

## Paint the Ceiling: Reflections on Illness

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### CASE HISTORY

I think the symptoms first began when I bent over to adjust the backyard sprinkler head. I was distinctly uncomfortable, unable to get enough air, or so it felt; as if my belt were cinched too tight, or my pants too small. But I persisted in squatting and adjusting the sprinkler until the tiny bright lights started to explode in my head, reminiscent of a 4th of July sparkler, and I found myself sitting on the wet ground, dizzy and confused. "Wow. I really do have to lose some weight," I thought.

About a month later I was trying to keep up with a small group of surgery residents as we jogged in the morning and prepared for a short race, a ritual of a professional society meeting. I couldn't do it. I couldn't keep up. I couldn't finish the race. My legs didn't really burn, and neither did my lungs. This was not from overuse or from too strenuous use. This felt different; I just couldn't do it. "Wow. I really do need to exercise more," I thought.

Another month went by, and finally it was time for a long-awaited week of summer vacation at a lake resort. My family had gone to this particular vacation spot in the past, and we were really looking forward to time away. "Maybe the rest will help," I thought as I packed the car. I sure was feeling tired a lot. But this sinus headache just wouldn't go away. I was starting to sleep on two or three pillows, because I couldn't lay flat without my head feeling like an over-filled balloon. Maybe decongestants would help. Aspirin and Motrin for the frequent headaches. Maybe I should start some antibiotics. I couldn't exercise at all. Just too tired. I nearly passed out once again trying to fill the kids' air mattress. "Wow. Shouldn't have a beer in the hot summer sun," I thought. You would have thought I would have caught on by now. But no.

It finally dawned on me in September. My wife and I had flown to Minneapolis to attend a friend's wedding. Dressing in the hotel, I started muttering to myself. "This shirt is too small," I muttered. I couldn't button the top button, so I complained that I'd have to look like a dwebe at this wedding of old friends and past classmates, with a big knot in my tie all cinched up tight to hide the open collar. Mumble, grumble, and more muttering.

But then I really looked in the mirror, and the swollen face



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was now so apparent, so clear, so obvious. A fleeting moment of satisfaction at finally knowing that there was actually a reason I had been feeling badly was replaced with a deep hollow sense of dread. A realization that this was serious, and not easily treatable. I, and my family, were in trouble. But then confusion. I wonder what I should do about it? Who should I see? Should I go to an ER here in Minneapolis? Call someone at the University? Fly home to Seattle now? I'm on call in 2 days; who can take my call?

Unresolved, we spent 2 days in Minneapolis as planned, visiting family, friends, and even attending the state fair. I sure didn't feel well. When we flew home we went straight from the airport to the hospital, where I got a "stealth" chest x-ray film taken. You know, one of those films that are unlabeled, and unregistered—a favor chit cashed in with the on-call radiologist and technician (Fig. 1).

When the film came out of the developer, and into my hands, I hesitated. Maybe I'm not reading this right. "What do you think, radiology resident?," I asked. The look in his eyes, the stutter in his voice, told much more than his spoken

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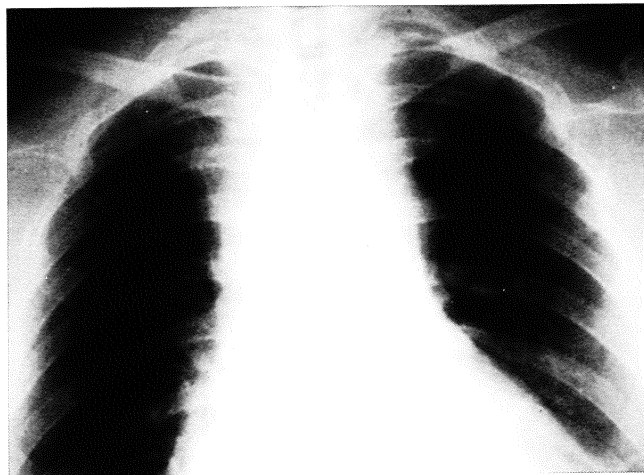


FIG 1. Presenting chest radiograph showing upper mediastinal.

words: "Well, ah, that's a mediastinal mass, Dr. Jurkovich. Ah, well, it could be many things, but yes, that's true sir, the most likely thing is a tumor. Yes, lymphoma."

### LYMPHOMA

Non-Hodgkin's lymphoma (NHL) is the seventh most common cause of cancer deaths, with 41,000 new cases per year, and 19,500 deaths per year. There has been a 75% increase in the incidence of this malignancy since 1973, in part due to the fact that about 3% of HIV-positive patients get NHL, although this does not account for this dramatic increase in incidence. The average age of patients presenting with non-Hodgkin's lymphoma is 42, exactly my age at time of presentation. There is a male predominance of this cancer (16.6 vs. 11.2 per 100,000), and whites are about twice as likely to have the cancer than non-whites.<sup>1</sup>

Primary sites of lymphocyte production are the bone marrow and the thymus. Secondary lymphoid organs are lymph nodes, the spleen, the oropharyngeal lymphoid tissue (Waldeyer's ring), and the gut or mucosa lining lymphoid tissue (MALT or GALT tissues). Lymphocytes are currently classified as T cells or B cells. B cells react to antigen presentation by the production of polyclonal immunoglobulins that contain both light and heavy chains. In contrast, B-cell lymphomas are monoclonal, usually containing single light chains. Classification of the cell surface markers (antigens) that differentiate lymphocytes was made possible by the development of a technique to produce large quantities of monoclonal antibody of a predefined specificity.<sup>2</sup> There are currently well over 50 antigenic markers expressed on lymphoid and hematopoietic cells known as "clusters of differentiation," or "CD." T cells and B cells, and their function, can be distinguished by these markers. For example, the helper/inducer T cells express CD-4, whereas the suppressor/cytotoxic T cells express CD-8.

The history of current medical understanding of lymphoma and leukemia's probably begins in 1845, when leukemia was first described. In that same year, Virchow made the significant distinction of leukemia from lymphosarcoma. The surgeon Billroth coined the phrase "malignant lymphoma" in

TABLE 1. Working formulation classification of nonHodgkin's lymphoma

Low Grade	Intermediate Grade	High Grade
Small lymphocytic	Follicular large cell	Diffuse small noncleaved Lymphoblastic
Follicular small cleaved cell	Diffuse mixed cell	Immunoblastic (large cell)
Follicular mixed cell	Diffuse large cell	
	Diffuse, small cleaved	

1871, but it wasn't until 1942 that criteria were established for distinguishing follicular hyperplasia from lymphoma. A major step in understanding lymphomas came with a widely accepted pathologic classification system developed by Rappaport in 1966, which largely classified non-Hodgkin's lymphomas into nodular, diffuse, or mixed groupings. This classification system has been modified several times, most notably by the National Cancer Institute in 1982 (the "Working Formulation"), and by a 1994 European-American consensus group (the "Revised Euro-American Classification of Lymphoma—REAL") (see Table 1).<sup>3,4</sup>

Non-Hodgkin's lymphomas are generally classified as one of three grades: low grade or indolent; intermediate grade or aggressive; and high grade. Without treatment, the expected survival of high-grade lymphomas is measured in weeks (36–67 weeks median survival), and for intermediate grade lymphomas median survival is measured in months (18–36 months median survival). Low-grade lymphomas are not curable with conventional chemotherapy or radiotherapy techniques, but median survival is measured in years, ranging for 5 to 7 years.<sup>1,4,5</sup> Although this classification system is useful for most patients, a number of subtypes of non-Hodgkin's lymphomas defy easy classification and present problems to both pathologists and oncologists in recommending treatments.

The cause of lymphoma remains enigmatic. There is evidence supporting a range of diverse etiologic agents including hereditary factors, environmental exposure, immunosuppression, viral causes, and chromosomal abnormalities.<sup>1</sup> Patients with inherited immunologic deficiency diseases such as Sjogren's, collagen vascular disease, and lupus are more prone to developing lymphoma. Transplant patients have a high incidence of lymphoma, primarily B-cell variety (85%), which seems more likely to occur with OKT3 immunosuppression and cyclosporine than with azathioprine or steroids. One of the most interesting observations of lymphoma incidence is a two- to fivefold increase in incidence in Midwestern farmers who have been exposed to phenoxy herbicides and pesticides and a 50% increase incidence in Vietnam War veterans. Although "agent orange" defoliant has been implicated (a 1:1 mix of di- and tri-chlorophenoxyacetic acid), the increased incidence has primarily been noted in Navy veterans. There is also an unexplained fourfold increase in incidence of lymphoma in U.S. flour mill workers.

The link between lymphoma and viral invasion is clear. The Epstein-Barr (EB) virus association with lymphoma is strong: in 98% of endemic cases of Burkitt's lymphoma, in most organ-transplant related lymphomas, and in 50% of

HIV-positive patients with lymphoma the EB virus can be detected. Many animal lymphomas are known to be viral caused, and in 1987 Poiesz' group demonstrated that adult T-cell leukemia-lymphoma was due to the HTLV-1 RNA tumor retrovirus.<sup>6</sup> Although the exact mechanism is unclear, it is felt that the viral invasion immortalizes lymphoid cell lines and predisposes to a second, carcinogenic event.

The best known association of chromosomal abnormality and lymphoma is the translocation of the BCL-2 gene (B-cell leukemia-lymphoma-2 gene) from chromosome 18 to the immunoglobulin heavy chain joining region on chromosome 14 (t14:18 translocation).<sup>7</sup> The result is a hybrid mRNA coding for BCL-2 protein productions that blocks apoptosis of B-cell lymphoma lines, thereby allowing unchecked and immortalized single B-cell line production. This t14:18 translocation is found in 85% of follicular lymphomas and in as many as 35% of diffuse large cell lymphomas and can serve as a sensitive indicator of minimal residual disease.

**MEDICAL CARE**

The frozen section pathologic examination of lymphoid tumors is often inadequate, and my personal case was no exception. The frozen section biopsy obtained by mediastinoscopy was initially interpreted as "malignant neoplasm, mixed cell type, probably lymphoma, favor Hodgkin's." This was good news, since Hodgkin's lymphoma has about a 90% cure rate. However, a day later, the permanent section evaluation returned, changing my and my families sense of some relief into concern and confusion, because the diagnosis was now "diffuse, large cell lymphoma, non-Hodgkin's." Surface antigen analysis revealed 83% CD19 and 61% CD20 positive cells, with 16% of the cells CD19-/CD5+ (T-cell marker); there were no surface immunoglobulin; 70% of the cells were MiB-1 marker positive; the CD4:CD8 ratio was 22:19. Clonal studies included Southern blot, which was positive for a B-cell population (confirming histology), but the tumor did not contain the t14:18 translocation.

The prognosis was now somewhat more cloudy, particularly because the immune cytochemistry tests were "most consistent with diffuse large B-cell lymphoma, but could be consistent with primary mediastinal B-cell lymphoma." The pathologist went on to say that "preliminary reports suggest that this entity does not respond as readily to therapy." The confusing nomenclature, and difficulty in matching classification of lymphoma to best treatment options remains a major problem in certain lymphomas. Whereas immune cytochemistry has helped with many of the past difficulties in classifying cancers of the hematopoietic system, it has not resolved all the difficulties with classifying these cancers. This tumor appears to have a 5-year survival rate of 65-75%, with improved chance for cure in those patients in whom the tumor was limited in size and extent (<10 cm, no pleural effusion, no bone marrow disease), and in those who receive more than 80% of the projected chemotherapeutic dose.<sup>8,9</sup>

The final pathologic diagnosis of my mediastinal tumor was mediastinal lymphoma, probably large B-cell, diffuse type (intermediate grade). I had no systemic symptoms, no

**TABLE 2. Details of initial hospitalization charges<sup>a</sup>**

Hospital Charges		Physician Charges	
CT scans	\$3,002	2 Surgeons	\$ 925
Supplies & IV	\$2,721	1 Anesthesiologist	\$ 826
Pharmacy	\$2,349	3 Oncologists	\$ 522
Radiation therapy	\$2,204	4 Radiologists	\$ 676
Daily	\$2,176	2 Radiation oncologist	\$1,232
OR room	\$1,746		
Laboratory	\$1,576	Others <sup>b</sup>	\$1,254
Pathology	\$ 650		
Anesthesia	\$ 525		
Recovery room	\$ 454		

<sup>a</sup> CT, computed tomographic; IV, intravenous fluids; OR, operating room.

<sup>b</sup> Includes lab medicine, general medicine, pulmonology, and one unknown physician.

pleural fluid, a bone marrow biopsy was normal, and there was no evidence of nodal involvement elsewhere in the body. Emergency radiation therapy (400 rads) was begun before the final pathologic diagnosis was known for immediate relief of my superior vena cava occlusion symptoms. A 6-cycle course (18 weeks) of chemotherapy was recommended, utilizing cyclophosphamide (Cytosan), hydroxyl-daunorubicin (Adriamycin), vincristine (Oncovin), and prednisone (CHOP). I received granulocyte colony stimulating factor (G-CSF) between courses of chemotherapy to boost white cell recovery and prevent infection. After chemotherapy, I underwent peripheral stem cell harvesting for cryostorage in anticipation of possible tumor recurrence, which would require chemoablative therapy and bone marrow reconstitution. Radiation therapy to my upper mediastinum was recommended as an adjunct to chemotherapy, and I received a total of 3,400 rads over 5 weeks, beginning about 1 month after completing chemotherapy. I was out of work for 8 months.

I had most of the usual "side effects" of chemotherapy and radiation therapy: disrupted GI tract function, nausea, loss of appetite and taste, and loss of all body hair (generally an advantage in personal hygiene). I developed a peripheral neuropathy from the vincristine, which led to some discussion about limiting planned chemotherapy doses. Chemotherapy is, after all, a poison, but it is most effective if the entire planned dose can be administered. I also developed a bothersome esophagitis from radiation. Bone marrow pain was more than minor from G-CSF injections, and fatigue persisted for a long time after radiation therapy. Depression, denial, anger, and ennui have all been part of my course. Fortunately, nearly all of the side effects were transient, and at 2 years I remain disease free. My chance for cure is good.

**MEDICAL EXPENSES**

A review of the charges of my treatment sheds some light on the frustration, irritation, anger, and incredulousness of patients as they try to understand today's medical "system." The total charges for my initial 4-day hospital stay was \$24,836, of which \$17,732 went to the hospital, \$5,435 went to physicians, and \$1,669 went to an ambulance company for transport to and from radiation treatment center. The initial hospital and physician charges are detailed in Table 2. What isn't

**TABLE 3.** Details of total medical care expenses

Initial hospitalization	\$24,800
Chemotherapy	\$13,800
Stem cell harvest	\$ 3,300
Radiation therapy	\$11,000
Diagnostic scans	\$ 5,800
HLA-typing & physician fees <sup>a</sup>	\$ 6,800
<b>Grand total</b>	<b>\$65,500</b>

<sup>a</sup> I suspect many physician visits were either not billed, or significantly discounted as a professional courtesy.

apparent from this cataloguing of charges is the amount of paperwork, phone calls, corrections, and clarifications that went into settling this bill. To completely settle my medical care expenses from these 4 days of hospitalization took 52 separate mailings, two different letters of confirmation and clarification from my oncologist and surgeon, innumerable phone calls, and total of 8 months from the time of surgery until the last insurance payment was made. I paid 2% of these charges out of my pocket, and my insurance company paid a total of 70% of charges, the remainder "discounted" or "adjusted."

Subsequent treatment costs are detailed in Table 3 and include outpatient chemotherapy (these drugs are really expensive), source stem cell harvesting, and HLA-typing of my siblings (in preparation for possible autologous or allogeneic bone marrow transplant), radiation therapy, and diagnostic studies, primarily computed tomographic scans of the chest. The total medical charges for my treatment for 1 year was \$65,500. Insurance paid 71% of these charges, 23.5% were insurance adjustments (written off), 2% was self-pay, and 3.5% remain unresolved nearly 1 year after treatment. I received a total of 143 separate billings and mailings regarding these charges, and resolution required dozens of phone calls and several letters from my physicians. Most charges took 3 to 6 months to finalize payments, with some charges unresolved at 1 year. Without the uncomplaining help of my physicians, navigating through the maze of insurance and disability forms would have been impossible. As it was, it was incredibly time consuming, frustrating, bothersome, and occasionally frightening, particularly when some treatment plan was challenged as not medically necessary, or not covered by insurance.

I should note that I had (and still retain) a non-HMO, non-capitated, charge-based payer medical insurance plan, otherwise known as a fee-for-service insurance plan. I had to buy this plan for myself and my family while I was disabled, and my monthly costs (family of five), discounted for a state employee, were \$525. I have done the math, and despite \$65,000 of charges and \$46,500 of insurance company payments, my insurance company is still ahead, or at least has broken even, on my personal medical bills and premiums paid over the past 10 years.

### PERSONAL COMMENTS

I'd like to spend a few minutes talking about how the illness has affected me personally, and professionally. I have strug-

gled with this part of this address for several months. One would think that with over a year to prepare, I would not have been spending the very last few days before this meeting drafting my words. I am not sure what has been the reason for avoiding this privilege of the Office I hold.

Perhaps it has been inadequacy: inadequate substance to really include in a Presidential Address; or a lack of direction in how to proceed; or too little hard data to present to an audience conditioned to respond only to tested and analyzed experiments with proven data. Or, on the other hand, perhaps the problem has been one of excess: too many personal feelings to convey; too much material to condense into a few minutes of phrases and prose. Or simply too much else to do.

And while all of those are reasonably true, the real problem was probably most precisely summarized by my 11-year-old daughter, Jessica: When informed that once I again I could not "come out and play" because I was working on this address, she responded, clearly irritated, "You're still not done with that?!" No I confessed, I am having trouble with the last part, the part on how having a grave illness has affected me. To which she succinctly captured the issue by saying, "So Dad, what's the point you are trying to make?" Indeed. What is the point?

The point is, I thought I might die much sooner than I had planned, and it frightened me. It forced me to address issues in my life that are so common to all of us, so universal, so widely written and talked about that they somehow have become mundane or even trite. How was I living my life? What was truly important to me? How had I allocated my time? Did my time spent match my priorities, or was I spending the least amount of time on what I said was the most important part of my life? More self-introspection: What is the best I can accomplish with my life? Have I accomplished what I set out to do? Did I want to do the right things?

To those who have yet to be confronted by the challenge of a truly disrupted life plan, these issues may sound simply like the homework assignment of a college philosophy class, or worse, the rambling's of a tele-evangelist, or the musings of a midlife self-help book. Probably important, but not really applicable to you. And what purpose does dwelling on the unsolvable have anyway? Isn't it just an unproductive exercise, a waste of time?

This is getting closer to the point. These questions are not a waste of time, and especially not a waste of time for physicians. Grave injury or illness is tremendously unsettling and disrupting to our patients, and for the most part, we ignore this fact. We ignore our patients subtle, yet clear calls for guidance, for understanding, and for emotional support. We treat the broken bones, but not the emotional disturbance that results from the car crash that cost a father his life, and forever scarred two families. We treat the pneumonia, but do we discuss the neglect and loneliness and questions of meaninglessness that confront our elderly patients? We do the lymph node biopsy, and tell the patient the operation went fine, and that someone will call them with the results. But do you really think they believe everything is "fine."

You might say it is not our job. That being a physician or surgeon is not about being a counselor or clergy or family

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member or friend. To that response I would disagree, and challenge you to reconsider your role and your purpose as a physician. The earliest Greek medical writings are from about 400 BC and are attributed to Hippocrates. Although Hippocrates was likely a real person, he came from a family that claimed to be descendants from the mythical family of Aesculapius, son of Apollo. In addition to the Oath of Hippocrates, this father of medicine is also the author of a number of "Aphorisms," with the following perhaps the most notable:

*"Life is short, and the Art long; the occasion fleeting; experience fallacious, and judgment difficult. The physician must not only be prepared to do what is right himself, but also to make the patient, the attendants, and the externals cooperate."*<sup>10</sup>

An interpretation of this aphorism is that it is not sufficient to do only the medically correct procedures or practices—we must also be prepared to involve ourselves in other aspects of our patient's lives, and we must include the patient themselves in our deliberations and decisions about their care. From my personal experience as a patient, this aphorism rings true. The point indeed is that it is not enough to care *for* our patients, but we must care *about* our patients.

The extreme to which we go to avoid dealing with the personal lives of our patients is reflected in how we sometimes refer to them. How often have we called the young boy injured while riding his bicycle home "the spleen we're watching on the floor"? Or the father and sole financial supporter of two young children "the bad head in the unit"? Or the young male, with a mother who is worried sick about him "the gunshot to the abdomen." The point is, our patients and their families have had their lives completely disrupted, their concept of life's meaning challenged, their foundation tested. We need to be attuned to the emotional well-being of our patients, because that emotional well-being is critical to their recovery and survival.

I must pause and tell you now that I felt very fortunate to have caring, understanding, and emotionally supportive physicians during my illness. And for me, it made a tremendous impact on my understanding of what it takes to be a good doctor. Simply put, it is not enough to make the correct diagnosis, or to perform the perfect surgery, or prescribe the right drugs. One must truly care about your patient, and attend to their emotional needs. As physicians, we must understand the tremendous strain a major illness or injury places on our patient's lives, and help them with the seemingly unprofessional and mundane aspects of care, like insurance forms and disability letters, and work-related paperwork. Listen to the needs and requests for help. Respond, call them back, see them in clinic, give them your time. Listen. Gain trust. For, whereas there are many decisions in medicine that have a clear right and wrong answer, there are many others situations in which it is simply our "judgment" that guides us. These are often not only the most difficult, but also the most important care decisions we make. We are asking our patients to trust in us, to trust in our judgment. To ask for such trust we must demonstrate that we truly care about them.

This is not an easy task in today's medical world. Care-

**TABLE 4.** Picker methodology: eight dimensions of care

Access to care
Respect for a patient's individual preferences
Coordination of services
Information, communication, and education
Physical comfort and pain control
Emotional support
Involvement of family, friends
Transition and continuity

giving has taken on the trappings of an efficient and economically motivated business. Hospitals and clinics are now more likely to be owned by corporations, beholden to stockholders primarily interested in profit. Insurance agencies are most concerned about excluding those most in need of health care because they are "cost losers." Doctors have seen their privileged role in society eroded by an increasingly skeptical and bitter public, put off by the cold and impersonal bureaucracy and the increasing expense of medical care, yet witnessed to the occasional but spectacular excess flaunted by some of our colleagues.

The business of health care has responded to this apparent dissatisfaction with research and studies and surveys on what patients want. Most of the literature on this topic emphasizes the differences between what patients see as important and what doctors or administrators perceive as important.

The American Hospital Association recently commissioned The Picker Institute to gather information about patients' perceptions and experiences with medical care.<sup>11</sup> My hospital, and perhaps yours, participated in the interviews and surveys from over 37,000 patients and 120 different hospitals. In addition, 31 focus groups were held in 16 different communities in 12 different states, supplemented by 1,000 phone interviews. The first of several planned reports is called "Eye on Patients" and gives an overview of patients' concerns and experiences in 1996. The emphasis of the report is on areas in which our patients (myself a few months ago), find concern and dissatisfaction in health care. The results indicate a serious sense of malaise about the American health system.

This survey and resultant discussion with focus groups has led to the identification of eight areas of greatest concern to patients (Table 4). Most of the categories are self-explanatory. The need for information and good communication between doctors and patients is particularly important to the patient who needs to manage their own care at home. Studies have shown that patients with such chronic conditions as hypertension and diabetes do better clinically when they play a more active part in the decisions about their care.<sup>12</sup> The issue of transition and continuity of care is of particular importance to the elderly, and has a special significance to patients as they move from in-patient care to out-patient care (postoperative patients are good examples of this need for seamless transition).

Patients gave the poorest scores to those areas listed in Table 5. The patients do not view modern health care as an efficient system—in fact, it is not a system at all from the patient's point of view. Despite that patients want to be involved in their care and they want to be able to anticipate



**TABLE 5.** Picker surveys: patient-ranked poorest scores

1. The system is a nightmare to navigate.
2. Doctors don't provide enough information.
3. Patients are not involved in decisions about their care.
4. The system's "gatekeepers" set up too many barriers.
5. Hospital caregivers are not emotionally supportive.

what will be happening to them, they feel doctors, and caregivers in general, don't provide enough information. This leads to patients feeling uninvolved in decisions about their own care. The barriers managed care "gatekeepers" establish between doctors and patients is a particular frustration and divisive issue among patients. And finally, the apparent lack of emotional support from hospital caregivers is especially damaging to doctors, and should be embarrassing to all of us. Virtually all of these issues highlight the appropriateness of Hippocrates's aphorism from 2,400 years ago: we must not simply provide the science of medical care, but we must also provide the art of healing as well.

Let me present some further examples of the results of these surveys. The national summary of response from hospitalized patients is shown in Table 6, with the percentage of patients reporting problems with each dimensions of care listed nationally, as well as at the hospital in which I received my care. Note that nationally, over 25% of hospitalized patients feel there were significant problems with the emotional support and the care and attention they received after being discharged. The findings from a group of University hospitals are no better. At my hospital, the single best correlation between these dimensions of care scores and overall patient satisfaction was "emotional support" followed closely by "respect for patient preferences" (correlation coefficient = 0.682 and 0.681, respectively). The emotional support dimension also had the second highest correlation with overall satisfaction for outpatients, following "access to care." Examples of the type of questions patients were asked on the topic of "emotional support" are listed in Table 7.

The Picker Institute survey emphasizes that patients expect certain basics, such as physical care and an effort to alleviate pain. However, hospitalized patients make little mention of the "hotel" amenities (such as the quality of the food or the variety of menu choices) that hospital administrators or marketers have often emphasized. Nor do clinic and office patients attach as much importance to the politeness of office

**TABLE 6.** Percent of hospitalized patients reporting problems with specific dimensions of care<sup>a</sup>

	National (%)	University Hospital (%)	Local (%)
Transition and continuity	28.7	27-29	38.2
Emotional support	26.6	26-29	33.9
Information and education	23.1	22-28	32.6
Involvement of family, friends	22.3	21-23	28.8
Coordination of care	22.9	21-29	32.6
Respect for patients' preferences	21.8	21-25	33.0
Physical comfort	10.4	11	14.7

<sup>a</sup> The three columns represent national average, a consortium of university hospitals, and at presenter's hospital.

**TABLE 7.** Example of questions asked in Picker Surgery regarding "emotional support"

1. If you had any anxieties or fears about your condition or treatment, did a doctor discuss them with you?
2. Did you have confidence and trust in the doctors treating you?
3. If you had any anxieties or fears about your condition or did a nurse discuss them with you?
4. Did you have confidence and trust in the nurses treating you?
5. Was it easy for you to find someone on the hospital staff to talk to about your concerns?
6. Did you get as much help as you wanted from someone on the hospital staff in figuring out how to pay your hospital bill?

staff as doctors think they do. And yet, perhaps because issues like these are fairly easy to address, they are often the first ones quality improvement programs take on. This is unfortunate, because these are not the issues of core concern to patients. Rather, patients want to be heard. They want personal care. They want to be treated as a partner in the decision making. They want their feelings and emotional concerns addressed. Put simply, patients want their doctors and nurses to care about them, not just care for them.

Fletcher and colleagues, in an article entitled "Patients Priorities for Medical Care" analyzed the experience of patients attending the medical clinics of the University of North Carolina.<sup>13</sup> In analyzing eight different aspects of care (similar to those tested in the Picker survey), these authors found that "compassion" was a more important priority to their patients than cost or convenience of care, and on an equal level with competency of caregivers. For all patients, continuity, compassion, and competence were consistently the highest priorities in care.

Perhaps even the business community is beginning to hear this perspective of patients. A recent editorial letter in the *Wall Street Journal*, commenting on the results of over 1 million patient surveys conducted from 545 hospitals, noted that "the results clearly and emphatically show that interpersonal issues such as attitude, interactive skills, and caring behavior dominate the factors most closely associated with the patient's overall satisfaction with a hospital and the likelihood of recommending it to others."<sup>14</sup> They go on to note that "patients need to be informed, treated with respect and have concern shown for the personal stress caused by health problems and hospitalizations. Patients want—and deserve—caring places, as well as curing ones."

Donald M. Sledz, a practicing urologist in Allentown, Pennsylvania, also recently wrote about his experiences as a patient in a letter to the editor of the *Wall Street Journal*.<sup>15</sup> In commenting on the pivotal role of nurses in providing care, he says "they have a matchless opportunity to befriend great numbers of troubled and suffering human beings. They listen to their patients, comforting and reassuring them and their families day and night. They are depended upon." This is what all the surveys and patient satisfaction reports are trying to tell us, and what my own personal experience supports. The world of the ill is quite different from the world of the well—and most of us, as I did, will one day find ourselves in that world. As Dr. Sledz noted, in the long dark night of illness and suffering, it is always 3 AM. And at that time, when

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we ring the call bell, we should expect not only to be cured, but perhaps more importantly, to be cared for.

A 1992 article in the *Annals of Internal Medicine* suggested that we monitor how well we as doctors are addressing our patient's needs by developing a sort of "patients' review" of the human quality of our care.<sup>16</sup> The authors suggested this review assess how well we as physicians respond to specific areas of patients' emotional and supportive needs, similar to those tested in the Picker Survey, and that this be incorporated in the medical record similar to a review of symptoms. But really, do we need to analyze this connection between patient and physician so objectively, so measurably? Can't we simply follow the ancient advise of Hippocrates, echoed in the modern words of Anatole Broyard: "A doctor's job would be so much more interesting and satisfying if he would occasionally let himself plunge into the patient, if he could lose his own fear of falling."<sup>17</sup>

There is a special bond between doctor and patient, but the modernization of medical care, the business of medicine, the specialization of medical careers, the dependence on expensive technology, and the entrepreneurial practice of individual doctors have all dehumanized the most human of contacts—that of the healer and the sick. We need to relieve and relinquish these pressures. I do not believe it can be done with surveys and slogans and quality improvement studies. It cannot be done with advertising or new administrative initiatives. It must be accomplished individually. We as individual doctors, caring for individual patients, must find some relief from the extraordinary pulls of our ordinary life and focus on our job, our mission, of not only caring for our patients, but we must care about our patients.

My personal odyssey with illness underscores these concerns. Whereas I once would have considered these concerns far secondary to "treating my cancer," they proved to be extremely important, emotionally draining, and beautifully satisfied and cared for by my doctors, nurses, administrators, bosses, and colleagues. And I see the importance. Perhaps my immense satisfaction with my care was because I was treated "special." Perhaps I was a unique case. Perhaps my doctors and nurses treated me special because they knew me, and cared not only for me, but cared about me. But isn't that the point? Don't all of our patients want, need, and deserve that type of care? I think they do, and I believe there is evidence to support the significance of this fundamental, historic fabric of our profession. But it is a draining, demanding challenge, and one cannot maintain such intensity for long without help, support, encouragement, and guidance. Yet I believe it will set us apart individually, and as a profession. I think it is worth the effort.

So I would like to propose that this organization, the Western Trauma Association, begin to address these needs and concerns of our patients by setting aside time at each annual meeting for a presentation dedicated to the views and perceptions of our patients. I would like us to take time from the scientific data, the objective measurements, and the clinical cases to hear from our patients about how they perceived their medical care. About what they thought was most important. About the issues that were central to their good

health. About how we as their doctors helped or nurtured or perhaps hindered their recovery. About how we can be better physicians and healers. About the *art* of medicine.

I am proposing that future program committees actively solicit contributions for one time slot in our Scientific Program dedicated to our patients and to the "Art of Medicine." I would encourage participation and presentations in an unrestricted format, with the presentation coming from our patients themselves, or their families and friends, or our own members who have seen the view from the patients perspective. Patients are a varied lot; they bring broad experience and expertise. They also hold an extraordinary personal stake, and I believe many would be eager not only to report on their experiences, but may also help us address the problems they see in modern medical care. I perceive this as a small step that may draw us closer to our patients and restore and strengthen public trust in medicine and in doctors. I believe it holds the promise of both improving the quality of our care and adding to the joy of being a doctor.

I can think of no better organization to take the lead in this initiative than the Western Trauma Association. I have an especially deep affection for this organization and the members that make it up. As a professional society it has many unique qualities: its casual style, the warm camaraderie of its professionally diverse membership, the spectacular settings of the annual meeting, the emphasis on family participation, and the increasing sophistication of its scientific program. But it is not any single one of these attributes that distinguishes this organization. It is the combination that give this organization its balance, a balance that I believe makes this Association uniquely qualified to listen and to hear and to respond to our patients needs.

I want to thank you for the opportunity to serve as your President. This organization struck a resonant cord with me many years ago, and being honored to serve as your president is something I am extremely proud of, and will always cherish. It would of course be impossible for me to be here without my partner in life, my wife Deanne. She is the balance in my life, and I love and respect her deeply. Not only has she nurtured and supported me and my career, but she is also the one primarily responsible for the daily care of our three children, Jessica, Allison, and Chelsea. My dealing with lymphoma and its treatment had many dark moments and trying times, but I have often told my closest friends that in some ways it has been one of the best things that has ever happened to me. It has afforded me a new perspective on how I match my time spent with my life's priorities; it has provided me with a better acceptance of limitations and a better acceptance of my lack of control over many aspects of life. That insight has been calming, and in some ways liberating. But mostly it has provided me the opportunity to get to know my children much better. They are a true joy and give meaning to life, and I am very thankful for that gift.

Finally, a word about the title of this talk. The hospital in which I received my care (and the hospital at which I practice) is modern, well-equipped, clean, and reasonably attractive. There is art on the walls of common areas, and the entrance is a particularly attractive art-deco style. There are

always custodians cleaning windows, waxing floors, and painting the walls. But the ceiling in my room had one large waterspot on it that I could not ignore, lying on my back for many hours contemplating my newly diagnosed cancer. And the CT scanner has a smudge right above the words "Danger. Do not stare directly into the laser light." And the hallway ceiling I viewed while being rolled to and from the OR had a few tiles that needed replacing. Patients are most often on their back, looking up at the ceiling. It is not a common perspective for doctors or administrators, but it is, after all, the patient's perspective, and that should matter the most.

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