



‘Where was patient-centered care?’

By Sabrina Sussman | February 23, 2018

The idea of patient-centered care is as ubiquitous today as hand sanitizer in healthcare institutions. Every doctor, nurse, and administrator strives to embody the adage that the patient comes first.

But what does that really mean? How do we, as caregivers – and as patients – know if we’ve made any real difference in the care we give and receive under this approach? And why do we sometimes still feel that patient-centered care is nothing but an empty PR promise?

Let me tell you our story. My father was diagnosed with stage IVc colon cancer in August of 2012 at the age of 57. His prognosis was 18 months. Always one to exceed expectations, he lived four and a half years.

During that time, my father meticulously managed the complex administrative challenges, shifting goal posts,

traumatizing physical side effects, and unimaginable social-emotional pressures of battling an aggressive and terminal disease. A computer scientist by training, he built complex spreadsheets to analyze trends in his weekly lab results. While an inpatient, he relied on a checklist to track how he personally could contribute to his recovery, performing the “job of the patient” to the nth degree.

And, in the process, he and our family saw both the best and worst of American healthcare. Ultimately we learned some valuable lessons.

One patient’s journey

My father had been very ill for a while, but despite the best efforts of both my parents, his diagnosis came months after they began seeking answers. Why?

Because appointments are hard to make. Because insurance companies deny coverage for basic diagnostic tests. Because administrative office staff work only Monday – Friday, 9 a.m. – 4. p.m. Because physician arrogance is not only tolerated, but accommodated.

Where was patient-centered care?

Over the course of my father's illness, there were hundreds of instances of miscommunication between physicians and their administrative staff, dozens of insurance denials of necessary treatments and diagnostic tests, endless of trips to the pharmacy and the lab, and hours in the hospital waiting room. And we encountered countless forks in the road where we found ourselves making important decisions, sometimes without enough information from his healthcare providers.

After four years of aggressive treatment, my father checked in to The Johns Hopkins hospital in Baltimore for an ostomy-reversal surgery that promised to enhance his quality of life. There, with the emotional, intellectual, and financial resources that empowered him to ask the right questions, be his own advocate, and include my mother, brother and me at every step, we hoped for patient-centered care.

But even then, it wasn't easy.

3 essential qualities

In his nearly 11 weeks in the hospital before his death, my father underwent two massive surgeries, was admitted to the ICU three times, was placed on a ventilator four times, received seven transfusions, had dozens of interdepartmental consults, had upward of 35 procedures in interventional radiology, and was subject to hundreds of X-rays, CT scans, blood draws, and IV lines.

Through it all, he had a surgeon who saw him not only as a case, but as a human story.

In those weeks, my mother and brother and I renegotiated our relationships with each other, with the

surgeons, doctors, and nurses who held my father in their hands, and with God. We struggled to define what personalized and responsive healthcare meant for my father, and what caregiver support would make our lives easier during the worst time of our life.

Here is what we learned:

Patient-centered care requires a big team

Personalized, responsive care falls not just to medical staff. It is the responsibility of every single person who interacts with a patient and his family. On one day, this was the duty of staff transporting my father to and from different parts of the hospital. On another, it was an environmental worker. On other days, it was me. In truth, it was all of us.

Technology is not a substitute for face-to-face communication

Johns Hopkins has what appeared to me, as a layperson, a modern electronic health records system; while he was in their care, my father's chart was updated every 10 minutes. It must have hundreds of gigabytes large, but no amount of data or electronic messages can make up for human-to-human communication. In rare family meetings, we sat in one room with all members of his care teams to align treatment goals and discuss next steps. Doctors new to his team were able to exchange impressions and information face-to-face with seasoned coworkers armed with their knowledge of my father. When one questioned my father's ability to overcome a rare bacterial infection, others challenged his assumption, citing their first-hand witnessing of a uniquely resilient patient.

The more personal the connection, the better the care

My father loved his dog almost as much as he loved his kids. He specialized in operational excellence. He played the French horn. The medical personnel who knew these personal details were best equipped to monitor his care. They set measureable goals, knowing they would appeal to his managerial nature. They realized that, as a lifelong horn player, his lungs were underperforming, even when his vital signs and X-rays didn't tell that story yet. And they found ways to allow Julius, his dog, to visit the ICU.

The unthinkable

As 2016 drew to a close, my father's doctors discussed what had for so long been the unthinkable: his prognosis wasn't going to change. If we wanted to support my father, we needed to find a way to tell him that his path was not one to recovery, but one to acceptance.

My devoted, determined, stubborn, strong, and incredible father was approaching the end of his remarkable life. And then, in those last days, I saw what true patient-centered care looked like.

It looked like unlimited servings of ice cream and sushi. It was long visits with the doctors and nurses who had become friends. It was hand-feeding Julius off the hospital menu, and it was paper snowflakes hung from ICU room windows. It was my mom slipping into bed next to my father for his last few hours.

It was patient-centered care, a reflection of the person my father was.

Sabrina Sussman is a daughter, sister, caregiver, former patient and writer in Washington, D.C. Her father, Harold L. Sussman, died December 9, 2016 at age 61.

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