations in the website of the Pancreatic Cancer Action Network, which I visited numerous times to search for some hopeful comments, indicated that *“not every patient with pancreatic cancer will have an elevated CA 19-9 level. In addition, some non-cancerous conditions can cause high CA 19-9 levels.”* A telling conclusion of the website was that *“a decline in CA 19-9 levels after treatment for pancreatic cancer followed by a later rise may suggest tumor recurrence or progression.”* I did not tell my wife of this conclusion.

As a precaution, we decided to have her tested by an oncologist at the Tucker Gosnell Center for Gastrointestinal Oncology, Massachusetts General Hospital (MGH) in Boston. My wife had CT scan and PET scan on October 2, 2014, and met the oncologist the next day. After discussing the findings with two radiologists, he told us that my wife was all clear at least at the moment. Sometimes, I wonder whether we could have had a better outcome if we stayed with him at MGH rather than searching for better-known treatment centers.

Year 2015 was a very long year for us. On February 18, 2015, my wife had a blood test that showed an increase of CA19-9 to 609. The blood test was followed by a CT scan on February 19 at the Mobile Infirmary. The CT scan found small nodules in the lung, an indication that my wife's cancer could be metastatic. Clearly, this was a time for serious concern.

We decided to seek treatment at the world-famous cancer center in Houston. Our contact to the cancer center was made easy with help from Ms. Celeste O'Neil, who was Patient and Liaison Services Associate at the Pancreatic Cancer Action. Numerous questions to her were answered in less than a few hours. This was early 2015. Unfortunately, my desperate and belated contact to Celeste was made again in late 2016.

The Cancer Center

The cancer center in Houston is an amazing place. Every place is patient friendly. They even had a wonderful policy of having to respond to email questions from patients within one business day, which was changed in 2016 to two business days, although the policy was not necessarily adhered to especially during the clinical trial.

We had direct flights from Mobile (Alabama) to Houston Bush International Airport. All daily direct flights were monopolized by United Air. Since my wife and I always traveled together, each trip cost us about \$1,200 per flight if we could make reservation early. If not, they cost more than \$1,600 per flight. Adding room and meal expenses for a 2-day stay, each trip cost, at least, \$2,000.

Our first visit to the cancer center in Houston was on March 25, 2015. Our first meeting with oncologist on March 31 went as well as it could. He even told my wife that if anyone could survive, it would be her. Around the time we were there, she was as healthy as any cancer patient could be. She regularly went to ladies only exercise gym, went to the University of South Alabama yoga classes twice a week, and played golf about once every week or two. With her physical condition, I had no doubt that the widely-respected cancer center would take a good care of her.

March 27, 2015 CT scan found whatever nodules appeared in her lung to be unlikely metastatic. Even the CA19-9 number was lowered to 305.6. We were ecstatic, repeating our admiration for the cancer center. Our oncologist told us to come back in June. Although CA19-9 number increased from 305.6 on March 27 to 365.8 on June 30, the CT scan on June 30 again indicated no cancer. Next appointment was scheduled for August 5. Our oncologist suggested PET scan on that day.

Blood test on August 5, 2015 showed a significant increase in CA19-9 number to 618.7. PET scan on the same day found nothing suspicious. One nodule was noticed but was too small even for PET imaging. The CA19-9 number during our next visit on October 26 increased to 961.9. Our oncologist then suggested a liver biopsy, saying that a small growing nodule was found in the liver. The November 11 blood test found CA19-9 to have increased to 1102.0. The liver biopsy on November 12, 2016 found no malignant cells. Year 2015 finally ended. We thought year 2015 was bad.

Worsening Fate

Year 2016 began with CT scan at the Houston cancer center on January 13 that revealed new nodules appearing in my wife's liver. We were told to return there in less than 2 weeks for another biopsy, this time concurrently with CT scan. My wife had the second liver biopsy on January 26 that confirmed that the nodules in the liver were cancer cells. Our oncologist in Houston called the cancer center in Mobile (AL) to begin her chemo treatment.

By the way, we kept an oncologist at the Mobile cancer center, called Mobile oncologist in this article, in addition to the oncologist at Houston cancer center, called Houston oncologist in this article. We kept both because of my desire to make sure that my wife would be taken care of if something happens at the Houston cancer center. We never failed to report to our Mobile oncologist upon returning home every time we had an appointment with our Houston oncologist.

Another CT scan in Houston on May 2, 2016 showed that the previous chemo was not working. Our Houston oncologist thus ordered new chemo. In chemo #2, my wife had to carry a pump for at least 46 hours with serious nausea, no food, and frequent throw-ups. She needed to take anti-nausea drug right after chemo before pump was attached to her body. When the pump was removed two days later, she took Zofran+fluids for nausea and had an injection of Neulasta for growth of white blood cells. It was almost impossible to endure the chemo #2 without hope that the cancer would be cured. This was the first time that my wife mentioned whether it was worth living.

Emotional ups and downs continued. When the June 22 CT scan in Houston showed shrinking cancer cells, our Houston oncologist lowered the dose of the strong chemo and side effects were less severe. More than anything else, our emotions were flying high again, believing that we were winning the war.

When our Houston oncologist mentioned genetic analysis at the Personalized Cancer Therapy (PCT), we immediately accepted and visited the PCT place to take care of the genetic analysis. We signed all the documents presented to us. There was no need for us to read any of them, because we simply trusted everything the Houston cancer center was doing for us. Actually, I web-searched about genetic analysis in cancer treatment in which doctors find out the type and nature of the cancer and target treatment specifically to these cancer cells. We never doubted that we were getting the cutting-edge treatment.

For the rest of the treatment including clinical trial later at the Houston cancer center, no one mentioned genetic analysis, let alone its use. I am still wondering whether it was considered at all in selecting the clinical trial, and in selecting drugs during the clinical trial. In the beginning, I did not ask the question because I did not want to give an impression of questioning their professionalism. Near the end, I could not ask the question because I was in a state of complete confusion.

Clinical Trial

The entire treatment process had been a roller coaster. When hopes were up during one visit, they were dumped quickly during the next visit. When we thought today was the worst day, the next day became a worse day. Worse than the worst day came on August 30, 2016, when our Houston oncologist told us that the chemo did not work, and the cancer was spreading. He then said he would select the clinical trial for the next phase of treatment.

Both of us were quiet, when the taxi was speeding toward the Bush International Airport for our return trip home. Although we did not say to each other, we both knew that we still had hope that our Houston oncologist would select the best clinical trial for us. Former President Jimmy Carter's cancer was cured, and we were treated at the most famous cancer center in the world. My wife appeared healthy and acted normal when we began the clinical trial. It was difficult for us to believe that she was carrying growing cancer cells in her body.

The first appointment for the clinical trial was on September 16 at the same Houston cancer center. We had a brief meeting with our trial physician, who prescribed MLN9708 which was yet to be approved by the FDA, and Vorinostat which was also known by its brand name Zolanza and was approved by the FDA. In total, there were five appointments between September 16 and November 21, 2016. We met our primary trial physician only twice.

Last Appointments with Oncologists

Our final visit on November 21 was for CT scan and November 22 for blood test and consultation with our trial physician, who had "full schedule" and thus was not able to meet with us. Medical persons told us that the clinical trial did not work, and there were no other Phase I options available for my wife. They told us they would call our Mobile oncologist to give my wife fluids for her low sodium so that we could return home next morning. The substitute doctor remained mostly silent, and his last word to my wife was a whispering that "*you and I were born in the same year.*"

November 22, 2016 appointment was the only time we drove, rather than flying, to Houston from Mobile, Alabama. That evening, we slept at Holiday Inn in Beaumont, Texas. As soon as we returned to Mobile on Nov. 23, we met our Mobile oncologist to report our trip to Houston and receive the fluid shot.

Our Mobile oncologist told us he communicated with the clinical trial people in Houston, agreed with their assessment, and said that "*no drug would be helpful at this time.*" He then said that my wife would live about one month, possibly less. He never mentioned low sodium level or fluids or pain, let alone prescription for pain control. It was unreal, considering that the only thing my wife had been asking during all our appointments with him was to make her painless when time comes for her to die. He just told us to call him when needed so that he could connect us to a good hospice program.

On December 1, a lady at the clinical trial called us to ask whether we contacted local oncologist, answered "*no*" to my pathetic question of whether there was anything the Houston cancer center could do to help my wife, and asked whether we contacted hospice services. During all our meetings at the Houston cancer center, including the last one, there was no mention of imminent death, how to prepare for it, and pain or prescription for pain. We were just dropped cold, very cold, once by the Houston cancer center, and again by the Mobile cancer center.

Rushing Toward the End

On the same day, November 23, I sent an email to the always reliable Celeste O'Neill of the Pancreatic Cancer Action Network, again asking whether there was any place where we could go for help. She sent me a list of clinical trials that catered to my wife's condition, Stage IV with futile prior treatments. I could not contact any of them because my wife was too weak to even stand up, let alone travel. My wife's condition was rapidly worsening, and both of us were confused. I knew any more treatment now would be total waste. What Celeste of PANCAN did for us was to give us hope and compassion, which we never received from our oncologists.

Since Nov. 23, my wife could not eat and barely drank Pepsi. I bought Glucerna. She drank two bottles a day because I almost forced her. After a couple of days, she could no longer take even Glucerna. After several days of struggle with Glucerna, Pepsi, and milk, we endured a long week-end. As soon as Monday came on November 28, I called our new and caring family doctor, Kimberly Bryan. I dragged my wife to Dr. Bryan's office.

We discussed options. In-patient hospice program was out because my wife was determined to spend last days at home. I wanted an IV fluid, and Dr. Bryan told us that she would have to place her in hospital to do it. That plan was also out because there was a strong possibility that the hospital might not discharge her after the IV injection because of her poor condition. Dr. Bryan called me outside the office and told me she had days, not weeks, to live.

During our meeting, Dr. Bryan gave us prescription for morphine, and called Springhill Hospice without even asking us. In fact, I mildly opposed the call because my wife was a very private person and did not want anyone to come home. Dr. Bryan never smiled or sweet-talked during our meetings, but she was full of compassion and caring.

On December 1 (Thursday), my wife's condition became visibly worse. Out of desperation, I called Ms. Lacey at Spring Hill Hospice, who told us that they could give her injection at home but needed doctor's direction. I again drove to Dr. Bryan's office to get the direction. She was off on Friday. Her nurse, Amy, contacted Dr. Bryan, who called me right away to hear my appeal. Dr. Bryan asked me whether I signed a contract with Springhill Hospice and whether my wife had a "port" for injection. I said I would sign it any time any place, and, yes, she had a port. Later in the afternoon, the efficient Ms. Lacey came out, had me sign the contract, gave her IV fluids, and gave us a prescription for steroids for temporary relief. That made my wife feel better even if it was only a couple of days.

The Worst Day in My Life

The worst day in my life was not the day my wife passed away. It was early morning hours of December 4 (Sunday). My wife and I were alone at home.

Around 1 am Sunday morning, I woke up from unfamiliar sound from my wife who was sleeping on the sofa, while I was sleeping on the floor in the same family room. My wife was having a really high fever. We treated the fever with aspirin and cold towels. Soon, the fever was replaced by cold and pain around 2 am. The pain was getting worse and worse. My wife rarely, if ever, complained about pain. She wanted morphine, and I gave her one pill.

Obviously, one tablet of morphine was not enough. Now the pain became brutal, and I can tell that the pain was totally unbearable to her. She then started begging for more morphine. She would never have begged for more unless it was absolutely unbearable. Unbelievably, I did not give it to her, because I was so scared of overdosing her to death. The struggle between my wife and me lasted about an hour, and finally at about 3:30 am, I gave her one more pill of morphine. About 30 min after that, my wife went into sleep. She never felt another serious pain after that until she finally passed away four days later. She later said that she died at that moment and came back to life.

Honestly if I had a gun, I might have shot her or I should have killed her because the pain she was experiencing was not for the living. I still cannot shake off the pain that my wife experienced during the early morning hours of December 4. I was really scared of overdosing her to death only four days before she passed away.

Wishful Thinking

I still believe that our primary clinical trial physician at Houston cancer center should have seen us during the last appointment and given us a prescription for pain control with step-by-step guide of what we should consider doing. Just maybe, the physician could have made an earlier decision on the failed clinical trial.

Perhaps, our Mobile oncologist whom we continuously updated on the treatment in Houston should have paid more attention to the progress of our treatment, and guided us on how we should prepare for the impending death. He never mentioned pain control, let alone giving us a prescription, when in fact pain control was the only request my wife had made to him every time we had an appointment with him.

After I moved to the Leisure World, an enclosed retirement community in Silver Spring, Maryland, I had an opportunity to testify at the Maryland House of Representatives for support of the proposed HB370 Richard E. Israel and Roger "Pip" Moyer End-of-Life Option Act. This allowed me to chat with several others who also lost their spouses. They all told me the same story. They did not like their oncologists and relied more on their family doctors during the last days of their spouses. These conversations helped me derive the underlying hypothesis of this article in that many, if not most, oncologists do not feel compassion for their patients. Doctors with compassion for their patients simply do not treat their hospice patients the way they treated my wife.

There were many heart-breaking stories that were told during the Maryland House testimony without making their way to mainstream media. One that made tells the story of an 84-year old man with advanced Parkinson's disease who ended his life by starving to death slowly over 10 days [9]. The man was the husband of Diane Rehm who hosted the nationally syndicated NPR "Diane Rehm Show" on WAMU-88.5FM in Washington, D.C. from 1979 to 2016.

Concluding Thoughts

You may ask why we did not ask for pain pills and how to use them. Your question assumes that obtaining pain pills is the patients' responsibility, not oncologists, and that hospice patients and their caregivers are in rational state when they hear the death sentence.

You may ask why we did not ask all those questions on genetic analysis of the cancer cell, and state of progress during the clinical trial. Your question assumes that oncologists make us feel comfortable enough to ask those questions. Once I asked our trial physician whether my wife would survive. Response was: "everyone survives, my friend," and she left the room.

You may ask why I did not call the hospice ladies sooner. Actually, I still regret that I did not call them sooner. They were just wonderful. Problem was that when the brutal pain began, I could not think of anything. By the time my wife was easing into her sleep, it was about 90 minutes after the real pain started. In reality, it would have taken that long for the helping lady to reach our home even if I called them sooner.

You may ask why we did not opt out of the clinical trial when the hospital made perfectly clear of our rights to opt out of it anytime we wanted. Clearly, the paper we signed for the right to opt out has to be based on the assumption that patients are capable of making the sophisticated medical decision on their own or with help from others, excluding clinical trial personnel. First of all, my wife and I were totally ignorant of making that medical decision on our own. Further, the Mobile oncologist we kept just in case and to whom we always reported the day after we had appointments in Houston never gave us any advice.

You may allege that we voluntarily signed all the papers that supposedly protected all our rights as patients. Here you are making the illusory assumption that these documents are prepared by lawyers to protect patients, not doctors and hospitals. In an ideal environment, we do not need any documents. My wife and I always told every doctor we met, with total sincerity, that "*we trust you and we will do everything you ask us to do.*" We have done exactly that.

You may say that prescribing pain pills is the job of the hospice program that comes after the last appointment with the oncologist. I do not know whether this is true. Regardless, please consider that repeating important words is never a waste of time in hospice care. Hospice patients and their close caregivers are not in normal state of mind. They may not even hear what you are saying.

Finally, compassion does not mean being nice or sweet-talking to patients. Compassion means to give patients medicine before they need it, explain them in detail what the future may hold, and guide them step by step so that they can leave this world with no pain, peace of mind, and most importantly dignity.

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