

Thinking Out Loud

“Science is the knowledge of consequences, and dependence of one fact upon another.”

—Thomas Hobbes, 1651

There are times in one’s life so different from prior times that we call them life changing. Such has been the case for me in recent months. Hence, the birth of an idea... Thinking Out Loud... a series of commentaries born literally out of talking to myself—as well as to friends and colleagues—about the realities related to a beloved one (my mother) as she successfully fought for life, and about the medical realities that have the potential to ultimately affect us all.

A physician friend asked me why I would write this series of commentaries. I explained that I am doing so to re-channel my energy from a personal sense of helplessness—experienced while I acted as my mother’s legal representative and personal caretaker—to a recognition that it would be used constructively; to dissect ideas, not resolve issues; and to investigate and question certain realities that exist, despite the fact that there may be no alternatives... at least not now.

I told him that I wanted to share what I have learned from this experience and about what I already knew, now understanding it a bit differently. I told him, for instance, that I had read about the nursing shortage, but had only just internalized its meaning as I provided my mother with discrete services that the nursing staff were too busy to do. I was only too happy to help out those competent, caring nurses whose effectiveness has been undercut by the nursing shortage that is impersonally written about in the newspapers.

I told him that I had studied the Institute of Medicine’s report, “To Err Is Human,” and similar reports, but had only just internalized them after a medical error occurred—up front and personal—while at home alone with my mother, just the two of us. It was all so frighteningly real as I pulled first-aid information (learned too many years ago) from the panicked recesses of my mind.

I told him that I had read statistics about untreated diabetes, but had only just encountered an actual case firsthand, citing my mother’s consistently elevated glucose levels over the last two years.

Closer to home, I had read about the link between heart disease and renal failure, but only recently saw it in action as my mother’s renal-related test results began to decline. Although she did not ultimately experience renal failure, I visually absorbed the cardiorenal relationship as I stood in the Cardiology ICU late one night and saw the dialysis machines move silently between rooms as if on tiny cat feet.

All of these events occurred between August 16 and October 16, 2001, and all in one case... my mother’s.

A True Learning Experience... in Medical Informatics

What did I learn from this experience? First, I learned that most of us have multiple medical records, not one. When we visit a medical specialty, each office has its own version of our medical record. Each office records what happened during our visit, re-records our medical history, and stores the record in their medical files.

Second, I learned that, at least currently, the best way to consolidate our dispersed medical records into a single record is to acquire a paper copy of each existing medical record and then combine all the paper records into a single record. This is, in fact, part of the action that I took during this two-month period.

I visited the Medical Records office of the hospital to request the Emergency Room record and the hospitalization records. I contacted the Skilled Nursing Facility for the records related to care subsequent to the hospitalization. I asked for these records from the cardiologist, the internist, and the gastroenterologist. In effect, I became a human

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conduit of my mother's medical records, taking them with me wherever I went, *just in case*.

During a visit to the Emergency Room in the very early morning hours, the attending cardiologist said in a stolid tone after looking at the compilation, "These are very helpful. I wish everyone had this kind of information when they come here."

Fourth, I learned that predominantly competent, caring people work in a medical system that is in need of repair... a good feeling to know firsthand, for we can fix a system more easily than we can the people who work within the system.

Third, I learned that an electronic medical record accelerates information acquisition in downstream visits. Between the first Emergency Room visit and the subsequent ones, I electronically entered (in the AMI TIME[®] System) my mother's medical information, keeping it up to date after each visit. As a result, we now have, and intend to always have, a current History and Physical, an updated Patient Profile Report, an Active and Inactive Medication list, test results, Progress Notes, and Consultation reports.

When I presented my mother's computer-generated medical records to the nurse during the second Emergency Room visit, she said that she could not use them. I asked her to at least take a look at them, just to see whether they might be helpful. Acquiescing, she leaned over the reports, looked them over carefully, and said simply, "I can use them." Using her

finger to locate information required for the form, she updated it within five minutes.

Unexpectedly, no one asked additional questions about my mother's medical information during the visit. This said, there was one request... the attending physician asked for my mother's medical record so he could review it.

In 1651, Thomas Hobbes wrote, "Science is the knowledge of consequences, and dependence of one fact upon another." And so it was in the Emergency Room in 2001.

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Let's Be Practical, and Dream

Let's be practical and dream about possibilities. Imagine a phone that's integrated with an information system that recognizes a patient before you pick up the handset and answer the call. Displayed on the screen is a picture of the patient, along with a snapshot of the patient's problem list, active medications, hospitalizations, and test results, as well as a list of current alerts and advisories.

Imagine what a national medical information format could do for a unified medical record. It would enable medical data sharing across information systems and create the data infrastructure necessary for a portable, unified medical record—*one to a person*.

And so, the purpose of my commentaries will be very practical. It will be to think out loud about what information technology is and what it can pragmatically become in the joined worlds of medicine and technology. The goal is to provide a human lens to medical informatics. I feel extraordinarily optimistic about the possibilities as we pursue excellence in what we do—in medicine and in technology. **D&T**