

Legal Advocacy for Health Care and Health Insurance Issues

Edward G. Connette, JD

Patients, physicians, providers, payers, and payees—like peas in a pod, we all participate in our health care system, and we all have our personal stories to describe how that system works. Dr. Atul Gawande, currently one of our most astute authors on health care issues, describes the complex health system with stories. In a recent *New Yorker* article, he wrote of his experience as a surgeon in Massachusetts, the first state since Hawaii to enact legislation to assure universal access to health care. He noted that the majority of Massachusetts's citizens were very satisfied with the program and would not go back to the old system:

I'm among them. For years, about one in 10 of my patients—I specialize in cancer surgery—had no insurance. Even though I'd waive my fee, they struggled to pay for their tests, medications, and hospital stay... For the past year, I haven't had a single Massachusetts patient who has had to ask how much the necessary tests will cost; not one has told me he needed to put off his cancer operation until he found a job that provided insurance coverage. And that's a remarkable change: a glimpse of American health care without the routine cruelty.¹

Like every reader of this *Journal*, I can regale you with my personal health care stories. I also have the stories of my clients. I am a lawyer. I help people whose health benefit plans have denied coverage for potentially life-saving medical treatment. The patients who come to me have experienced the health care system at its worst. Their stories, like Dr. Gawande's and your own stories, can guide us in making informed choices as we seek to improve or reform our health care system.

I have seen the evolution of our health care system through the eyes of my clients. In the 1980s I watched health insurance companies and plan administrators begin working in earnest to curb rising health care costs. They worked quickly, establishing networks of preferred providers and HMOs, negotiating broad provider discount rates, and implementing complex, graduated scales of patient copayments, deductibles, and policy caps. Physicians and community practice groups, accustomed to traditional fee-for-service reimbursement

models, were slow to react. Consumers reacted much more slowly. Physicians, patients, consumers, and lawyers all were accustomed to traditional notions of health insurance. A "self-funded" health *plan* with something called a third-party administrator was an alien concept. ERISA sounded like the capital of an underdeveloped nation.

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Many of those early cost-cutting initiatives were primitive but well-intentioned. Some have become routine components of our health care system. Other cost-saving measures were much cruder. Treatment for many patients was senselessly delayed or denied. People died.

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someone calling for help with a health benefit issue. Typical were the patients suffering from stage III or IV breast or ovarian cancer, seeking admission to hospitals at Duke, UNC, Wake Forest, or East Carolina for enrollment in promising treatment protocols using high dose chemotherapy supported by autologous bone marrow cell transplants. Treatment centers would not admit these women without precertification of insurance coverage.

Many insurance companies considered the treatment to be “experimental,” “investigative,” or “not medically necessary.” These benign sounding words, buried deep in the health plans of the day, had been inserted to bar insurance coverage for the more outlandish forms of quackery, such as the laetrile treatment^a for cancer that lured desperate patients to places like Mexico in the 1970s. Suddenly, these loosely defined terms were being used to exclude coverage for costly treatment at the nation’s leading hospitals.

Within the insurance companies, the benefit decisions were often being made by unqualified personnel. Coverage decisions for complex cancer protocols were sometimes made by the same claims examiners who reviewed and approved coverage for sutures and flu shots. When they sought independent review by oncologists or other medical specialists, they did not even know what questions to ask.

By the early 1990s, the challenge faced by health plan administrators in making informed, rational coverage decisions was compounded by the dramatic transformation of standard treatment options, particularly in the field of oncology. While insurance companies were accustomed to determining standard treatment modalities based on peer-reviewed medical literature, cancer researchers were developing a body of data and treatment protocols that seemed to change weekly, sharing their research using this new thing called the internet.

The patients’ stories were compelling. Without insurance coverage, they could not be admitted for treatment. Without treatment, they would die. The coverage denials always seemed to occur during that narrow time window of remission where the patient could best tolerate a stem cell harvest followed by the high dose infusion of chemo. Time was critical. My strategy was to fax hundreds of pages of patient medical records, supported by medical literature and the details of the treatment protocols, to the insurance company, with an urgent letter asking for them to allow coverage immediately or deal with me going before a federal judge to obtain a temporary restraining order. A handful of lawyers around the country were doing similar work. We shared court rulings and other information by fax.

Much of our current jurisprudence governing health benefit denial issues was shaped by this early stem cell litigation. Many

of the cases were decided following an expedited preliminary injunction hearing, with little or no opportunity for the parties to gather complete information and fully develop their presentations. A patient’s life hung in the balance, and all the parties to the litigation were mindful of the urgency and gravity of the decision to be made by the judge. It was high drama, but it was a terrible way to make health benefit determinations.

Fortunately, we have enjoyed a decline in the number of health benefit claims being litigated over the past 10-15 years. I attribute this to several factors:

- Health plan administrators have developed much more sophisticated processes for analyzing the merits of benefit claims for cutting-edge medical treatment. Today, valid claims are more likely to be allowed, and questionable claims are more difficult to challenge.
- Health plans have developed provider discount arrangements with research hospitals and “centers of excellence,” which enable more patients to participate in research protocols that once would have been off limits.
- Health plan language is drafted much more explicitly today. In most situations, the language of the plan itself is clear enough to support granting or denying benefits.

The role of lawyers in representing patients with health care access issues is shrinking for additional reasons. First, the cases usually are governed by ERISA, which gives deference to the benefit determinations of the health plan and comes packaged in a complex web of US Labor Department regulations that are incomprehensible to most attorneys. Many cases today involve complex medical issues where coverage may not be clear cut, and in those cases the health benefit administrators are given broad latitude to make coverage decisions. In most cases under ERISA, the patient must show that the plan administrator “abused its discretion” in denying coverage.^b The administrator does not have to follow the recommendations of the patient’s treating physician as long as there is some reasoned, principled basis to support the decision.

The final reason for shrinking attorney involvement may be the most important: we have witnessed the development of a network of highly-trained non-attorney “patient navigators” who typically come from nursing, medical claims processing, or insurance backgrounds. They talk the talk, and they have an uncanny ability to know the secret, direct telephone number of just the right person inside every health benefit administrator’s shop. They perform miracles, and they do it quickly, usually at no cost to the patient. A prime example is the team of patient

a Laetrile is a substance that commonly is derived from apricot pits. It is related chemically to amygdalin and sometimes is marketed as “Vitamin B-17.” In the 1970s, it became known as a treatment option for cancer even though it had no proven clinical efficacy and was never approved by the FDA. Cancer patients seeking laetrile treatment typically went to private clinics in Mexico to receive the substance.

b This standard of review—the amount of deference given to plan administrators—is a threshold consideration in every ERISA benefits case. A good starting point for understanding the issue and its importance is a recent US Supreme Court decision, *Metropolitan Life Insurance Co. v. Glenn*, ---U.S. ---, 128 S.Ct. 2343, 171 L.Ed.2d 299 (2008).

Patient Advocate Foundation: Partnering with Patients and Physicians to Solve Access Issues

Nancy Davenport-Ennis

The Patient Advocate Foundation (PAF), the leading direct patient assistance organization in the country, was established in 1996 to provide individualized, direct assistance to chronically and severely ill patients facing access to health care challenges. PAF's professional staff works with patients who are fighting to gain and/or maintain health coverage; struggling to resolve reimbursement and billing problems; and wrestling with medical debt crisis and job retention issues. Through its professional mediation and arbitration services, the Patient Advocate Foundation seeks to safeguard patients through effective mediation, assuring access to care, maintenance of employment, and preservation of their financial stability relative to their diagnosis of life threatening or debilitating disease.

PAF also facilitates the patient-physician relationship by assisting patients in resolving pre-authorization appeals, coding and billing issues, and coordination of benefit services. Additionally, PAF expedites Social Security Disability Insurance applications and Medicare and Medicaid applications. PAF partners with physicians to encourage patients to comply with their recommended protocols to assure the greatest benefit in disease management.

According to recent estimates, approximately 1.5 million of North Carolina's 8.9 million residents (more than 15% of the state's population)¹ do not have health insurance. Of these uninsured North Carolinians, nearly 91% will not qualify for Medicaid support, leaving them with few available options for accessing vitally needed health care.

Last year, PAF received more than 9.5 million online inquiries seeking information, including 239,264 from the state of North Carolina. Of this number nationally, 48,860 became full patient cases requiring professional negotiation and mediation to achieve resolution; these involved communications made by PAF staff on behalf of a patient in order to reach positive resolution. Of those patients served, 65.3% had medical debt issues resulting in loss of access to health care. Of that population, 56.5% had debt issues

related directly to the patient's medical care, not lifestyle choices. Furthermore, over 93% of patients reporting medical debt as their primary issue were insured.

PAF services include:

- Mediation and arbitration services to help patients negotiate access to medical devices, surgical procedures, medications, clinical trials, and complex therapeutic protocols
- Negotiation of access to charity care at hospitals
- Copayment assistance for medications
- Procurement of medical write-offs for treatment services
- Negotiation of transportation and lodging for patients who must travel for treatment
- Negotiation of both public and private health insurance coverage through COBRA, Medicaid, Medicare, and state high risk pools created January 2009
- Negotiation and identification of resources for cost of living assistance, including rental and mortgage delinquencies; eviction and foreclosure problems; food and nutritional needs; and utility assistance
- Provision of assistance to expedite enrollment into and appeal negotiations with Social Security Disability Insurance; Supplemental Security Income; Long Term Disability and Short Term Disability; and the complete compliment of Federal, State, Local, ecumenical and social resources

For more information, contact the Patient Advocate Foundation by calling 800.532.5274 or online at <http://www.patientadvocate.org>.

Nancy Davenport-Ennis is the founder, CEO, and president of the Patient Advocate Foundation.

¹ Henry J Kaiser Family Foundation, 2007 State Health Facts.

navigators working with the Patient Advocate Foundation (PAF).^c The PAF staff of trained, professional case managers fields calls from patients throughout the United States and help them obtain access to available coverage under private

health plans, government or military plans, Medicare, Medicaid, or charity waivers. (See the sidebar on this page for more information on the Patient Advocate Foundation.)

Other organizations of patient navigators operate from

c Disclosure: I serve as an unpaid volunteer on their Executive Board of Patient Advocate Foundation and its related policy organization, the National Patient Advocate Foundation, and acted as its board chair for the past two years. For more information on these organizations, visit www.patientadvocate.org and www.npaf.org.

various platforms throughout the country. Here in North Carolina, the Managed Care Patient Assistance Program, within the Consumer Protection Division of the Department of Justice, offers help to patients facing health benefit problems. At the national level, the federal Patient Navigator Outreach and Chronic Disease Prevention Act of 2005^d was passed to provide funding to organizations that offered patient navigator services. To date, funding authorized for the program has been minimal. As of this writing, it is expected that the current administration will seek \$9 million in funding in the 2009 budget.

What is a patient navigator? The challenge for patients is that there is no standard definition. There are no minimum standards of education, training, and experience. Nor is there any form of certification or accreditation for patient navigators. Today, the job title of “patient navigator” is ubiquitous. They are found working in hospitals and community practices, insurance companies, pharmaceutical companies, and a wide range of nonprofit and health advocacy organizations. Some are social workers. Others come from managed care or patient billing and accounts backgrounds. Many are former patients with good hearts but little training. At a minimum, the patient advocacy community needs to develop education, training, and experience standards for patient navigators. Ideally, a national certification standard will emerge, with additional criteria for ethical behavior, continuing education, and supervision by an accrediting organization.

With the evolution of experienced patient navigators, I believe the role of lawyers in challenging health benefit denials will continue to shrink. As our health care system continues to evolve, so also will the role of attorneys representing patients. For example, when an employer withholds health insurance premiums from workers’ paychecks but allows the insurance to lapse, the employees will need lawyers.

Embedded within the system are more insidious pitfalls for patients where lawyers will be needed. For example, the out-of-network “usual and customary” reimbursement rates for treatment services followed by virtually all large plan administrators are set by Ingenix, a wholly owned subsidiary of UnitedHealthcare. As every patient knows, these reimbursement rates are unconscionably low, but it would be

virtually impossible for any single patient to challenge the reasonableness of those rates.

On January 13, 2009, New York Attorney General Andrew Cuomo announced a settlement with UnitedHealthcare that will require the insurer, among other measures, to pay \$50 million to establish a new, independent database run by a qualified nonprofit organization. This nonprofit will own and operate the new database, and it will make all decisions regarding compilation and interpretation of cost data. To help patients, the nonprofit will make reimbursement rates public on a website where patients can find out in advance how much they may be reimbursed for common out-of-network medical services in their area.^{2,3} The New York attorney general’s investigation of other insurers is continuing, but we can expect to see more individual and class litigation by patients challenging the Ingenix-generated reimbursement rates and seeking recovery of underpayments.

This commentary is quite different from what I would have written in 1992, 2000, or even last year. It differs from what I might write a year from now. In my earlier years, I regarded insurance plan administrators as the enemy. I now recognize the pioneering work they have done in trying to manage health care costs. Indeed, the largest single barrier to health care access for all people is its cost. While I applaud the evolution of new pharmaceuticals, I am terrified by what their cost will do for the system as a whole. My doctor friends’ practices have been radically transformed by the evolution of managed care. I hear their stories and worry that they will burn out, become disillusioned, and leave practice. I worry about the challenges of attracting and retaining physicians in front-line community family practices and internal medicine. These trusted family doctors have been recast as “primary care physicians,” but they still are the soul of our system.

We all share responsibility for creating affordable health care that is accessible to all. We all are patients, and we all regard ourselves as patient advocates. “I am a patient advocate” is one of the most common declarations I hear. Physicians, nurses, hospital and medical practice administrators, third party administrators, pharmaceutical industry workers, attorneys—we all say it and believe it. Let’s use our shared commitment to quality patient care to forge a better system. **NCMJ**

d HR 1812.

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