A Patient's "Tail"

Lessons From The Bedside

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The Case History

C.K. is a 55-year-old, 5’2”, 80-pound female whose steady-state weight over the past three years has been around 90 pounds (normal: 110 pounds). C.K. has a 14-year history of pseudomyxoma peritoneii for which she has undergone six extensive surgeries to “debulk” the tumor, including an oophorectemy, hysterectomy, splenectomy, removal of the omentum and gall bladder, and excision of all but 5 feet of her small bowel and two thirds of her large bowel. She had three courses of “hot” intraperitoneal chemotherapy intraoperatively and post-surgically. The tumor tissue is slow growing and because it is mucinous in nature, difficult to excise. It arises in the peritoneum and does not metastasize, but can be seeded into the skin and abdominal wall through surgery. The lay term for the cancer is “jelly belly.” The past 7 years have been particularly difficult for the patient who has suffered from short bowel syndrome (12 to 20 crampy bowel movements daily, which she treats with tincture of opium); frequent episodes of lower gastrointestinal obstruction requiring several emergency hospitalizations for bowel rest; malnutrition; severe anemia of chronic disease requiring epoetin therapy; and inoperable fistulas.

Over the Christmas and New Year holidays, the patient began to develop more severe upper gastrointestinal pain and signs she attributed to obstruction. Her cramping and diarrhea worsened and she began to cut back on her nutrition to avoid the inevitable “pay backs.” The oncologist thought these new symptoms could be due to multiple tumors growing in the abdominal wall that were beginning to impinge on the duodenum. After consultation with two surgeons, a decision was made to perform a “minimally invasive surgery.” The goal was to debulk these tumors without invading the bowel or peritoneum. If the surgery went as planned, the patient would have one day in the ICU and less than 1 week in the hospital. Life expectancy could be measured in “years” rather than “months.” Two weeks before surgery, the patient developed massive bleeding from a gastric ulcer (probably from chronic use of ibuprofen), which was treated by the local family physician with 3 units of blood and famotidine. Omeprazole exacerbated her diarrhea and was discontinued by the patient. Despite this set back, surgery was performed as originally scheduled on Tuesday, February 24, 2004.

The patient is my sister, Carole, and this is the story of our most recent healthcare experience.

I tell this story because I have been immersed in it for the past three months or so and because it has reawakened in me the urgent need for us all – as we are called upon by the Institute of Medicine to address *systems* of care[1,2,] - to become equally engaged in providing more individualized and humanistic care as well.

The Surgery and Hospitalization

I could not be with my sister on Monday, the night before her surgery, but I arrived at the hospital early Tuesday morning to await her discharge from the recovery room and her admission into the Intensive Care Unit (ICU). While waiting there, I learned from her husband, Gary, that Carole had had stopped eating 5 days ago when her 7-month old puppy became ill. On her way into the hospital the afternoon before her surgery, she had had to make the difficult decision to put Finn, who was diagnosed with a rare fulminant autoimmune hemolytic anemia, to sleep. Her decision to bring a young dog into her life last fall had signaled to us all that she intended to continue to engage in her battle with this cancer. Here is how Carole described her life with Finn in an e-mail she sent to friends 3 weeks after surgery.

Dear Friends and Family,

"Appetite's good, spirit's fine except for still a lot of grief about the death of my constant companion Finn McCool. He and I had spent just about every minute together since he came to us in September, so I feel as if I've lost a limb or something. My sensory world was filled with his soft curly hair, the smell of his paws and breath and skin, his cantering gait, his triumphant little grins, the weight of him against me. We spent his last hours at home in bed together, he was too weak to get up."

Carole spent the afternoon and night before surgery grieving over Finn. She cried and cried until her new son-in-law who is in his second year of osteopathic school said to her, "Carole, you have a job to do tomorrow. You can't take all this sorrow with you into surgery. Think about the lessons learned from Finn and take them with you." This worked. Carole stopped crying and instead reflected on what she had learned. When the anesthesiologist asked how she was doing on her way to operating room, she smiled and said, "Well, my tail's wagging. I hope yours is too!" "Oh," he exclaimed, "I like that line. Mind if I use it with other patients?"

Parenthetically, no one who cared for Carole during her hospitalization knew of Finn's demise; most were unfamiliar with her full history, the nature of her daily life, and the complications that had developed over the past 7 years. Most understood that she had undergone excision of tumors and that this was yet another in a series of multiple surgeries for a condition they had never heard about. She was, in our shorthand lingo, a "post surgical wound care case."

The Happy Tale or What Went Well

Many good things can be said about Carole’s recent hospital experience:

- Her health insurance permitted self-referral to a surgeon who was not a member of her Health Maintenance Organization (HMO). She easily shifted into a Preferred Provider Organization (PPO) plan.
- The “systems” of care within the hospital were generally excellent.
    - Electrolytes and vital signs were monitored and managed by nurses according to protocol. No physician’s orders were needed.
    - All hospital personnel showed consistent concern with pain management and control.
    - There were liberal family visiting policies in both the ICU and surgical wards.
    - The nurses were well trained and caring.
    - The surgeon and surgical residents were exceptional. They openly discussed issues and post-surgical problems at the bedside and maintained an optimistic attitude. This was despite their observation, in retrospect, that my sister’s condition had been “grave” and that they had been quite worried.
    - Clinical pharmacy services in the ICU were new to the hospital. The pharmacist, a relatively fresh graduate was competent, highly regarded by both nurses and physicians, and effective in modifying medication use.
    - All hospital personnel were friendly, responsive and “service” oriented.

    - A broad range of specialists – nutritionists, wound care nurses, and even a music therapist to distract Carole during her dressing changes – were available for care.

- Carole has had the same visiting wound care nurse throughout her home stay. This nurse has been thoughtful and creative, trying many ways to maintain the vacuum dressing on a wound that persists in breaking its seal.
- Large quantities of narcotics were dispensed without question by the community pharmacy. Computerized systems allowed easy access to the prescription in both Sacramento and San Francisco.

Tales of Woe or What Could Have Gone Better

Nevertheless, as I joined my sister in her most recent episode of ill health, I observed many things that could have gone better and found myself intervening too frequently on her behalf.

Assessing the Patient's Goals. Carole sought the advice of two oncology surgeons. The first surgeon immediately assessed her situation as incurable and terminal. Although he kept this to himself, my sister sensed his ominous view because he maintained a distant and dispassionate demeanor throughout her examination. He recommended full excision of the tumors, which my mother described as grapefruits and cantaloupes and my sister as cauliflower heads. He would operate in collaboration with a plastic surgeon, who would have to help him close the wounds with harvested skin. My sister – distressed by the impersonal nature of the interaction – turned on her charm. In fluent Spanish, she assured this surgeon who had a Hispanic background, that she was not seeking a cure, only symptomatic relief. His relief was visible; he relaxed and warmed up to Carole. The surgeon's own anxieties could have been allayed, and his bedside manner improved, if he had asked my sister one or two simple questions early on. (I will have more to say about this later). Given Carole's current state of health and past history we did not think she would have a good chance of surviving such an aggressive approach, so we sought a second opinion.

The second surgeon had expertise in this rare cancer and approached Carole more sympathetically. He, too, recommended excision of the tumors, but acknowledged our fears that this could be a life-threatening procedure for her. My sister asked why he couldn't simply debulk the tumors superficially in an effort to relieve pressure on the gastrointestinal tract. He liked this idea and agreed to try this approach. He also sought the advice of a world-renowned surgeon who had performed Carole's life-saving operation in 1996.

We encountered several problems during Carole's post-operative period.

Misadventures in pain management. There were several misadventures in Carole's pain management. She came out of surgery with four incisions, one of which extended the length of her abdomen from the xyphoid process to her pubic bone. Her pain was to be managed with patient-controlled analgesia (PCA) and morphine boluses as needed. She was in severe pain when she emerged from anesthesia and this was made tolerable with three 5 mg boluses of morphine sulfate (MS). The PCA pump was set to deliver a basal rate of 1 mg/hr and Carole was allowed to self-administer 2 mg bolus doses as needed every 10 minutes (maximum 13 mg/hour). If her brows furrowed, I would ask Carole if she was in pain and remind her that she had the option to "press the button," which was often lost in the linen or dangling at the bedside out of easy reach.

That afternoon and evening Carole's respirations were shallow. Her respiratory rate frequently dropped to 5-7 breaths/minute, and the monitor would occasionally beep and blink "apnea, apnea." In these moments, Carole would and could breathe deeply if instructed to do so. I spent the night reminding her to breathe and watching over her general management. The next day Carole had several "hypotensive" episodes. Her BP had dropped from 120/70 mmHg to 90/60 mmHg (her normal). Nevertheless, she was managed with hetastarch, fluids, and several saline boluses. Even though Carole was tolerating her pain and took her first short walk, the hypotension was attributed to an overdose of morphine. Incredibly, this tiny person had received 100 mg over two shifts and she was a little too cheerful, creating great adventures in search of cave drawings. (Remember that Carole had been using tincture of opium to manage her short bowel syndrome for several years). When the nurse asked how she was feeling, Carole grinned and told him that her tail was wagging like this (swinging her arm side to side), not like this (swinging her arm up and down). This clinched the nurse's assessment that she was on far too much morphine. The dose was cut by two thirds and acetaminophen 600 mg as needed was ordered, per rectum. I was aghast, and suggested oral administration. The following morning, morphine was discontinued and replaced with a hydrocodone and acetaminophen liquid preparation. I asked that the prn acetaminophen be discontinued to prevent an inadvertent overdose. Carole was incapacitated that day with a severe headache and nausea, symptoms of morphine withdrawal. She could neither sit up or take a walk. Eventually, the morphine PCA was resumed and her pain management once again came under control.

Fluids and nutrition. Management of Carole's fluids and nutrition could have been more optimal. Lactated ringer's solution was ordered for fluid replacement; there was no glucose. On the second ICU day (Wednesday), I asked the pharmacist to help me think about my sister's nutrition. She had not eaten for 6 days, her albumin was 2.5 g/L (Normal: 4-6 g/L), and she had wounds to heal. The pharmacist consulted with the nutritionist and TPN was begun the next evening. Over the next 2 days, it became apparent that Carole had been over-treated for her hypotensive episodes. Her weight increased a whopping 30 pounds to 110 (one-third of her usual steady-state weight). As you might imagine, Carole felt like an overblown balloon; she was extremely uncomfortable until she eventually diuresed the excess fluid.

Antibiotic coverage. Antibiotic selection could have been improved. Carole developed a fever, which was attributed to cellulitis. Nafcillin was ordered. When the wound continued to swell, one staple was removed, releasing copious amounts of discharge. The puzzled resident learned from my sister on that day that she had had an active fistula connecting bowel to bladder to vagina and skin, which had developed over one year ago. (My sister had affectionately named this unpredictable fistula that opened just above her pubis and made embarrassing noises, "Mount Vesuvius.") The surgeon's incomplete history or his failure to carefully review the history he had taken 4 weeks prior left him "surprised" to find that one of the tumors was contiguous with a large open cavity about the size of my fist. The next day, 12 staples were removed to permit full wound drainage and healing. That afternoon, I consulted with the pharmacist because Carole continued to run a fever. Given the nature of the discharge I described, she suggested an antibiotic that would cover enteric organisms. The wound had not been cultured and no note had been made in the chart regarding this discharge. Zosyn (piperacillin and tazobactam) was *added* to the nafcillin.

Anemia. On day three, the hemoglobin had fallen from 12 to 9.5 g/dL. My sister asked for a transfusion, because she knew from long experience that her attitude and gut function deteriorate when levels fall below 10. According to hospital protocol, transfusions are not given until the hemoglobin falls to a value of 8.0 or less. It did by the next day and 2 units of blood were ordered. In the meanwhile, Carole suffered from abdominal cramping and unusual crankiness.

Discontinuity of Care. There was no continuity of care in the ICU, which I renamed the IMU or intensive monitoring unit. Nurses worked 12-hour shifts, ostensibly to improve continuity of care, but during our four-day stay there, we saw only one nurse twice. Wound care was complex and involved vacuum dressings. The surgeons and three different nurses dressed my sister's wounds. An improper dressing resulted in abscess formation.

An Unrestful Space. Finally, the general ICU environment was unnecessarily noisy and unintentionally disrespectful. Loud conversations about who would cover an impending cardiac arrest or a basketball team's performance felt improper in a place where patients were distressingly ill and some dying.

A Future Tale – Improving Education and Care Through Bedside Lessons

As an observer and intimate participant in my sister's health care I have learned many lessons that apply to my various roles as a clinician, educator, the closest family caregiver, and friend of the sick. Many of these lessons, I have been taught and have taught myself, but my personal experience has brought them into full bloom. I know that those of you in the audience who have had similar experiences will know what I mean. First, I share the lessons I have learned for my clinician self.

Lessons for Clinicians

Flexible protocols. In our zeal to create good systems through protocols, it is important to recall what we already know: “normal” values can fall outside the norm for some individuals. We must be prepared to listen to the patient’s wisdom and adjust our “rules” to meet their needs. One experienced oncology nurse said it well. “Everyone’s functional hemoglobin is different and I try to help the patient understand what level works best for her.” Certainly, an understanding of Carole’s normal blood pressure might have minimized the extraordinary fluid overload she experienced, and she might have been spared a day of abdominal cramps had she been given a blood transfusion when she asked for it.

Follow the patient, not the paper. As we move into a world of computerized medical records and electronic communication, it will be increasingly tempting to monitor patients from afar. We must remind ourselves that key information sometimes does not get recorded and that the patient and family will provide insight that we can never gain from two-dimensional numbers and reports. Pharmacists, in particular, must get to the bedside, see the patient, meet with the families, look at the wounds, check the drug delivery devices, and independently assess drug selections, drug doses and responses to therapy based on their patient interactions and observations. Had the pharmacist done so, she might have been able to intervene earlier in antibiotic selection; help my sister avoid unnecessary morphine withdrawal; and initiate appropriate nutrition.

In our hospital, the pharmacist provided the greatest continuity of care, but she would have been invisible to us had I not asked to see her, for she never came into the room.

Take time to learn the patient's story and perspective beyond the medical record. As I have already noted, none of Carole's caregivers knew important facts about her recent history, her life, or her goals, and this affected treatment. Even if these facts had been available, the nature of the medical record and our own notions of what constitutes a proper " shift report" would have obstructed routine or easy transmission of this information from one caregiver to the next. My brother-in-law, Gary Snyder, thought a "patient abstract" built from a few key questions might be useful. He reflected on questions his Zen Buddhist teacher asked him when they first met in Japan. The teacher asks the new student-to-be a few questions like: What brings you here? What are your deepest questions? What is it that you're unsure of about yourself? Or most fundamentally, "Who comes before me?" At our conversation's end, he chuckled, "I realize that these are probably not quite what a doctor would usually ask. Interesting though…"

Here's another way of looking at it from my sister's perspective. Carole was editing one of Gary's essays entitled "Language Goes Two Ways" that appears in his book, *A Place in Space*. In this exceptional essay about writing, Gary puts forward a view of the twelfth century Zen Buddhist philosopher, Dogen, which Carole found a bit obtuse. To clarify Dogen's thinking for the readers, she suggested to Gary a retelling based on a more contemporary experience. (It is important to note here that my sister is an avid observer of birds). Her example provides the essence of what I mean when I encourage us all to get to know the patient beyond what our medical records tell us.

"To see a wren in a bush, call it "wren," and go on walking is to have (self-importantly) seen nothing. To see a bird and stop, watch, feel, forget yourself for a moment, be in the bush shadows, maybe then feel "wren" – that is to have joined in a larger moment with the world."[3]

Had Carole's clinicians taken the time to get to know my sister – to feel "Carole" – they would have approached their consultations differently, would never have considered delivering a drug per rectum, and would have understood why my sister – as tiny as she was – could tolerate such large doses of morphine.

Lessons for Educators

How can we, as educators provide our students with experiences that help them begin to see how care looks and feels from the patient's and family's perspective?

It seems to me that we ought to *provide at least one experience that allows the student to travel the health care road alongside the patient.* This might involve sitting at a patient's bedside for 24 to 48 hours, as would a close member of the family, or working with a patient from home to clinic to pharmacy to home again. These kinds of experiences would allow the student to observe the ebb and flow of care; comprehend the jagged nature of a patient's health status; get a sense of the worry, fear, sadness, and impatience the patient and their families experience as they navigate the health care system when they are most vulnerable; identify system solutions that might enhance care; and develop a personal approach to care that maximizes continuity of care and a human touch. As clinician educators, we can model direct patient practice for our students and provide them with the confidence to work at the bedside as well as from medical records.

We can make students more aware of how much they can learn from and through the patient. As we guide our students through their practice experiences, we can bring into bold relief the lessons they can glean from conversations with patients and their families and through their own clinical observations. In doing so, we will imbue them with the essence of individualized pharmacotherapy.

We can encourage students to modify our delivery systems and their approach to care with the patient's perspective in mind. For every less-than-ideal situation that our students encounter, we can challenge them to think actively about how things could be done differently if they were in charge or how they might modify their own practices in ways that enhance patient experiences.

Finally, let's ask our students to think about and use the lessons they learn at the bedside to *teach the families and friends of patients how to effectively advocate for best care.*

Lessons for Loved Ones – Friends and Family

Here are some of the lessons I have learned as Carole's sister.

Become a member of the health care team. Although I have exhorted us all to get to know the patient beyond what we find in the medical record, I acknowledge that even the best systems and most competent clinicians will sometimes fail in providing optimal care for our family members. Certainly, we cannot expect clinicians to know our loved ones as intimately as we do. Therefore, we must ourselves become members of the health care team and serve as advocates for our family members when they cannot.

Carole and our family have learned that *there is no predictable or natural progression in her health status – only better or worse.* Here's how Carole views her situation:

"Until 1996, when I had my third abdominal surgery followed by six months of chemotherapy, I was a physically vigorous woman. Now, I'm not as physically strong as I once was. Somehow, though, I've adjusted to this body that is so different from the one I expected to grow old with. My illness has taught me that I essentially have very little control over my life or anyone else's and that everything is impermanent. Both elation and despair eventually turn into something else. I never would have predicted this, but I'm a happier person now than I was when I thought I could boss my body around and do anything that I set my mind and will to. The only way I've been able to continue loving life is to place myself at the mercy of the mysterious universe...and to keep laughing at all the unexpectedly funny stuff that happens along the way."

We have learned to accept and appreciate the *different but important roles of each member of our immediate family*. Years ago, I would become easily aggravated when family members could not assess or anticipate Carole's medical needs, which seemed so obvious to me. As time has progressed, each of us has fallen into the roles we do best: health care advocates, organizers, protectors, advisors, intellectual muses, cooks, reporters, stand-in parents, and cheer leaders.

Healing is hard work and takes all the physical and emotional energy one can muster. It is job one when there is an acute event. Thus, our family does everything we can to maintain a restful, worry-free, healing environment for Carole.

We have many other family members and friends and they have become skilled at making *gestures of kindness unintrusively*. They have learned that visits and phone calls take energy away from Carole's healing and can never be planned to coincide with her "good" moments. Instead, we let Carole decide when and how she will begin to interact with the outside world. Examples of energy-giving gifts have included letters, poetry, and photos sharing life outside Carole's confined environment; garden magazines to browse in quiet moments; books on tape; a weeded garden to come home to; meals in disposable containers left quietly; and freed moments and support for the closest care givers. I share one example of an e-mail sent by Carole's friend who lives nearby her home, which they call Kitkitdizee (KKD). It is located in the California hills north of the South Yuba River.

> *"Tell Carole that the sandhill cranes were circling and chattering right over KKD shortly after noon. I didn't get every nuance of it, but the message was something about springtime: the urge to fly, how the sap rises and the trees bud, why the tree frogs go dizzy for croaking.... Anyway, it was definitely a message for her. Feel the power, Carole! Feel the power!"*

An Ode to My Sister

One might look at Carole's life and consider her unlucky, but as we have already learned, she does not.   She is easy to care for because she is intellectually and emotionally deep and strong; great-hearted and grateful; funny; engaged in matters of importance; a gifted observer, listener, and writer; imaginative; spiritual; open to all possibilities; optimistic but realistic; interested and interesting; and present in the moment – always present. But these are just words. Let me illustrate these qualities with one last Carole story.

In the late 1980's Carole turned her attention to capturing the oral histories of my mother's family, second generation Japanese-Americans. She spent 10 years on this project and vowed to complete this work before their demise and perhaps hers. In the week before she departed for Washington DC for the surgery of her life, she presented to our family a book filled with lovingly collected photos, thoughtful historical notes that put the stories into context, and the authentic voices of my aunties and uncles. The book is entitled Homegrown and at its end, Carole offers a "Parting Wish."[4] The invocation provides an insight into the workings of Carole's mind and spirit and reminds us that even with the greatest effort we can only hold a slice of what makes up the whole of another's life. Nevertheless, that perspective is important and valid. Think of our family's story as that of a patient's.

A Parting Wish

What we have in our hands now is one version of our family's story. The oral histories are small scattered points. It's as if we were standing on a high peak in a vast landscape of mountains and made our family history out of just the prominent summits and ridges that stand about the clouds. From these memories we try to imagine the rest of the range…its bulk, its length, the hardness of the rock, the smaller perfect summits that stand below the clouds, the rivers and forests, the animals, the forgotten ghosts of huge old trees on the ground. Each of us is standing at a different place; each has a slightly different view when the clouds thin.

May we all explore the landscape – both the landscape of story and memory and the actual one beneath our feet. May they intertwine until we have our own story to tell about where we are living and how we are living here. May we learn to listen.

Carole's Progress…and My Parting Wish

After a 2-week hospitalization, Carole was discharged to my home where our family has provided care along with visiting nurses. Overall, healing has gone amazingly well, but we are reminded each day of how much energy this takes – Carole has a voracious appetite and takes lengthy naps. The human body is an amazing thing. After only 4 weeks, the gaping hole that made up part of her wound is now the size of a ping pong ball. We are looking forward to a naturally formed fistula with a nice pucker that will hold a pediatric ostomy bag. All is well for now. Carole is looking forward to a summer in Maine with her daughter, a fall in Italy with her husband, and a new pooch in her life when she returns. My parting wish is that Carole's tale will inspire you to take the time to explore your patients' storied landscapes, and to use the insight you gain beyond the medical record to provide more personalized and humanistic care. Then, when your patient reports that she is "wagging her tail," perhaps you will pause to feel the "wren." It may well be that your patient is signaling that she is on her way to the next jagged peak of wellness.

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