

## **The Heart and Science of Health Care Quality**

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Some time ago, Janak asked me if I would be willing to make a presentation about my illness, particularly in regard to what improvements I might make.

I gave it a great deal of thought, and I discovered that about the only improvement I could think of was reducing wait times; perhaps not the wait times as such, but the communication about why we are waiting. I doubt that is a surprise to anyone, but in our defense, is there any business or industry that doesn't suffer from lengthy wait times? And.....the lack of communication about them. Take, for example, how many times we sit on the Airport tarmac, waiting to take off, without knowing why we aren't; waiting for an item we ordered that was due in 5 days still hasn't arrived after 8 days with no explanation, or waiting in traffic where there is a bottleneck for no apparent reason.

As I reflected a bit more on Janak's request, I decided to look at my illness from a broader perspective, that is, something that could encompass all types of illnesses.

This is what I thought:

Medicine and therefore, health care, is considered to be both "an art and science"; However, I prefer to think of it as "Heart and Science". I would like to propose that for my remarks today I spend a small amount of time exploring my illness from the perspective of the "science", and then, the majority of our time with my experience and the many experiences of SSM health care in the way of the "Heart". While I may treat them separately, I believe that they must be integrated.

As I do this, I will be using some of the same material I used two years ago in Gothenburg. I hope this will be okay, because many of you here today were not at that presentation, and for those of you who were, I hope you won't mind hearing it again.

So, here's the "science" part. I have CLL, that is chronic lymphocytic leukemia, often called the "old persons' leukemia"; that pretty well describes me. This is a Cancer, but when compared to the health problems of many other IAQ members, as well as other people with CLL, my CLL pales in significance. However, it offered me an opportunity to experience health care as a "receiver" instead of a "giver".

I was diagnosed in early March of 2012 just prior to our IAQ meeting in St. Petersburg. CLL is a disease of the blood when the White Blood Cells and Lymphocytes, which are useful for fighting infections, grow out of control and crowd out healthy blood cells. The

diagnosis was made based on the results of a biopsy of an enlarged lymph node that I discovered just above my left clavicle. I was referred to an oncologist who determined that while I certainly had the disease, he did not feel the need for any treatment until my WBC and Lymphocytes reached a certain level. That level was reached on August 1<sup>st</sup> of 2014; the normal range for WBC is 4,500-11,000/mm of the sample; mine was 100,000. The normal range for Lymphocytes is 20-50% of the total blood sample; mine was 83%. I had a Port-a-Cath inserted in my right subclavian vein on August 4, and my first chemo therapy about a week later. A week after that my WBC had dropped to 3,700 and my lymphocytes to 43%. My second treatment was scheduled for about a month later with weekly blood draws to chart my progress. However, my platelets had dropped significantly, and since they are cells that help stop bleeding, it would not have been prudent to go forward with my second treatment. Unfortunately, that meant that I had to cancel my trip to Japan, as my physician did not want me that far away during that time. Ultimately, I had a second treatment, had my Port removed on November 7<sup>th</sup>, 2014. I had monthly and quarterly blood draws throughout 2015, and I was declared to be “in remission” in March of this year.

I also believe that many prayers on my behalf played a role in my recovery.

So that’s the “science” part of my health care, and without question, that part cured me, (for which I’m grateful) so why should I even mention “heart”? As a reason why heart should be mentioned, let me read a quote from Rachel Naomi Remen, a physician: “The ways and means by which people serve may vary from time to time and from culture to culture, but the nature of service has not changed since our beginnings. No matter what means we use, service is always a work of the heart. There are times when the power of science is so seductive that we may come to feel that all that is required to serve others is to get our science right, our diagnosis, our treatment. But science can never serve unless it is first translated by people into a work of the heart.”

What did this mean in my experience? It meant a cold cloth on my forehead when I experienced vomiting during my first treatment, it meant bringing me a warm blanket when the nurses knew I would be cold, and it meant receiving a hug from my oncologist and nurse practitioner every time I arrived and when I left. It meant being treated with respect by ensuring that I was included in treatment options before anything was done. It meant that I truly felt like I was being served, that I wasn’t just one more chemo therapy subject. It meant that my confidence in my caregivers was such that I never worried that I wouldn’t get well, or that I could actually die. And it meant having caregivers celebrate with me when it was determined that I was in remission. In two words what I experienced: Caring and compassion. And most of all, I experienced our Mission statement in action: “Through our exceptional health care services, we reveal the healing presence of God”.

As I mention these things, I have to wonder if my experience is so very unique from yours. That is, when others of you have been hospitalized or spent time in some health care setting, have you not experienced these same things? I sincerely hope that you have, and I especially hope that if you did, that you recognized that this was not just science at work, but it was rather a work of the heart.

I also do not want to suggest that this work of the heart should only be present in health care; obviously it would manifest itself differently in other settings. But I wonder if some service you received at some time didn't have something special in it? Perhaps someone sincerely welcomed you to a place of business as a person, rather than just a potential sale. It could have been something as simple as a sincere smile with a "Thank you", or actually making eye contact, recognizing you as another human being, rather than merely giving a grunt of acknowledgement.

So, with your indulgence, I would like to explore the notion of service as a work of the heart with a series of stories, some from SSM, and others that are from other sources. I'll begin with three short stories from SSM:

The first happened at one of our St. Louis hospitals. A 17-year-old patient had been in the hospital for quite a while, and he was tired of being there and tired of hospital food. . . His nurses knew that. And so they bought a pizza and brought it to him. . . . Now buying the pizza was a small act – certainly nothing that would make the evening news. Yet it was an act of kindness that made a huge difference for one young man.

My second story is about one of our hospital presidents. This president visited a young patient in the hospital several times – and her parents were astonished. They couldn't believe that a hospital president would take time out of his busy day to visit with their daughter. . . . And not just once, but SEVERAL times. . . . Again, a small act. But one that made a big difference to that family.

My third story is about a woman who's been an aide with our hospice for many years. She went to a patient's home at 6:30 in the morning – because that's when the patient wanted her bath. And our employee took a space heater along to make sure the shower area was warm and comfortable. .... Not a really big thing, yet, at the same time, so huge.

Simple acts, but undeniably, works of the heart.

Regrettably, there are times when acts of kindness can be misunderstood: Let me tell you an example of this. The daughter of a friend of mine was hospitalized (not at an SSM hospital) for an extended period of time because she was having a difficult pregnancy. She told me that one of the nicer things she experienced during her hospital stay was when the person from housekeeping came to her room every day, did her work and then spent a little time just talking with her. When the patient returned home, she received a satisfaction survey to complete about her hospital experience. However, she did not mention the kindness of the housekeeper, because she was afraid the person would get in trouble for spending too much time "not doing her job."

Interestingly, because of their service, the dictionary would define the persons from these 4 stories as "servants," a definition we might well find offensive.

But I would suggest that we cannot define a “servant” by the task performed, but rather by the attitude brought to the task. It’s an attitude of readiness and anticipation; of availability and willingness.

This attitude of service is not a quality that is conferred like a degree or a diploma. Rather, it develops from within, like a seed that begins its journey underground. It is, more than anything else – an attitude, an attitude of openness and generosity of spirit.

Getting back to the quote from Dr. Remen, she tells the story of Molly, one of her former patients, who was hospitalized with fractures of both elbows. Molly had been in an automobile accident as she was driving to the airport in a city 2,000 miles away from her home. When she awoke in the hospital, her arms were encased in rigid casts that went from her shoulders to her wrists.

Molly has multiple food allergies and other very special dietary needs and can become dangerously ill if she inadvertently eats the wrong things. So it was critical that her food needs were addressed while she was in the hospital. Soon after she was settled into her bed, a dietitian took more than an hour to carefully document her unusual food needs. “The questions she asked were so thoughtful,” Molly told Dr. Remen. “She really knew her stuff. In all these years no one has ever asked me some of those questions or understood so quickly and completely how things were with me. I was really impressed.”

Within a few hours, special food was ordered for Molly. Three times a day, this food was served to her by competent dietary staff, who brought it to her bedside on a tray and put it before her on her bed table. Then they left.

“The first time this happened,” she told Dr. Remen, “I just sat there, looking at the food, unable to feed myself. I was certain that someone would come to help me, but no one did. After a while, the woman in the next bed noticed that I could not eat. Trailing her own IV lines, she had gotten out of bed and fed me my dinner.”

“The same thing had happened at every meal. In the four days that Molly was in the hospital without the use of her arms, no one on the staff ever helped her to eat. Day after day, the right food would be brought in, and the patient in the next bed would feed it to her.”

Now Molly’s caregivers did everything right – technically. Her fractured elbows were correctly diagnosed. Her casts were no doubt of the highest quality. The dietician questioned her with great care and attention to her dietary needs. All the correct foods were carefully placed on her trays. And her trays were undoubtedly delivered promptly every day – with the food hot, even. What was missing from the picture was “heart.”

Everyone in that hospital was so busy going through their processes that they did not see Molly as a human being; they didn’t observe that she could not eat her food without assistance

This story demonstrates perfect science, but not much heart; in this instance the heart was actually provided by the other patient. I hate to think that something like that could happen at any SSM hospital, or any health care facility for that matter. Because while our patients receive the highest quality care, they must also experience caring and compassion from everyone with whom they come in contact.

When it comes to caring and compassion, I know that our employees and physicians are wonderful examples of that, but because they always are, it's sometimes easy to overlook how very special they are.

But, several years ago, as we were researching speakers to keynote our annual Leadership Conference at SSM, we had a moment of enlightenment and decided to have some of our employees be the keynotes. In three to five minutes, for the three days, 12 to 15 employees spoke of their experiences being present to people, some who were suffering, while others related joyful experiences. This is a couple of the "suffering" ones: "Bill": when Bill, a homeless man, arrived in the Emergency Room at St. Mary's Health Center in St. Louis, he was filthy and covered in his own waste and blood. Our caregivers in the Emergency Room, however, saw Bill, the person rather than Bill, the dirty homeless man. They treated him with the utmost dignity and respect, and hope and meaning were restored to him. Just as a follow up to that, Bill was diagnosed with inoperable colon cancer and then provided with whatever care he needed. In addition, a sister who had been attempting to locate him for a very long time was found by our social service personnel and she and her brother were reunited.

A second story from another of our employee keynotes is this:

One of our nurses described the angry, threatening, violent woman who arrived in a wheelchair on the behavioral health unit. When she was placed in a lift, she broke down sobbing and asked the nurse if she could use the lift when her husband came to visit that evening. She wanted to surprise him by standing, putting her arms around him and kissing him face to face, just as she had on their wedding day. She was transformed into a sweet almost shy young woman.

I've told stories like these to other groups and after one such presentation someone came and asked me how did we get such wonderful employees. I told her that from our earliest days, and throughout the years, our Sisters imbued us with a deep and lifelong respect for the people we served. We learned about healing in the truest sense: curing whenever possible, but always, ALWAYS caring. I'm sure that you will not be surprised to know that our employees and physicians are wonderful, loyal and dedicated people, and I'm proud to say that SSM has a culture of caring and compassion, integrated into quality and safety. Here's another example of that told by one of our nurses from another of our St. Mary's hospital in Jefferson City, Mo, our State capitol.

In her words: "It was a Saturday morning, not different from any other, until I walked into Mr. Smith's (not his real name) room. Mr. Smith had been a patient many times lately in

our ICU. He frequently was admitted due to fatigue and dangerously low hemoglobin due to a blood disease. He was in his late 40's, and was usually a talkative, jovial patient. On this Saturday morning, he barely said a word when I came in to do his morning assessment, and did not make eye contact.

After I finished, I sat down on the side of his bed and simply said, 'Do you need to talk?' I was not prepared to see a grown man cry. You see, it was his 20<sup>th</sup> wedding anniversary that day, and he was afraid that he would not live to see his 21st.

He told me how he and his wife had met and how happy they were as a family with 3 children. He kept apologizing for his tears. About that time the physician came in making rounds. My mind and heart were churning as I went to assess my next patient. When the gift shop opened, I went down to see if they had any anniversary cards. They had two! I explained the situation to the gift shop volunteer, who allowed me to take both cards upstairs to the patient, so he could pick the one that suited him. When I returned to the gift shop to pay for the card, I surveyed the possible gifts that might be available for a husband to buy his wife for their anniversary.

I went back up to Mr. Smith's room and shared possible gift ideas. He insisted it had to be his money, though, and would I call his 19-year-old son and ask him to bring his wallet. In the meanwhile, I hung a unit of blood as ordered. I then called the house supervisor and explained the situation. Together we set forth to create a surprise dinner for two.

I contacted Mr. Smith's physician to see if it would be okay, after two units of blood and some rest, if the patient could have his IV locked off for an hour in the evening if all was stable. I called dietary to order a special dinner for two. We called maintenance to have them deliver a table for two from our OB department (where the tables are used for dinner for new parents). We found an arrangement of flowers that had been left by a patient who had been discharged.

I asked Mr. Smith's son to bring in a shirt and a pair of pants for his dad. (And not to let his mother know.) The patient was very excited at the idea of dinner alone with his wife on their anniversary. We clinically completed all that was ordered for that day. Vital signs and labs were stable, and the patient took a nap.

At 6 p.m. his wife arrived to a surprise anniversary supper with her husband – gift, card, and music from the radio from the break room included. The curtains to the room were closed, the door was pulled shut, and they had some quiet time alone together.

We worked hard that day, but somehow we did not feel as tired as usual going home that night. Because this is what nursing is truly about!

It WAS the last anniversary dinner for Mr. and Mrs. Smith .... Mr. Smith died a few months later."

This story clearly illustrates heart and science; the nurse thoroughly fulfilled her duties regarding the patient's physical treatment, but she also ensured that his non-physical needs were realized, and therefore she treated the whole person..... body, mind, and spirit.

Some of you know that one of our hospitals is a Pediatric hospital which was established to care for poor and sick children in St. Louis, (I believe that some IAQ members visited the hospital the year that the WCQI was held there.) This is a very special place for children and their families. A few years ago, we produced a video about Footprints, a Glennon program that helps families whose children are likely to die before they reach the age of 18.

Footprints helps these children live their lives to the fullest, during the brief time they have. During the taping of the video, several caregivers recounted the same story . . . a story that had touched them deeply more than 20 years earlier; it's a story that we have promised to keep alive.

A baby was born that year with multiple severe birth defects, and it was obvious he would never go home from Glennon. But his mother had one wish before he died. Even though he was hooked up to IVs and other equipment, she wanted him to be taken outside to feel the breeze on his face.

It was a challenging task, given the baby's condition, but the Glennon staff felt it was important to honor the mother's request. So on a cool, fall day, the mother held her baby in her arms, and, accompanied by our caregivers, went outside to a courtyard. As they stood together, the baby's doctor – who was an intern at the time – picked a flower, and placed it in the baby's hand.

Well, the baby died shortly after that, but our doctors and nurses were grateful that the mother had felt some semblance of peace because they'd been able to grant her simple wish.

During the taping, one of our nurses who was present that day decided to let the mother know that her son's story was being told to the video crew by many of our employees. Even though she knew the mother had moved several times, the nurse wrote to her, hoping against hope that the letter would reach its intended destination.

Several weeks after she sent the letter, our nurse received a phone call from the mother. She'd received the letter and had read it tearfully, because so few of the people in her life now knew about her baby boy. The two women talked – somewhat emotionally – for 20 minutes, and then the mother had one more request. "Please use my son's name whenever you tell this story," she said, "As a remembrance of his life."

So I will tell you his name: Andrew Kilmer . . . As a remembrance of his life.

How different it would have been had our staff convinced the mother not to go outside because of Andrew's condition; how different if our nurse had not made the follow-up call that provoked such deep emotions for both women. To me, that story is all about a work of the heart.

As I begin to close my remarks, I want to quote a parable that I believe sums up what the stories that I've shared with you have in common: "There is a parable about the difference between heaven and hell. In hell, people are seated at a table overflowing with delicious food. But they have splints on their elbows and so they cannot reach their mouths with their spoons. They sit through eternity experiencing a terrible hunger in the midst of abundance. In heaven, people are also seated at a table overflowing with delicious food. They, too, have splints on their elbows and cannot reach their mouths. But in heaven, people use their spoons to feed one another. Perhaps hell is always of our own making. In the end, the difference between heaven and hell may only be that in hell, people have forgotten how to bless one another."

Earlier in my remarks, I mentioned how the example of our early Sisters created a culture of caring and compassion in order to make a difference for the people we serve. so my final story is not a story; it is a letter. While it was written many years ago, in 1989, it could have been written last week. It is to our St. Anthony Hospital in Oklahoma City, and speaks for itself.

"1989 -- To Whom It May Concern:

On February 8, 1939, my father was killed in an automobile accident. He left a widow, three months pregnant with her eighth child. Four of the children were born at St. Anthony Hospital. Because of her drastic economic situation, my mother planned to have her eighth child at home. But in August 1939, the sisters from St. Anthony contacted my mother and insisted her eighth child be delivered at the hospital – at no charge.

Over the years my mother stressed to us that this was the only act of charity she ever accepted. She taught us the value of hard work and the pride of independence.

My mother is now eight-six years old and still lives in Oklahoma City. In honor her I enclose \$1000 to repay the sisters for their charity. Perhaps it will offset the account never paid in 1939 ..... By the way, I happen to be the eighth child."

I spoke earlier about service, and a work of the heart; I want to close with Dr. Remen's definition of service. She says: "Service is a relationship between people who bring the full resources of their combined humanity to the table and share them generously. Service, she says, is the way the world can heal".

I don't know about you, but I believe that IAQ meets that definition. Let me remind you of the IAQ Purpose: "By our mutual contributions IAQ advances quality throughout the world for the benefit of humanity." The last part is further elaborated in this way:

The benefit we seek is for humanity in terms of

physical, emotional and intellectual well-being  
of people that could lead to peace and harmony  
with equity and justice for the greater good.

Combined with our Values, this Purpose gives life and meaning to IAQ, and gives all of us a reason to be very proud and grateful to be part of it.

Thank you and may you be richly blessed.