

Thinking Out Loud... Information and Hope Should Know No Barriers

“He who owns the interface owns the information.”

—attribution unknown

“To the sick, while there is life there is hope.”

—Cicero, Roman philosopher (106–43 BC)

Several years ago, I read a sentence that has since reverberated in my mind and does so especially when I revisit the five months during which I was my mother’s personal caretaker. I have searched my own library and others to locate its source, with no success. Despite the lack of attribution, I will still quote it: *“He who owns the interface owns the information.”*

While this sentence relates to a computer interface—i.e., programmed instructions that organize data into an intelligible, interpretable format—it also relates to entities such as web portals, news stations, and a knowledge worker’s output, such as the interactions that occur among patients and caregivers. Each one provides information drawn from a knowledge bank of data upon which we, the receivers, base our decisions.

In my caretaker role, I soon discovered that the *interface* with those who cared for my mother was complex... one that was circumstantial and honest, requiring an emotional fortitude I had not anticipated until I was well into the caretaker cycle. I soon appreciated the importance of hope in the healing process and the art of communicating it without compromising the message’s authenticity. I found out firsthand that my own emotions would interfere with the message I ultimately had to accept, as evidenced by her visit to the doctor.

A Visit to the Doctor

The day that my son, my mother, and I trekked to the cardiologist’s office was luckily a sunny, not too warm day that imbued us with a sense of going on a vacation rather

than to a doctor’s office visit. We carefully snapped the seat buckle around Mom, stored the lightweight wheelchair easily in the car’s trunk, and were on the road without a hitch. The three of us joked and talked about grandchildren, recipes, and life in general, enjoying each other’s company, ignoring the seriousness of our journey.

Mom had been diagnosed with congestive heart failure (CHF), a diagnosis she had discussed privately some time ago with her cardiologist. When we learned about her CHF, we began our research first by speaking with our physician friends about it, and then by accessing reputable medical websites and reading their knowledge. Although we felt we were mentally prepared for what would ensue, we found out that there would be a surprise, and not the kind that one would expect.

I maneuvered her wheelchair into the small exam room with racecar precision. Mom relished directing my wimpy efforts as much as I enjoyed pretending that I had welterweight strength to do so—not too much strength, just enough to get the job done with respect. Because she was sitting low in the chair, Mom’s stature seemed diminished by the higher exam table and the stool perched in the corner of the room next to the high writing table, above which hung wall-pockets of information that described a variety of heart ailments. The lights glared down on her frailty, yet her eyes retained their luminescence.

As the doctor entered the room, Mom shifted her head to the right and raised her eyes upward with a crinkled welcome. He looked straight down on her and smiled with his eyes.

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THINKING OUT LOUD

In a moment quicker than a hummingbird's wings in flight, they locked their eyes with an awareness that seemed reserved for them. That is how the visit with her cardiologist began that day.

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Owner of the Interface

He reviewed the vitals his nurse had just a few moments ago taken, and was careful to keep predominant eye contact with Mom. He looked over her medications after she pointed out several symptoms. Her eyes were intent during this discussion as she carefully listed each of the eleven medications she was taking and their dosages. When he mentioned that a medication change had been made two visits ago, she corrected the date to a period a little more in the past. After looking at his notes, he acceded that she was correct. Mom seemed proud of her retentive memory and relieved that she could still use it effectively, as the new chemistries her body endured seemed to slowly steal its speed and efficiency.

When I asked her physician about the implications of the increasing trend of her BUN and creatinine test results, he said, "This is part of the disease syndrome. It's to be expected and is not a cause for alarm."

I noticed from the side of my eye that when he said, "This is part of the disease syndrome," Mom seemed to sink lower in her chair, and her head seemed to drop slightly. However, when he said that it "is not a cause for alarm," she seemed to sit a little taller and her head came up to its original height. In

that moment, I understood the complex and delicate art of speaking to those who would understand *their* truth.

The owner of the interface... the physician... shared the data in a way that would likely be understood differently by each of the two listeners, an understanding I was just beginning to grasp. What I had not anticipated was the emotional duress I felt as I appreciated an important role I knew I had to assume—a protector of her hope. Hope could sustain Mom as much as could medical technology. I was in new territory and felt powerless to make a difference... when making a difference was paramount in importance.

Let's Be Practical, and Dream

I believe that technology—specifically, "push" technology, a concept that underpins the AMI vision—will shrink the gap that now exists between information, communication, and the patient care team. Push technology *shares the interface*—that is, the information—by automatically sending (that is, pushing) updates, alerts, and advisories to the right person; in this case, the right person in the care team... whether it is the patient, the clinician, the medical technician, the social worker, the dietitian, or the patient's family.

In the above scenario, push technology could have shared the appropriate information with us, the patient's family, when we needed it without our having to contact a plethora of caretakers to acquire it. It could, I believe, have increased our sense of inclusion, and minimized our out-of-control feelings and sense of powerlessness. Many times, I felt I had to relinquish a greater part of the decision-making responsibility to someone else, albeit a knowledgeable someone else, and despite knowing this I nevertheless felt totally responsible for a decision over which I had marginal control.

The world of business has long ago adopted the concept of push technology to its advantage. I believe that we can do the same in the patient care world, and in so doing revitalize hope for our loved ones and also for us. **D&T**