

More chemo or home hospice? Narrative results from an N-of-1 trial

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Abstract: Words matter. They have tremendous power to heal or hurt. And although the patients we care for in oncology and palliative medicine often die from, or despite, their neoplastic illness; caregivers and loved ones often hold onto the words that clinicians share with them during their times of struggle and grief. In this narrative, the author (as first person) reflects on some systemic challenges he faced in dealing with illness and loss when his father battled two distinct neoplastic processes. He explores the commonalities and differences that he experienced as a palliative care physician, and how that has guided his medical practice moving forward. Moreover, he shares his observations regarding breaking bad news, code status discussions, and transitioning to hospice—as a cautionary tale to all clinical providers that what we say to patients and families matters. He encourages clinicians to avoid losing sight of the power and responsibility we all have to provide optimal, patient-centered care.

Keywords: Caregiver; management and treatment; palliative care; quality of care; treatment related issues; advocacy; communication; doctor-patient communication

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No ordinary clinic day

One rainy afternoon during my senior year of medicine residency, I rushed to wrap up clinic and head on family vacation. My wife was pregnant with our second child and we looked forward to a weekend away from residency. I was paged, expecting a request for stool softeners, or “Can the patient eat?” Surprisingly, it was my home phone—not my wife, but my parents 1,000 miles away. I grinned wryly, amazed they could figure this technology out.

It was my father—a stoic, hard-working “drop-anything-for-anyone” kind of man. He asked if I could log into his online “Patient Portal” to help him interpret recent bloodwork. I did, seeing “... hemoglobin 12.1 g/dL”. Not what I expected from a meat-eating 58-year-old man. “Colon cancer”, I thought, since doctors always suspect the worst. His red cell indices were normal, so I took a deep breath. Chemistries looked fine—electrolytes and renal function were all normal—as I skipped over the Total Protein. As a senior medical resident, I rarely found the Total Protein informative. Except this time, it was 9.8 g/dL

(H). “Myeloma”, I thought, quickly reassured by the normal calcium, creatinine, and platelet count. I scrolled onward to the next page—Immunoglobulins: IgA 25 (L), IgG 30 (L), IgM 4,232 (H).

“You have cancer” were the first unfiltered words I uttered, forgetting all my training on breaking bad news as an aspiring palliative care physician. “That’s what I thought”, Dad replied, “that’s why the doctor’s office called and the secretary told me I need to see a hematologist/oncologist. I have an appointment in 4 weeks.”

Training at a tertiary care center, I encountered rare diagnoses, with my default often considering zebras not horses. An IgM that high had to mean Waldenström’s macroglobulinemia. Though rare, affecting only four in one million patients, I was prone to consider the worse, instantly fearing hyperviscosity syndrome—a complication of “thick blood” from excess abnormal protein.

“Dad, are you having headaches?” I asked.

“Yes, real pounders.”

“And nosebleeds?”

“Everyday, Mom thinks it’s the dry heat in the house”

“And your vision?”

“A little bit blurry, but I think it from the headaches and that I need new glasses.”

For a moment, I thought like a resident, not a son. Dad needs a central venous catheter; we need to call transfusion medicine for plasmapheresis; he needs a bone marrow biopsy and a 24-hour urine, and a CT. Then I reverted to helpless son a thousand miles away. “Dad, has anyone told you?”

“No, son, you just did. I thought something was wrong though.” he said.

Hours of frenzied calls, unanswered messages, emails and pages ensued. I knew a month with hyperviscosity was too long to wait—risking stroke, vision problems, or worse. I encouraged him to go to our local community hospital, but would they even suspect such a grave problem in someone who looked otherwise healthy? I am forever grateful to my medical school mentor, a hematologist, for answering my frantic plea and scheduling Dad to be evaluated next week to begin plasmapheresis to bring down his elevated protein levels.

Things were relatively smooth from that point onward. Cladribine was the first chemotherapy, and as clinicians, we often talked about risk of infection with that drug. However, I never made much of that until a year after, once Dad was in a “biochemical remission” with normalized protein levels. I received a call that Dad was hospitalized with pneumonia and fluid in his chest. Over the phone, I heard him gasping and grunting with dyspnea and chest wall pain. He recovered well, only to develop shingles later that summer. The man who never took anesthetic for dental work told me, “This is the worst pain I have ever felt” (despite his history of kidney stones). His shingles and pain resolved, but I was terrified 6 weeks later when his platelet count was dangerously low at 10,000. I feared for worsening cancer in his bone marrow, but my mentor reassured me this was a classic complication of low platelets after shingles, and after a few weeks of steroids everything would be better. Near my father’s 59th birthday was the first time I heard him say, “I feel like I am falling apart... what can happen next.”

After I finished palliative medicine fellowship, Dad talked about early retirement so he could travel and visit more. Though the Waldenström’s acted up again, we caught it early, and Dad had a dramatic response—this to a different combination of chemotherapy. This also allowed him to have periodic checkups at my hospital where I was now an attending palliative care physician.

Making lemonade with lemons

The following spring, Dad developed blood in his urine, and since he worked in Urology, he sought prompt evaluation. He updated me by phone while I sat with my 1-day-old newborn in the NICU. Without much warning Dad blurted “You know that spot on the kidney they were following... It looks like cancer, my kidney needs to come out.” I never envisioned that Easter my home would be a rehab center: having my newborn, my wife status post cesarean, and Dad recovering status-post open partial nephrectomy.

It was around this time that I seriously began to reflect on what was my vocation. Yes, I had a job in academic palliative medicine where I was called to serve others, to help some find comfort and meaning in illness, and to participate in nuanced discussions that affirmed life and respected goals of care. It was comforting for me to believe that something greater than I was driving who I was, where I was at, and what my purpose in this life was.

With this in mind, the ensuing months were among the best of my life. We spend time together—my family, my brother’s family, my parents—all together, no fighting or drama. However, something seemed somber and sacred about that summer vacation. Stoic Dad would never complain about anything, but he just didn’t seem to be tolerating the mid-summer mugginess. When I asked how he was, he said (as always) that he was having the time of his life with all of his grandchildren. A week later, as I was attending on the hospital medicine/oncology service, Dad called me from his ICU bed with a chest tube in place. “Now I know why I’ve been feeling so out of breath.” he said.

Before my eyes, 7 days of the vacation flashed. Frequently pacing to “catch some fresh air”, sitting on the bench often or staying with the stroller to “take a break”, fanning his face with a park brochure. “I have a hemothorax,” he said, “chest tube put out 2 liters out already.”

“How are you?” I asked.

“Tube hurts like a bitch, but at least I can breathe now.” He claimed a fall at work was the etiology. Unfortunately, sitting on the oncology ward at my hospital it struck me—this is the beginning of the end. And in a metaphorical sense, that seared through me like a 5-French chest tube.

The cytology seemed to take forever, but 9 days later, the pathologist paged me. “... Renal cell, histologically the same as the previous tumor. I am so very sorry.” she said, with empathy not often ascribed to pathologists. My genitourinary oncology colleague took excellent care of Dad and Mom. We were hopeful as stage IV renal cancer

has several treatment options. However, he cautiously tempered our optimism, warning us that the data on non-clear cell subtypes was not robust. Though non-clear cell subtypes may remain indolent longer, they tended recur as “bad actors”.

Sunitinib was the formulary first-line option; taken faithfully as prescribed, and followed by stomatitis, anorexia, asthenia. “So much for just being a pill”, Dad remarked, lulled like so many other patients into thinking that an oral agent is better tolerated than parenteral antineoplastics. Mom said, “If he is going to suffer like this... he can stop this if he wants.” But Dad pulled it together and made it through a college football road trip so he could buy his grandsons cotton candy. A 50% dose reduction eased side effects, but the tumor had a mixed response. He switched to everolimus and tolerated it fine, but with uncertainty and the holidays approaching, we opted to spend Thanksgiving together.

Thanksgiving eve we celebrated my parent’s 37th wedding anniversary, reveling in the food and companionship. But as readers likely suspect, the story’s end is nearing and I knew that preparing to accept that end was important. I hoped that all my preparation, rationalization, professional and counseling experience, and medical knowledge made those final months go well. Unfortunately, all of that did not.

The long road winds to its end

After a rough Christmas, Dad was admitted with pneumonia, leading me to fly home in the New Year’s ice storm to visit him. As I entered his hospital room, he greeted me with, “What the hell are you doing here? You have a family at home that needs you.” I gave the only answer I could think of.

“That family is going to have their father for a long time, but I won’t.”

Mom worried Dad was in denial and shutting her out from talking about issues. Dad experienced anger suspecting that I knew he had metastases and no one was telling him. Palliatively, I asked why he thought that.

“Because I hurt all over”, he replied, “... there has to be something stronger than Percocet.” Fortunately, the hospitalists agreed and started long-acting opioids. His CT scan confirmed the expected—progressive cancer.

Dad was determined to travel to see those grandkids, but we watched him struggle to move bed to bathroom. The nurse reassured us his oxygen saturation was fine despite

pulse =140 and respirations =24. When he finally made it to the bathroom, it didn’t take rummaging to see what he jotted down on a piece of paper at his bedside: “Funeral Home. Wake-yes. Mass-yes. Cremation-no. Burial-Cemetery. Ruby ring-Keith. Birthstone ring-etc.” I assured Mom that Dad thought about this more than anyone gave him credit for. For now, he looked forward to his checkup at our home in 2 weeks, pending stabilization. Unfortunately, he was readmitted directly from his 1-week clinic follow-up.

My wife and I knew what we had to do. Our vocation as children called us to be present. We wanted the kids to see Dad when he could enjoy them, so 24 h later we were on an airplane and walking into his hospital room. Opening his eyes, Dad said, “I was just dreaming about seeing you, and you walked right through the door.”

That hospitalization represented the low in our medical experience. The hospitalist approached me immediately upon arrival and called me to the hall. “You know your father is still ‘Full Code’, right?” I asked him if anyone had talked to him otherwise. Since the answer was “No, doesn’t he know”, we approached it together with Dad deferring to his “power of attorney”—me.

We talked about the facts. Dad was approaching the end of his life; if he went on a ventilator he likely would not get off of it; it would be hard on Mom and us to have to decide then, and I thought it was consistent with his goals of care to elect for “Do Not Resuscitate” status. He agreed. The first thing he did when his longtime friend/co-worker walked in later was to show her his new “DNR” wristband. She wept.

We, as family, knew Dad was dwindling. Though not hypoxic, he felt better with oxygen and morphine. We expected lower response rates and more toxicity with third-line treatments given poor performance status. Simply I asked Dad, “do you want to spend time here in the hospital, or do you want me to take you home and you can spend time with Mom and the kids?” He always picked family first, answering as expected.

We waited to discuss hospice with his local oncologist—my colleague back at home was already fully supportive. The local oncologist arrived several hours late to the family meeting. He was a talk, dark, slender man who had worked elsewhere for several years before joining the VA to help with the large oncology caseload.

He stood at Dad’s bedside on the right, towering over him the entire time. I sat across from the doctor next to

Mom, seated on Dad's left. "You have progressed through everolimus, Mr. Swetz. Let's get you over this pneumonia, have you come back to clinic in a week or two, and I recommend starting pazopanib at that time." My mother and I sat quietly; Dad glanced over at us with a "please-say-something" look.

"We are considering other options", I replied. The oncologist retorted, "We could do temsirolimus, but you just had everolimus so I would not recommend that now. We could do interferon/bevacizumab. We can do interleukin-2; I used it quite a bit back in the days before these other treatments. It can be quite tolerable." After we said none of those, he inquired if I knew of a clinical trial elsewhere we desired. "We have opted for home hospice and supportive care." I said on my family's behalf.

"I would never recommend hospice for your father, he has only progressed through two lines of chemotherapy!"

We reflected. The silence was broken when the physician's cell phone rang. He answered it at the bedside speaking to the person in non-English language. My family always wondered if he was talking about getting groceries on the way home, or about being annoyed by a patient/family and their know-it-all doctor son from out-of-town (the one all clinicians dread). Eventually he hung up, looked at Dad and asked him why he did not want to do more chemotherapy, as there were many more options. I explained, in my opinion, third-line treatment was more likely to produce toxicity rather than control of tumor burden or survival benefit. Given Dad's performance status of 3 we didn't believe additional therapy was appropriate. The physician looked at me, retorting, "You do not understand the biology of renal cell cancer... there can be periods of rapid growth followed by quiescence. We have only tried two treatments so far..."

Mom exited—leaving the physician, Dad and me. "So this is what you want? You want to give up?" he asked Dad. Dad nodded affirmatively, somewhat timidly, but with peace and purpose. And with that, the team left.

After I enrolled him in hospice with his primary care physician—as no one believed it could be done at that VA on the Friday before a federal holiday so I had called to make the referral—we all went home. The rest of the visit was marked with indelible images, particularly seeing how amazing the children were with the concept of hospice. Without prompting, they realized Dad was sick, and that the help Dad was getting was just how their Daddy helped

other people and why he sometimes gets home late.

The pictures are priceless. Dad painted the girls' nails in his home hospital bed with oxygen on. My sons did word-searches on Dad's lap during nebs. Everyone signed Dad's forehead and said the Our Father when Father Mike anointed him. We left trying not to focus on this being the last time that the kids would see Dad. My wife sat with Dad having conversations at night, but that was too hard for me right then, so I would go to bed. I had hoped I would have time to have those conversations later.

With hospice, we found peace with symptom management, but also with clear communication with me regarding performance status. When the Palliative Performance Scale was 30, I knew it was time to come home. When that time came, our extended family had a hard time understanding why I was being so negative, feeling that Dad's end was near. I have counseled patients and families that a PPS of 30 often correlates with survival of "hours to days," and I knew it would be naïve to ignore that.

Those final days went by quickly—with confusion, delirium, pain—all treated fairly well, speckled with moments of lucidity. Despite all the clinical palliative care experience and preparation I had, and all the intellectual rationalization, nothing prepared me for the inexorable grief of that moment. "My daddy is gone..." I said repeatedly, tears still welling up every time I read this.

Everything I learned about being a good husband and daddy, everything I learned about truly caring for patients as a medical professional—I learned from my dad. People say you become your parents over time, and we often say we never will. But I assure you, I hope I am living out my vocation the way my father lived out his. It is not about socioeconomic status, education, employment, where you come from or where you live—to me it appears to be more about how you live your life and serve your fellow mankind. I think of this daily, when caring for patients, or counselling families, or when struggling to balance work and family.

I share Dad's story not with malice or seeking pity, but because it still teaches me so much, and I believe it can teach us all. The illustrations of suboptimal health care-related communication in Dad's story happen every day at hospitals and clinics. Unless we, as clinicians and educators make it a priority to be effective, empathetic communicators, this will not change. And that may have lasting effects on our patients and/or their families. Dad, through to his final days, commented on how difficult it was for him that his

primary care physician never personally shared his diagnosis of Waldenström's with him, and that it happened from me over the phone. Trust eroded and could never be restored, and that could have been avoided. I hope that my journey on this vocation will continue to allow me to serve my family, my patients, my fellow humankind. Moreover, I hope that the way Dad lived and died encourages us to all do our best in all aspects of our clinical vocation.

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Footnote

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