
ESSAYS/PERSONAL REFLECTIONS

Thoughts from an old clinician: The well-intentioned stewards of the sword of Damocles

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As a group, we are in the vast majority people of good will, kindness, and skills that benefit other human beings—healers. We sometimes overestimate our powers and underestimate the impact of our words. After more than four decades of practice, I continue to be surprised about and in awe of the force of the impact that our words have on patients and patient-recovery outcomes. We are all in danger of developing a script of routine responses, which to the patient takes on the proportions of a well-crafted pronouncement made by a “near-deity.”

The language we employ to communicate with patients and how we categorize them are so essential that it offers a therapeutic bonus or therapeutic threat regardless of what stage of illness or injury exists in the patient’s life.

Early in my career, I witnessed a massive display of the power of words—not our words, but the words of a voodoo doctor. I was working as a clinician in the acute intake unit of a massive 2000-bed state mental hospital, which did exist in those days—unfortunately. The words spoken were lethal. The patient was a 24-year-old woman with an unremarkable medical history and an equally unremarkable psychiatric history. She did not move a muscle but lay totally prone on the gurney. She was admitted to the intensive care unit and died on the sixth day after admission. Not surprisingly, the result of her postmortem was that no remarkable pathology was found and that the cause of death was unknown.

I took three lessons from this experience: (1) never offend a voodoo doctor, (2) the words of an authority figure can be so powerful for a patient as to cause death or disruption of the recovery process, and, inadvertently, (3) clinicians can cause great harm with words that are not well chosen and evidence based.

A good many years ago, I was on the staff of a faith-based community hospital. The hospital was unevenly divided into two parts. The “new wing,” which by my time was just over 30 years old, and the “charity annex.” The new wing was air-conditioned, had double or private rooms, was staffed by the patient’s private physicians, and had an ICU.

The charity annex was situated between the staff elevator and the cafeteria, requiring staff to pass through the annex to reach the cafeteria at all times of the day or night. I am ever ready for a conversation, which led me to know virtually all the patients housed in the annex. I became especially friendly with a large, powerful farmer who had a work-related accident that resulted in a fractured hip. Though past 80, he was recovering well from the surgery and the often-fatal anesthesia associated with it. One source of intrigue with him was that he was an “Arkansas badlands” farmer from Dyess, Arkansas, the home of Johnny Cash’s father and the childhood home of the Man in Black himself. That was as close as I had come to a celebrity, so I was definitely captivated.

On one occasion, I saw a large crowd standing around the farmer’s bed—never a good sign. I asked the charge nurse what was happening. She quite irritably said, “Can’t you see that he’s going?” More confused, I asked where he was going. With even greater exasperation, she said, “He is going to his reward.”

When I could break through the crowd and got to see him, I saw a mildly cyanotic man having some difficulty with breathing who was obviously agitated. He clearly was in distress but did not look like the traditional dying patient that I had experience with. Some intervention seemed called for.

With help, we sat him upright. I put my hand in his mouth and dislodged a large hunk of half-chewed food. He began breathing better and his color began to pink up. While attempting to work on him, the two men from the morgue with their stretcher arrived to take the corpse. The ward secretary was furious with us, as she had rearranged the chart to meet

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the morgue protocol, and now she would need to reverse the process.

Why the staff responded to him in this manner was a question for me to ruminate on for a while. I decided that the problem was that he belonged to many groups, some assigned and some inherited, with each having its preassigned rules. In his case, none of the groups of which he was a member worked to his advantage in receiving thoughtful, energetic, and appropriate medical intervention. The groups to which he belonged were: the elderly, the poor, the poorly educated, and those in need of nursing care. He was also large, had a loud voice that was frightening to some of the staff, and from time to time practiced questionable hygiene. Each group membership by itself could be sufficient to reduce the quality of care he received. I do not think that the assignment of values to groups was for the most part conscious, but this process was nevertheless operating powerfully. The farmer's life would have been significantly less in jeopardy if he had been a well-manicured hedge fund manager in a private room on the "new wing." The greatest damage done to many patients is caused by the words we use to describe them *in our own minds*.

I know that assignment to a group can negatively impact patient care. Diagnostic groups are among the most dangerous, as they profess to scientifically tell us something that may or may not fit snugly with the patient's identity and may represent only one dimension of that person's complex makeup.

For the most part, the clinician sets the rules for how the illness "game" is to be played. Whether the ill person conducts their life in a restrictive or expansive manner is to a large extent in our hands. Most people strive to achieve what is expected of them—not all, but most. What I have seen is that, when in a new situation—an illness, disability, at the end of life (surely unique situations)—most take their cue from those in authority around them.

I am profoundly aware that the course of my life for many months was governed by a clinical misstatement, which was, "YOU ARE PARALYZED. Accept your limits."

During the Vietnam experiment I was the pilot of a small Forward Air Control aircraft. Someone in maintaining the aircraft, ahead of me waiting to take off had overfilled the fuel system with jet fuel. Jet fuel is highly combustible at a fairly low temperature. The flash point, the spontaneous combustion point, is approximately 100 °F. Usually on the tarmac in Vietnam mid day, the temperature reaches about 120 °F. The fuel exploded, the other pilots were killed, and I reached consciousness four months later in an Air Force Hospital.

I cannot believe that there ever existed a more naive, concrete, non-communicating, question-averse person who had an almost holy belief in the chain of command than the 21-year-old version of myself.

What I was told I was, and who in essence I became, was a permanently disabled person who would never walk again. I believed them. Would I ever question them? I began conducting my life and my beliefs about my future accordingly. The result was that I decided to do nothing and embraced the new reality that I would always do nothing until I died, whenever that was to be.

Had it not been for another accident, I would have continued shrinking my life indefinitely, as I thought the situation demanded. One day I fell out of bed. I was not hurt. Startled, I got up from the floor and scrambled back into bed.

Continuing my highly developed skill of being clueless, the event passed me by with no flashing lights or alarms going off, and I went back to sleep. My real luck was that the airman in the next bed had witnessed my fall and thought it noteworthy. When the corpsman made his next rounds, my ward-mate said, "You should have seen Strauss when he fell out of the bed and then stood up to get back to the bed." He went on to say that he did not know that paralyzed people could do that. Though my treatment regimen immediately changed, it took me many months to stop thinking of myself as a totally disabled and paralyzed person.

The problem was not the diagnosis, which I think was accurate within the state of the art, but the labeling of me as a disabled person with little future potential. The problem was that this diagnosis was not revisited, something that proved extremely harmful for me.

Living and Dying at Murray Manor (Gubrium, 1975), a study of aging, documented the problem that exists at the end of life for patients who rally and do not die or those who do not die on cue, who become alienated from their families when they do not die within what is expected to be a normal timeframe. They do not meet our expectations in terms of the dying process.

When a patient tells me that they are now in hospice care, it is a powerful role assignment that dictates much of what people will do when they are waiting to die. The clinician's proclamation of a person's role is so far reaching as to define the framework within which a person is to die and the timeframe in which things are supposed to take place.

A patient who I have seen over a number of months with end-of-life issues returned to see me after an absence of several weeks. This woman was remarkable in her investment and participation in change-oriented

work in the face of her predicted limited lifespan. She had an acceptance of her prognosis intertwined with a lifelong belief that positive change is possible until the last moment of consciousness. One of her unselfconscious remarks to me was that the immediate prospect of death offered her an unprecedented opportunity for growth and change.

When she did return after several weeks, she was in a jubilant frame of mind: "The governor has called at the eleventh hour with a stay of execution." She told me that her loving, supportive, attentive, protective, and committed family, her physician, her dear friends, and her long-term pastor had launched three well-coordinated campaigns to relocate her in a hospice. She successfully resisted three efforts, which explained her opening remark of "the governor has called at the eleventh hour," marking her successful avoidance of assignment to hospice care.

She skillfully evaded the term "hospice" and referred to the facility as "you know, those places where pitiful hopeless people are sent to die," or the "Dickensian death house," or whimsically, the "roach motel" (a reference to a commercial for roach traps where cockroaches check in, but they don't check out).

The service that I provided most often was a forum in which her thoughts could be discussed. The most tangible service I provided was as a buffer between the patient and her family, physician, friends, and pastor—all of whom saw me at best as an evil and misguided person who was colluding with the patient to take a stand against her own best interests.

While all this hospice conflict was taking place, she continued to utilize cognitive behavioral therapy to "tidy up" old issues and improve her "real-time" functioning.

Several months later, her daughter called to let me know that she had died in her own bed with her three elderly cats in attendance.

Once a person is designated as a person in the last stages of life or as a "hospice patient," or even given the old-fashioned classification of "dying," their social environment—with its former rights, responsibilities, privileges, and independence—which had been constructed over the course of a lifetime, is in jeopardy of experiencing significant unplanned alteration.

People given an end-of-life status are almost always viewed as less capable by others in their environment than was the case before they were designated as members of the "end-of-life" class. People in this group often cease to be viewed as fully functioning individuals and take on the status of a "project," for which the end-of-life individual is not the chair of the planning committee. They often do not even have a seat at the table where decision are made. So no seat, no vote, and little to no self-determination. In this process, there appear to be few vil-

lains, but mostly people trying to be empathic, helpful, and compassionate to a fellow human, often one they love.

In today's milieu, people are purposefully insulated from the dying process. Television, movies, and video games offer a variety of incorrect information and distorted images of dying.

When I was a child in the Deep South of the 1940s, the entire extended family (including the children) were involved in the dying process. Family members died at home and remained in the parlor until the ground could be prepared for the burial. The family gathered, sat shiva, and recited the Kad-dish. We then returned to everyday life, and death was experienced as normal, and as natural as the coming of spring.

I was once part of an event that illustrates the continued human potential for experiencing life when membership in the group of the dying is disregarded in favor of life as usual.

My grandfather was a farmer, a shoket, and a mohel. He was a large man who had fathered 15 daughters and a son. I was the youngest of 17 children born to my grandfather's only male child.

My grandfather was an ardent fan of the St. Louis Cardinals baseball team, and he loved to listen to the colorful broadcasts of Dizzy Dean. From time to time, he took the overnight train to see his team play in person. When I was 12, he invited me to accompany him on one of these trips.

The day before we were to leave, a number of my 15 aunts attempted to persuade him not to make the trip in the heat of summer. They had no chance of changing his mind, but all held fast to that course. The discussion went on until my aunt Nettie said, "Papa, you can't go. You are too old, and something might happen to you." He responded, "You say that I am too old to live my life as I see fit because something might happen to me? I am over 100 years of age and have lived more than my share. Nothing can happen to me. I will be the safest person in St. Louis." Four years later—aged 104—he passed away when his tractor fell on him while plowing the fields, something he loved to do. His death was a great sadness for me, but definitely not a tragedy. He refused to accept the invitation to join the group of the elderly or take on the attributes of that group.

Over the years, I have worked with seven patients who have been destroyed by Lou Gehrig's disease. Months before we reached endstage, the patient and I, joined by anyone invited by the patient, would create a list of topics, events, memories, beliefs, and any subjects deemed important or of interest to the patient. When the patient was no longer able to communicate or make their selection known, the list served as a template for our meetings.

What do I know about the impact of these sessions? Absolutely nothing. Are they useful in any conventional sense? Again, I do not know. What I believe, with no evidence to support such belief, is that these sessions serve to support the suffering patient and make it possible for them to remain a person of worth and not be disregarded or discounted in their silent struggle.

I have learned that predicting when a person will die, regardless of an identifiable disease process, is neither art nor science. It is more closely akin to betting on a sporting event. My father-in-law was a country doctor and a combat veteran of World War II. He was elected mayor of his town many times, and he was one who raised and lowered the American flag daily. On the day I want to tell you about, "Doc" was in the final stages of dying from pancreatic cancer. It was summer in West Tennessee, with the full intensity of the heat of a Southern summer bearing down on us.

Early in the day, he roused and asked what day it was. He was told that it was Sunday. "No damn it. What day is it?" he asked intensely. After a puzzled silence, it dawned on us that he wanted to know the calendar date, not the day of the week. He was told that today was the Fourth of July. This seemed to satisfy him, and he went back to sleep.

Several times during the day he wanted to know if it was storming yet. It seemed a strange question, as no clouds were visible in the sky.

Late in the afternoon, seemingly out of nowhere, a dark cloud appeared, bringing with it a violent thunderstorm.

With the appearance of the storm, he smiled, squeezed the hands of his daughters, and took his last breath. It appeared that he had been waiting for the storm to make his departure. I always like to say, with a melodramatic flourish, that the storm came for him, and he left with it.

Fifteen minutes later, as with most summer storms, the clouds had totally disappeared and the sky was again blue and cloudless.

I can draw no conclusions from the manner of his dying, but I can only use it as an illustration of the unique mysteries of the dying process.

My goal for those in the last stages of dying is beautifully stated in William Cullen Bryant's poem, *Thanatopsis*:

So live, that when thy summons comes to join
The innumerable caravan, which moves
To that mysterious realm, where each shall take
His chamber in the silent halls of death,
Thou go not, like the quarry-slave at night,
Scourged to his dungeon, but, sustained and soothed
By an unfaltering trust, approach thy grave
Like one who wraps the drapery of his couch
About him, and lies down to pleasant dreams. (Bryant, 1900)

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