Patient–Doctor

On a recent visit to New York City, as I was taking a 15-block walk in midtown Manhattan, I was thinking about how fortunate I have been. In 1998 I underwent a transluminal coronary angioplasty with stent placement and subsequently I received anticoagulant therapy, which resulted in painless hematuria. This led to the discovery of renal-cell carcinoma, for which I had a radical nephrectomy. This experience has prompted me to share with you my perspective as a patient for 44 years, now facing the added uncertainty that a cancer patient has to live with.

You see, I have had arthritis since age 12, and my physician at the time, the chief of orthopedic surgery at the local university hospital, treated me with frequent bed rests and hospitalizations. There were no rheumatologists in Pakistan in those days. He at one point prescribed 1 full year of antituberculous treatment (streptomycin injections, isoniazid, and para-aminosalicylic acid), without any resultant clinical benefit. Later on, he treated me intravenously with honey imported from West Germany. By then I was 16 years old and had just become a medical student.

Two years later, during my first clinical rotation in medical school, I spoke to my teacher, a professor in the department of medicine, about my symptoms. He examined me and diagnosed my disease as ankylosing spondylitis. It primarily involved my back, hip joints, and, to a lesser extent, my neck and shoulders. He prescribed phenylbutazone, a nonsteroidal anti-inflammatory drug, to relieve my pain and stiffness, and it worked effectively.

Soon after I graduated from medical school in 1965, when I was 21, Pakistan was attacked by its neighbor, and I decided to enlist in the Pakistan Army Medical Corps. In my zeal to serve the nation in its hour of need—a nation that had accepted me as a 3-year-old refugee and had provided me with almost free medical education—I did not reveal my illness. My service in the Pakistani Armed Forces was a great experience.

In 1967, when I had just left the army, I received a call for assistance from the very professor from medical school who had diagnosed my ankylosing spondylitis. This professor wanted me to treat his best friend, a prominent local businessman, who had just experienced an acute myocardial infarction. I provided the necessary care, including, later that day, successfully resuscitating the patient when he experienced cardiac arrest. (He would go on to live for another 28 years and help build a hospital for the needy, but that is another story entirely.)

I arrived in London in the summer of 1967 to begin my postgraduate medical studies—despite my arthritis, which never ceased to plague me—in an effort to pursue my goal of an academic career in medicine. Cardiology was my initial choice for a medical subspecialty, but I felt that the anticipated progressive decrease of my spinal mobility, as well as having limited chest expansion due to my ankylosing spondylitis, might one day impair my ability to resuscitate patients. During the required 1 year of residency training, I chose orthopedics as my surgical elective. While assisting the surgeons in various orthopedic procedures, including total hip arthroplasty, I was keenly aware that the tables would someday be turned and I would be the one at the receiving end of the operation.

I came to the United States in the summer of 1969 and have successfully pursued an academic career in rheumatology. Knowing what it feels like to be an arthritis sufferer, and therefore having a special empathy for patients with this condition, my choice of subspecialty was an easy one to make. Not surprisingly, my primary research interests have included ankylosing spondylitis and related spondyloarthropathies, along with the associated genetic marker HLA-B27.

Inevitably, the tables did turn, and I experienced the following: bilateral total hip joint replacement; revision hip arthroplasty; fracture of the cervical spine; nonunion of the fracture, despite 5 months of wearing a halo with vest immobilization; surgical fusion of the fracture and another 3 months of immobilization; recurrent episodes of acute anterior uveitis; hypertension and coronary artery disease; coronary transluminal balloon angioplasties on three separate occasions; and, most recently, right radical nephrectomy. Perhaps you will agree that my many encounters as a patient serve as sufficient "qualifications," if we can call them that, to assert my own viewpoint. I am very grateful to modern medicine for keeping me going. In some ways, I consider myself a "bionic man." My ankylosing spondylitis, however, has resulted in a complete fusion of my whole spine, including the neck. I cannot turn or even nod my head, and I have to bend at my hip joints to give an impression of a nod. I need to grab onto something to pull myself up from a squatting position. I have virtually no

chest expansion. One can imagine what might happen to me if I were to have the misfortune of being in an accident or needing cardiac resuscitation; the probability would be high that, inadvertently, my death would be hastened because of a possible neck fracture or broken ribs.

Although I have always sought the best care possible for myself, I have been unlucky on many occasions in not receiving optimum medical care. However, being a perpetual optimist, I am thankful that I am still alive. I sometimes like to give the analogy of the old Timex watch commercial, because I keep on ticking. But if my personal experiences as a patient were extrapolated to the population at large, they would unfortunately highlight many deficiencies in the current practices of medicine, even here in the United States: the unreceptive receptionists, the allied health professionals who lack empathy for their "clients," and the physicians for whom time is such a precious commodity that they start looking at their wrist watches just minutes into the history-taking to signal their impatience.

We physicians frequently do not acquire the skills of a good communicator, and we often neglect patient education. The word "doctor," as I understand it, means an educator or communicator. Yet some physicians apparently lack the traits required to be a good communicator, and some claim that they simply have no time for it, anyway. In such situations, an allied health professional, such as a nurse practitioner, could better handle communications with the patients. Better physician–patient communication is certainly needed.

I underwent bilateral hip arthroplasty as a single surgical procedure at a hospital that specializes in such surgeries. A few years later, I had to undergo a revision hip arthroplasty. Before I left the hospital, I noticed that one leg was now shorter than the other by about a half inch, but my surgeon would not acknowledge this. I still, to this day, wear a shoe lift to minimize my limp.

My first transluminal coronary angioplasty resulted in an extensive intimal tear. When I subsequently had restenosis of the involved artery, I was advised by an independent consultant to have a stent inserted at the time of the revision angioplasty. I had my second angioplasty performed at a highly rated medical center and, although I had requested a stent placement, none was given, and my angina symptoms recurred shortly thereafter.

When I fractured my neck, I was treated with the placement of a halo and a vest to immobilize the fracture. I pointed out to my surgeon on numerous occasions that the fracture was not fully immobilized, as was most noticeable when I leaned back or tried to lie on my back. I voiced my concern that the back plate of the vest was not properly conforming to my thoracic kyphosis, but the surgeon repeatedly reassured me that everything was fine. I had to sleep sitting upright. After 3 months, a radiograph revealed nonunion of the fracture. Subsequently, the vest was changed, but precious time had already been wasted; because months of further immobilization did not heal the fracture, I ultimately needed a surgical fusion.

I have never sued anyone. My forgiving and nonlitigious nature tells me that as patients we should always give our physicians the benefit of the doubt, just as we physicians, likewise, should always show respect for our patients and give them some degree of latitude. But in our current health care system, there is an obvious need for a more open dialogue between physicians and their patients.

During the 7-month period in which I wore a halo that was screwed into my skull and attached to a vest that surrounded my chest (just imagine trying to sleep at night wearing all that hardware!), I continued to care for my patients. I found myself in ever greater awe at the power we, as physicians, hold as healers. On one occasion, a new patient came to see me, and after our initial handshake, I noticed that his face was turning pale. I immediately had him lie down on the examination table just before he fainted. When he felt better the patient started to laugh, and said, "Doc, I had been hurting and waiting to see you for 2 weeks, but with one look at you all my pains are gone!"

One morning, a few days later, I was walking by the emergency room on my way to the office and had not yet donned my white coat. A young child noticed my halo and asked, "What happened?"

"I had an accident," I replied.

Having surmised that I was en route to the emergency room for acute medical attention, the child inquired, "Is that the steering wheel of your car that is stuck around your head?"

I have enjoyed every bit of my life, with all its humor, hardships, hurdles, and dramatics that could even appeal to the Hollywood movie moguls. And I continue to enjoy my walks. After all, my doctor has instructed me to get daily exercise.

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