

Thinking Out Loud... Trust

“The Information Age is also empowering patients. As patients start to get the kind of information about the outcomes of care that was once reserved for doctors, we will begin to become partners with our doctors.”

—Michael L. Millenson, author of *Demanding Medical Excellence: Doctors and Accountability in the Information Age*¹

How many times I looked at my mother during her last few months of life and wondered how the zippy, fun-loving person I knew had dwindled into the frail person who now sat in front of me. It was almost as if she were evaporating in front of my eyes.

As her personal caretaker, I felt the weight and the honor of the service I gave her. I also experienced the nagging feeling that I had to learn as much about her condition as I reasonably could so that I would be in a position to make the right decision for her when it became necessary to do so. It is only now that I ask myself, “Why did I have this feeling?” The answer I have been able to deduce from the facts in my memory bank is that I had a *wavering sense of trust that our medical system would work to her benefit.*

Trust and Experience

The topic of trust has been on my mind for some time since then. Trust is more complex than meets the eye.

Often, those who are trustworthy may not be trusted, while those who should not be trusted give the appearance of being trustworthy and, so, are trusted. This observation was corroborated during an internal symposium at our company. What I learned at the symposium—in actuality, what I already subconsciously understood—is that personal expectations and the quality of communication among the participants are likely causes for this inconsistent result.

Looking back on the events that occurred during the three and a half months when

Mom slowly descended into death, I believe that my feelings of distrust revolved around my expectations of the “good care” that I was promised during the initial conversation with her caretaker... *“I will take good care of your mother.”* Expectations that were not reinforced by continuous, consistent, reliable, and predictable communications and actions.

Additionally, events from the outside world affected my thinking in the back corridors of my mind. Revelations about fraud and cover-ups by once-trusted companies and organizations lent nothing to my feelings

of comfort, although their actions do not directly relate to our situation. Distrust was, and still is, in the air, impelling us to pay close attention to details that we may have otherwise overlooked.

For example, the Emergency Room (ER) physician was an empathetic and warm-natured fellow in his late-thirties who proudly told us that he was to be wed in two months and cheerfully

confided that he loved sports (an explanation for the crutches he used to hobble around the ER). When he became somewhat testy, I became sensitized to our circumstance. I noticed his irritability seeped out after three hours of trying to contact Mom’s physician, whose office was in the same building as the hospital we were in. He finally gave up trying and realistically decided to admit her into the hospital. While I believe this would probably have occurred whether or not the two had made

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contact, I still feel somewhat betrayed by her physician, who had been managing her care for over two years.

With mental distance now as my friend, I can now ask myself whether the feeling of betrayal was valid, or whether it was the result of appearance versus reality, an appearance that was at odds with my expectations of good care. Perhaps the questions should be: "Was her physician there to receive the call? Was his staff schooled to understand the critical importance of the call, so they would contact him? What did his staff say to the ER physician that seemed to bring a sudden furrow between his brows? Was there another reason for the four-hour delay between ER and hospital admission? Did he abandon her when she needed him? What were my expectations of good care? Did the entire care team share the same expectations?" These are all good questions whose answers will most likely never reach the light of day.

Technology's Evolving Social Role

There is growing public impatience with what is perceived as flawed medical care. Technology could have helped by seamlessly leveraging contact with Mom's care team. Instead, we used a sequential route, a course of action that flexed time in a single direction. The outcome? The ER care team waited and Mom suffered in physical time. Perhaps more importantly, I, like many other caregivers and patients, have become increasingly sensitized to glaring medical mistakes such as those publicly highlighted by Dr. Donald Berwick, a Harvard-educated physician and the President/CEO of the Institute of Healthcare Improvement. I, like others now in their fifties, inwardly fear that I could, through no fault of my own, become a medical error statistic. I, like they, will more likely than not research a physician, hospital, or

facility before I or my loved ones become their patient.

Without a doubt, technology is gradually being knit into our social awareness and patients are becoming empowered with information—i.e., facts about care providers and the quality of their care. Check out the website www.medicare.gov/Dialysis/Home.asp, where renal facility-specific information is available detailing the percentage of patients with a urea reduction ratio (URR)

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of 65, the percentage of patients with a hematocrit of 33% or greater being treated with Epogen®, and patient survival data. Today, several states publish outcome statistics about their hospitals. Look over the background information about physicians that some state medical societies publicly post, although it may exclude disciplinary action (generally optionally self-reported by the physician). All of this information had previously been unavailable to the general public. Finally, check out www.informationtherapy.org. Information therapy, while in its infancy as an industry, is emerging.

The Practice of Information

In the February 1999 issue of this journal, I wrote, "In the not-too-dis-

tant future, I believe we will not be able to imagine patient care without medical informatics. In fact, we already find ourselves saying that the delivery of medicine will be based on the practice of information."² This is no longer a concept argued about at conventions. It is becoming expected. The good news is that the practice of information seems to be creating partnerships within the care team and re-surfacing goodwill among them.

Shared Communication Engenders Trust

History teaches us that shared communication engenders understanding when the communication is consistent and reliable. Without shared communication, misunderstanding is more likely to occur, because human beings fill in the dots where none exist and emerge with a version of reality that can be truly unreal. As medical and outcome information becomes more open among medical providers, healthcare organizations, and patients, and as patients become more active participants in their own care, the shared communication among them will become the basis of their renewed trust in each other... a trust I believe each craves and hopes to achieve. I know I do.

And here's the good news... There is evidence that patients who feel a part of their care regimen and also feel they have a say in their treatment experience better outcomes. They are, in essence, empowered by information and are using it to begin a renewal of trust in our medical system.

References

1. From an interview with Michael L. Millenson, author of *Demanding Medical Excellence: Doctors and Accountability in the Information Age*. Chicago: University of Chicago Press, 1997.
2. Evans EA. The influence of medical informatics on improved patient outcomes: The TIME System. *Dial Transplant* 1999; 28(2):84-86. **D&T**