



Family Medicine Moments

June 1, 2023

Introduction: Over the next few weeks, I plan to honour Warren Ferguson, our former Senior Vice Chair of Community Health, who is retiring at the end of the month. He has written 26 pieces for Family Medicine Moments over our 15-year history. He has written about everything from deep patient connection to his own observations as a care giver and as a patient. This piece is the first one he wrote back in 2009. Below, I include the introduction from then.

Caregiver Observations

By Ferguson, Warren

Introduction September 3, 2009

Welcome back to the 2nd year of the Thursday Morning Memo, which I hope will serve as a refreshing reminder of why we do this and how we might do it a little better based on the example of others. This week, Warren Ferguson, faculty member at the Family Health Center and Vice Chair for Community Health, talks about his observations of how we in the medical profession sometimes get it wrong, and other times get it right, as we communicate with patients. In this case, Warren is sharing thoughts about his own father, and nothing hits home more for us in health care about problems in healthcare than when our own family members are facing illness:

Caregiver Observations

Down a familiar road. Dad can't swallow his Christmas dinner. Mom had lung cancer. Now what? Esophageal cancer. Two memories so far. Only one gastroenterologist on call. His response? "How can I help?" RELIEF. Eight hours in the emergency room. "Nurse, he needs an IV." Her response? "It's not my job. Talk to the resident." RAGE.

I wrote this quickly while sitting next to my sleeping and gurgling father in the recovery room (January 15, 2009) following his endoscopic ultrasound confirming his advanced esophageal cancer. My father died on May 20, 2009. Ironically, he did not die from his cancer but from arrhythmias a few days following a small heart attack. While this came unexpectedly just two weeks after he finished palliative radiation treatment for his esophageal cancer, most of us are comforted to know that he did not suffer a lingering death from his cancer.

Part of the "job description" of a health care profession is the role of health navigator for friends and family. Many have written of the need for a vigilant family member playing the role of "safety officer" as Don Berwick (CEO of the Institute for Healthcare Improvement) so aptly wrote in his seminal article. I write now, perhaps in grief and certainly with the critical lens of a protective son, about a few of the several hundred poignant experiences over his five months of illness. The common thread to these experiences is not the typical medical errors such as duplicate medications, appointment communication errors or hand off errors, of which there were more than a few, but of good, bad and ugly examples of communication and relationship building which either provided hope or took it away.

When we teach about delivering bad news, we teach that this is about the "big" bad news, delivering the cancer diagnosis, for example. The gastroenterologist, a UMass grad, did this perfectly. However, it's really about delivering ANY bad news. A patient of mine from Albania taught me that it's so important for the patient to maintain hope. When you are struggling with nausea, fatigue, pain, hunger, the humiliation of illness (almost a universal feeling), every piece of bad news, no matter how small, is magnified in the eyes of the patient who is just trying to cope.

While my father was hospitalized for a pulmonary embolism with rapid atrial fibrillation that was difficult to control and had spent 10 days in the ICU, it appeared that he may have a small bowel obstruction. It turned out to be an ileus. The surgical resident evaluating him, who had no relationship with him, emphasized three times late at night how unfortunate it was that he had advanced esophageal cancer. I felt like saying, "Do you think that he doesn't know it? Why do you keep saying that? How is it helping him?" The surgical attending on the next day nonchalantly told him that he thought surgery

might be needed. Here's what my father heard: "They told me that they need to operate. I don't think that I can survive an operation right now." He was probably right.

When my father was diagnosed with his small heart attack just a few days before his death, the emergency room resident walked in, having just met him, efficiently confirmed, "Mr. Ferguson, you've had a myocardial infarction". My father looked up at me with tired, confused and grieving eyes. I told him, you've had a small heart attack. "Oh my God, what else can go wrong?" In retrospect, he was telling me, "I think I've had enough".

Here are a few of the good examples. "Mr. Ferguson, you are a wise man to make the decision not to have surgery. People with this cancer do very well with radiation and chemotherapy and your quality of life will be so much better." This oncologist must know how disempowering the patient role can be. He complimented him and gave him hope. "Mr. Ferguson, I can't believe how quickly you've recovered from this serious illness and am pleased to see that the tumor has responded to treatment." "I think that you should finish radiation and we'll hold off on more chemotherapy for three months. You just might make it back to that golf course." While my father never made it back to golfing, this provided him a goal and invigorated him. It provided a bright day and was such a gift in his eyes.

For those too young to know yet or lucky enough to have avoided it, the sick role is a role that is difficult to endure. There are the physical discomforts, the emotional loss of function, the shame and humiliation of depending on others for the simplest of things, not wanting to burden those that you love. With your next patient who's going through something serious, try to offer a compliment and a gift of hope, no matter how small. These few words will be embraced and quench the thirst of those lost in the desert of sickness.

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