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LESSONS FOR DOCTORS AND PATIENTS: THE LAST COLLABORATION*

Millie Niss was a talented young woman. Trained at the graduate level in mathematics and fine arts, and a widely published Web artist (<http://www.sporkworld.org>), she suffered from Behcet's disease, a disorder of unknown cause which can produce blisters and sores in many areas of the body as well as inflammation in the joints and brain. She also suffered greatly from the effects of the medication she required, which produced immune suppression with consequent susceptibility to infection; massive weight gain with consequent joint pain and movement difficulty; osteoporosis (loss of bone substance) with consequent fragility of bone; and the negative cultural stereotyping associated with increased body size. In 2009 she died of a staphylococcal infection which originated in an intravenous tube and spread to her spine, where it caused a paralysis that was mistakenly assumed to be due to the underlying Behcet's disease. She was 36 years old.

Martha Deed, Millie's mother, has created a collage in book form that brings alive her daughter and the circumstances around her ultimately fatal illnesses. Constructed from poems, photos, emails, notebook diaries, medical records, and the documents of state regulatory agencies, the collage has an effect that is at once compelling, infuriating, and saddening. Difficult to read yet hard to put down, it is a memoir that is both a work of art and a textbook, filled with lessons for patients, caregivers and students of contemporary health care systems.

As I read, I was especially struck by the complex network of communications perceptively described by Deed, and the misperceptions and misunderstandings that resulted. Deed writes, for example, of conversations in the ICU (p. 80):

At least four levels of conversation are happening in the ICU. Each one has its own authority: The medical staff have their own agendas. These require minimal consent from either the patient or her family.

Next, the patient's conversation with staff. She creates a persona, "persona" because she expresses only the aspects of herself she cares to reveal.

Moving outward, there is the conversation between the patient and her family. Since her mother is her advocate she [the patient] emphasizes dissatisfactions and tasks in her communications. There is little room for friendship, sharing of interests, because time is short—and the patient's energies are limited. Advocacy distorts their relationship.

This can lead to misperceptions by staff that Mother is disturbing patient. In fact patient is saving her unhappiness to direct Mother to "fix" it.

Mother is left with impression that patient is more distressed than patient appears to others.

And finally — in this case — there is the face the patient wishes to show the world.

Distrust and frustration can and did result from the failure to communicate authentically. Deed provides an example (p. 117), in her notes of a meeting between her and a patient representative who commented repeatedly about Millie's "agitation," but failed to act when provided with the information that Millie was receiving Ativan, a drug that was known from prior experience, paradoxically, to cause agitation in her. As Deed accurately perceived, the "patient representative" actually "represented the hospital, not patients."

I discuss the book with my wife, who comments that the relationship of patients and physicians "shouldn't be a war in which the patients are guerrilla fighters resisting an invading army." I agree, and yet I remember when, as she was recuperating from an operation, she and the other three patients in her hospital room allied themselves to stop any nurse entering with a medication to ask what it was and for whom it was intended. Twenty years ago that "guerrilla resistance" successfully prevented several medication errors. Today, hospital accrediting organizations encourage hospitals to teach their patients to ask such questions and to teach their staffs to expect such assertiveness. Deed's book documents that additional movement is needed on the part of medical institutions and practitioners, to fully shift the paradigm from viewing assertiveness as adversarial to viewing it as partnership.

Believing that there are valuable learnings to be found in its text, I share the book with four advanced trainees and schedule some time to discuss it. One of the four clearly gets the message that prejudice, stereotyping and callousness adversely shaped many of the relationships between Millie and members of her health care team. The other three seem uncertain about why we are discussing communication rather than reviewing more recent technical advances in our discipline. I had hoped for more.

In 1910, the Flexner Report started a revolution in medical education by calling for reform that would make it academically equivalent to graduate education in science. Sixteen years later, in 1926, Francis Peabody, a physician at Harvard, gave a talk to the medical students there entitled "The Care of the Patient." In that lecture, most famous for its concluding aphorism that "The secret of the care of the patient is in caring for the patient," Peabody stated his belief that creating a personal relationship with patients was essential for correct and complete diagnosis, clinical effectiveness, and personal satisfaction as a physician. As he put it, "What is spoken of as a 'clinical picture' is not just a photograph of a sick man in bed; it is an impressionistic painting of the patient surrounded by his home, his work, his relations, his friends, his joys, sorrows, hopes and fears. Now all of this background of sickness which bears so strongly on the symptomatology is liable to be lost

sight of in the hospital..." These observations, made over 85 years ago, have particular relevance to the care of Millie Niss, who, as the book makes clear, was never viewed in such a holistic frame during her last illness.

Authenticity in communication, mutual trust, and a painstaking scientific approach to diagnosis and treatment cannot guarantee a good medical outcome, but their presence is essential to assuring the best one possible. *The Last Collaboration* describes a sequence of events that might have been altered at many points in its course by their presence.

A good friend of mine describes her own communication with her physician quite differently from the complex model above. My friend sees their relationship as an "equal partnership" to which the physician brings her specialized skills and knowledge while my friend, as patient, brings her expertise about her own body and circumstances. Not by coincidence, both my African American friend and her white, Jewish physician are experienced in the practice of a particular model of interaction, the Be Present Empowerment Model. My friend is committed to speaking and listening with an awareness of those prejudices and emotional reactions which she has developed as a result of her past life experience and yet doing so from a place in her spirit that is aware of her own prejudices and reactions and yet is apart from and unaffected by them. Her physician is committed to hearing her while holding the same self-awareness. They agree to focus on the current moment in which they are both present to each other and to recognize and honor each other's essential humanity. For each, this approach is not limited to the context of medical care but is a perspective and practice that carries into all aspects of her life.

These two conceptualizations of the communication between patient and practitioner are grounded in two different visions of the world. The first, self-protective, results from experiencing the world as imperfect, impersonal, and dangerous. The second grows from a vision of how we would like the world to be. If we, both patients and health professionals, want our relationships to have the authenticity that fosters mutual trust and clarity of communication, then we will need to commit ourselves to learning and practicing the tools that can change us into the people we want to be and our society into the one in which we want to live.

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The Last Collaboration is available from Amazon.com

See also <http://www.sporkworld.org/Deed/tlc.html>