

**In Search of a Standard
Legal and Ethical Dimensions of American Health Care Reform
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This presentation is not the standard compilation of black letter law and case analysis contained in most lawyerly lectures. Instead, it is a critique of current trends in health care reform in the United States and a challenge to all audiences to rethink their roles as health care consumers and professionals. I will talk a little about health standards, law, financing and cost, and a lot about ethics, paradigm shifts and quality of life. Depending upon your cultural background, I may seriously challenge your view of health and your role in health care reform.

THE CURRENT U.S. HEALTH CARE SYSTEM

In the United States nearly every newspaper and every television news show carries lead stories on the public dissatisfaction with health care. In my numerous presentations to health care audiences, I ask what is causing this dissatisfaction, and the answers that I receive most often include the following.

Rising Expectations. It seems that the American public has been sold an expectation of near perfect health. Health care providers -- doctors and institutions -- bombard the public with Madison-avenue hype about their cures and treatments. Not surprisingly, then, the public demands such perfection, and complains bitterly when they don't get what they perceive as perfection. This is a pivotal concern which I will address further. Additionally, the cost of health care continues to rise dramatically, and impacts the consumer directly.¹Copyright 1999 Ronald Scott Mangum. All rights reserved.

Lifestyle Abuse and Societal Violence. We live in a disposable society. Everything can be replaced for a newer model, and it seems that based on the rising expectation of health referred to above, that includes our bodies. Concomitant with disposable society is the apparent lack of personal responsibility for one's actions. The result is a devil-may-care attitude about personal health. After all, if I get sick, the medical system will repair me. And anyway, sooner or later it's time for a face-lift or body tuck to maintain my perpetual youth. This attitude also seems to have produced a cheapening of concern for person or property, which evidences in a rise in societal violence. Disposable goods cost money, and the repair of what turns out to be not so

¹It has been recently estimated that \$1200 of the cost of every General Motors car pays for GM employee health programs.

disposable bodily parts, costs more money.²

Defensive Medicine. One famous aphorism from Shakespeare is that upon remaking society we must kill all the lawyers. Although taken out of context, this is ripe fodder for those health care professionals who are the targets of the burgeoning medical malpractice industry in America. Judgements are often in the tens of millions of dollars, based on the rising expectation of perfect health. Consequently, the standard of testing and drug application rises daily. It is safer to perform the test than to be later criticized by a jury for not discovering, or ruling out, some physical error. Likewise, with the average patient demanding a cure for often undiagnosable illness, the easy way to “do something” is to give a drug. It is estimated that as much as 80% of prescribed drugs are unnecessary or ineffective. The result - over utilization of health care resources and more cost.

Fraud and Abuse. This is an easy one that we all should have seen coming. When the U.S. government pumps billions of dollars into an industry, practitioners will take advantage of it, and some will take more than advantage by defrauding the system. That would be the simple explanation, but unfortunately this is not a simple issue. The government throws billions of dollars out to “improve health” in some vague fashion. Practitioners spend that money, and suddenly the government wants to stop spending it, but is now caught in public entitlement politics. How to get out? Blame someone else. The cost increase is not the government’s fault. It is the fault of the practitioners who are defrauding the system. If only we can catch all of those that are defrauding the government, then costs will go down. Unfortunately, this just leads to making previously acceptable practices now fraudulent, and ignores the fact that although some leakage in government spending occurs through fraud, putting the crooks (and not so crooked) out of business reduces access, but doesn’t reduce by one iota the public demand for more health care, and thus more cost.

Over Regulation and Bureaucracy. A second government standard initiative when a program is out of hand, is to regulate it to death (no pun intended). Keep up the reporting requirements, constantly change the rules on delivery and billing, and maybe, just maybe, some magic answer will appear. Not likely, and of course complying with the regulations of a self-sustaining bureaucracy creates more government jobs and costs money.

Disease Advertising. To my knowledge, America is the only society that advertises disease. Just the other day I was driving along with my car radio on, when the announcer asked “do you ever have pain in your legs?”. Thinking for a moment I had to admit that at some times I have pain in my legs, especially when running after an absence of exercise. So, intoned the announcer “you may have

²In 1996, national health expenditures just for alcohol and drug abuse treatment was \$12.6 billion. Source: Federal Substance Abuse and Mental Health Services Administration, Office of Managed Care, U.S. Department of Health and Human Services, 1998.

a caudal occlusion,” and proceeded to encourage me to contact a local hospital which would pay me for participating in a study of caudal occlusion. Before I heard the advertisement, I never would have given occasional leg pains a second thought, but now I had something to tell my family and friends. It could become an excuse for all sorts of problems: “honey, I can’t cut the lawn - you know, my caudal occlusion,” or “boss, I would love to work late, but my caudal occlusion is acting up.” And even better, someone will pay me for this condition - what a bargain. It is axiomatic that when a new disease is discovered and reported, numerous Americans check in with their doctors, sure that they are the living example of the new illness. They want treatment now, and we have more cost.

History of the Current System

So how did we get here? Before World War II, the American health care system was relatively primitive, especially when compared to primarily state sponsored health care systems in Europe.³ During the war, however, the military medical system expanded exponentially to provide preventive and restorative care to over 16 million U.S. servicemen and women. When those service members returned home, they expected to see a comparable health care system in the private sector. It wasn’t there, so in the mid-1940's the U.S. Congress passed the Hill-Burton Act⁴ which distributed millions of dollars of grants to health care providers primarily to construct modern, expanded health care facilities across the country.

Having spurred the physical asset side of the health care balance sheet, in 1966 the Congress passed the Medicare and Medicaid Programs.⁵ Originally conceived of as a method to provide “one door” access to health care, these programs provided billions of dollars of funding for new health care professionals and services. Still realizing that the full potential of every American to achieve good health was not yet in place, and somewhat self-consciously realizing that some European countries still provided better health care to their citizens, Congress passed the Health Maintenance Act in 1973.⁶ This law

³Although the first compulsory deduction from wages for health insurance for the U.S. Marine Hospital Service was instituted in 1798, and the first U.S. health insurance carrier, Massachusetts Health Insurance Company, was established in 1847.

⁴Hospital Survey and Construction Act, (P.L. 60-725) Ch. 958, 60 Stat. 1041, adopted August 13, 1946 (popularly known as the Hill Burton Act.)

⁵Social Security Amendments of 1965, (P.L. 89-97), adopted July 30, 1965, now codified at 42 U.S.C. Sections 1395 and 1396.

⁶Health Maintenance Organization Act, (P.L. 93-222), adopted December 29, 1973.

provided more billions of dollars to encourage citizens to enroll in pre-paid health care plans and visit them frequently to provide prevention and early detection of disease. It didn't take long, however, for this well oiled money machine to begin to cause budget headaches.

In 1974, Congress passed the National Health Planning Act⁷ with the specific intention of reducing or retarding the growth of hospital physical plant and equipment expansion. It seems that every hospital wanted to become a medical center, and every medical center wanted to become a regional medical center, and the cost spiral was out of control. Health "planning" stopped that to the point that in many states there have been long years of moratoriums on any new health care construction. Then in 1982, Congress began to tighten the program side of health care by mandating that Medicare would only pay for health care after any other private insurance plan had been tapped for the patient.⁸ That helped, but didn't stem the flow of dollars, so in 1983, Congress initiated a new semi-capitated method of hospital payment by Diagnosis Related Groups.⁹ Under this system, hospitals were paid a fixed sum for an illness and the risk of gain or loss was shifted from the government program to the hospital.

Health care costs continued to soar. By 1995, government health spending topped 20% of the federal budget,¹⁰ and the atmosphere changed once again. Now the government is into a full press to catch those who abuse the payment system. The Health Insurance Portability and Accountability Act of 1996,¹¹ made overbilling, underserving, and a host of other practices federal crimes, subject at the lowest end to exclusion from participating in the Medicare and Medicaid programs to the high end of decades in jail, and always accompanied by payment of huge fines. Now health care costs are under control? Hardly. The growth in health care costs has slowed, but the system is still in a shambles, with no reasonable prospect of real reform in sight.

How the Current System Works

⁷National Health Planning and Resources Development Act of 1974, (P.L. 93-641), adopted January 4, 1975.

⁸Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, (P.L. 97-248), adopted September 3, 1982.

⁹Id., and Social Security Amendments of 1983, adopted April 20, 1983, established Diagnosis Related Groups as the basis of payment for hospitals.

¹⁰"Rural Conditions and Trends", Vol. 7, No. 2, Economic Research Service, U.S. Department of Agriculture, Washington D.C.

¹¹Health Insurance Portability and Accountability Act (P.L. 104-191) adopted August 21, 1996.

The majority of Americans have health insurance coverage through private insurance companies, either as individuals or as members of groups such as employees of their employer. The two federally funded health care programs - Medicare and Medicaid - were established to provide a safety net for the uninsured. The Medicare program is funded by contributions from working insureds, and provides benefits to all covered individuals over the age of 65, and a limited number of totally disabled individuals under 65. Medicare generally pays all hospital bills and a portion of physicians' services, but a very limited amount of long term or custodial care. The difficulty with the program funding is that 80% of the resources are used by the very elderly population, usually at the very end of life. In addition, although worker contributions are credited to a "trust fund", in actuality most of the contributed dollars are used to pay current benefits for those over 65. As the American population ages, the so-called "baby boomers" will create a bulge in the population demographics such that the numbers of workers will shrink as the elderly population grows. Contributions will not be sufficient to pay for the then retirees. Hence, the health care funding crisis.

With respect to Medicaid, benefits are available to the impoverished. To qualify for Medicaid, an individual must exhaust his or her assets down to about US\$2500, and have monthly income of not over US\$2000. There are no contributions paid by individuals, and funding comes out of current tax dollars. Since most health care expenses are incurred in the last years of life, Medicaid pays for the long term care that Medicare does not cover. Over 50% of all residents in U.S. long term care facilities are paid for by Medicaid. The Federal government pays a portion of the bill, from 50% to 65%, and each state pays the balance. The rising cost of Medicaid payments have threatened to bankrupt some states, and as a result funding is always tenuous. The irony of the system is that the individual contribution portion (Medicare) pays for health care for everyone, including a multi-millionaire, over 65, while the general tax revenue portion (Medicaid) forces individuals to become impoverished wards of the state before it pays for any care. Despite these government "safety net" programs, in 1997 more than eighteen percent of the American population were without health insurance of any type.¹²

The federal government has established a huge bureaucracy in order to maintain standards within this vast federally funded health care system. The usual assumption is that these standards of health care are set by one of the federal agencies concerned with overall health of Americans such as the National Institutes of Health, the Institute of Medicine or the Agency for Health Care Policy and Research - all prestigious medical bodies. And, of course, the Surgeon General of the United States must be at the helm of this bureaucracy. No such luck. The "standards" of health care for these two federally funded programs that

¹²Cited in The Health Care Lawyer, Illinois State Bar Association, Health Care Law Section, Vol. 15, No. 3, May 1999.

drive the U.S. health care system are set by the Health Care Financing Administration (HCFA)! What is stranger is that the health care standards promulgated by HCFA are based on recommendations developed by the Institute of Medicine in 1984 and codified into law in 1987 - over fifteen years ago! So, decisions as to what constitutes good health care in America are not based on current scientific research. They are based on the insurance concept of what was an appropriate covered service fifteen years ago. No wonder that the American health care system is in disarray.

And what do we get for this out-of-control system? The rage *du Jour* to control health care costs is managed care. It is a lot like the benign Health Maintenance Organizations of the 1970's, but with an ugly twist. Do you remember that with an HMO, patients were expected to fully utilize the preventive services of the system? Well, with managed care, the less utilization the better. Managed care is not the friendly physician directed system that HMOs were. Managed care is akin to the oriental devil guardians in that it is charged with stopping entry to all but the most needy patients. Instead of directing patients to the appropriate health care provider, managed care employees are deemed most effective when they prevent the patient from entering the health care system at all, and thus preventing patient use of expensive health care resources.¹³ Short sighted? Of course! Patients thus enter the system much sicker and needing to consume more resources later on. But the goal is to reduce health care spending on the front end, so managed care plans have adopted techniques such as “gag rules” which prohibit managed care plan providers from telling patients about any treatment other than covered treatments. This causes direct conflict between a physician’s professional responsibility to deal fairly and openly with his or her patient, and the cost containment goals of the plan. Likewise, managed care cannot afford to publicize successes. Imagine the financial bottom line of the managed care plan that advertises an effective treatment for AIDS. Every AIDS patient who sees the add will sign up, causing the plan to spend too much of its premium dollars on expensive AIDS treatment.

The U.S. judicial system has responded to the challenge of managed care. In one of the most publicized lawsuits¹⁴, a surviving husband of a plan patient sued the insurance carrier for failing to permit timely referral of his wife to a cancer specialist. The wife died from the cancer, and the jury returned a \$79 million dollar verdict in the husband’s favor. Subsequently, courts have found managed care entities liable for failing to provide appropriate care. The irony is that in all of the court cases that I have reviewed, not a single court has inquired into whether the premium paid was sufficient to pay for the care demanded. The

¹³Ironically, in 1996, Managed Care Organizations and Health Insurance Companies spent from 20% to 40% of health care premiums on advertising alone.

¹⁴ *Fox v. Healthnet*, unreported California lower court decision awarding \$79 million judgement, subsequently settled before trial for \$7 million.

courts are simply not interested in the economics of the health care debate; their only issue is whether or not the care was necessary to improve the health of the insured. I call it economic un reality.

Since managed care has been so unsuccessful in lowering health care costs in the HMO setting, you would expect that it is a concept that has passed its time. To the contrary, the government, having no other plan in sight, proposes to expand managed care to cover hospitals, nursing homes, home health agencies and other types of health care providers! Interestingly, the current legislative proposals give great freedom to insurance companies and managed care companies to deny care, but none of the proposals significantly limit physician practice. It is estimated that as the true health care gatekeepers, physicians control up to 80% of all health care expenditures. No wonder we can't control health care costs. So what can we do?

CHANGING THE PARADIGM

There is a concept in the study of rhetoric called "infomeme." An infomeme is a core term in a rhetoric discussion which is assumed to be true. It is not questioned, but taken as a given. Infomemes are useful because if we are stuck without consensus on an issue, we may want to re-frame the issue by examining the validity of the infomemes. With regard to health care reform, the traditional argument focuses on the term reform. Health and care are infomemes whose meaning and content is seldom questioned. What I would like to do, is question the infomeme, and see if that may produce a different result. The infomeme that I want to focus on is the term "health".

"Health" is defined generally in the dictionary as (1) a general condition of the body, (2) soundness of body or mind, or (3) absence of disease. All well and good. But what really does "health" mean? It is a difficult term to pin down because at bottom, health is self-defined. If you ask a person if they are healthy, they usually don't stop to call their doctor, they will tell you based on their self perception. Further, health is defined differently in different cultures and among different ethnic groups. For example, a recent study in the United States found that Caucasian Male Americans tend to define health with respect to function of mind and body parts, while Black Male Americans tend to define health with respect to the absence of pain¹⁵. So a white who cannot walk well because of a problem with a leg would say that he is unhealthy, while a black who can walk but with pain may state that he is unhealthy.

I am sure that the physicians who read this will say that health is clearly defined by the standard of normal conditions produced through medical

¹⁵ Black - White differences in health perceptions among the indigent", Celia O. Larson, Ph.D., Michael Colangelo, M.B.A. and Kimberly Goods, M.S.P.H., Journal of Ambulatory Care Management, Vol. 21, Number 2 (Jan. 1998).

research. The difficulty with such studies is that they are based only on averages. In fact, the practice of western medicine is based on averages. When a patient presents to a physician, the physician takes into account all of the presenting conditions and compares them to “normal” ranges and draws his or her conclusions. The fact remains, however, that those conclusions are only educated guesses based on how “most” people function. All of the statistics of hospital mortality, for example, cannot predict whether or not any single patient will be helped or hurt by a medical intervention. If that is startling, consider “despite the cultural centrality of medicine, its undeniable successes in the treatment of complex diseases, and the money spent on medical research and care in the Western world, there is little evidence that medicine has had a major impact on disease pattern in general”¹⁶

This conclusion is supported by studies in the United Kingdom which found that with respect to declines in mortality since 1700, the causes were (1) improvement in nutritional patterns (e.g. pasteurization), (2) improvement in environmental conditions (e.g. public drinking water, inoculations) and (3) changes in personal behavior (e.g. contraception).¹⁷ And by studies in the United States which found that “for all but one cause of death, the first effective medical intervention occurred after the majority of the decline in deaths from that cause had already occurred.”¹⁸ In fact, the life span of a male over fifty years of age has not increased substantially in the past two thousand years. Of course, the ability to reach age fifty has increased substantially, but clearly due more to societal changes rather than to medical intervention.

Do I think that medicine is unnecessary? Of course not. The specific advances of medicine have produced dramatic results when viewed from the perspective of the individual patient. The ability of an individual with coronary disease to be diagnosed, cut open, have multiple arteries replaced, sewn up and regain normal life in a few weeks is astounding. But on the average, medicine has a long way to go to really understand health. And that brings us to the heart, so to speak, of our discussion today.

Indulge me for a moment. If you are listening to this, close your eyes and sit quietly. If you are reading this, read on and then sit quietly. Feel your clothes – the weight and texture of the cloth; the smoothness or scratchiness of the material. Did you feel your clothes before I asked? Probably not. Continue to concentrate on your body. Do you feel any discomfort anywhere? Too much

¹⁶A Sociology of Health, Second Edition, Andrew C. Twaddle & Richard M. Hessler, MacMillan Publishing Company, New York, 1987, P. 84.

¹⁷The Role of Medicine: Dream, Mirage or Nemesis, Thomas McKeown, Princeton University Press, Princeton, N.J. 1978.

¹⁸Twaddle & Hessler, p.85.

pressure, any bit of pain, restlessness? Most of us feel, but don't pay attention to, hundreds of small discomforts each day. Such is life, and that is my point. We are constantly bombarded by small aches, pains and discomfort - perhaps part of the penalty of walking upright. But most of us live with these small discomforts, and even relish them as indicators of how our bodies are reacting to daily stress, and what levels of rest and recuperation we need. I am not suggesting that every person who goes to a physician to be relieved of pain or discomfort is a hypochondriac, but I am suggesting that until we develop a national consensus of what constitutes health, we are unable to develop a national consensus of what type of health care we need, and how much we are willing to pay for it.

I had a great uncle who served in the Confederate Army in the American Civil War. During that war, he was hit by a train while standing guard duty. I don't know much of the circumstances, because I only know of his injury by reading the application he filed in 1895, thirty years after the war, seeking a veteran's pension. In his application, he described that ever since the injury he had an open wound on his thigh, which drained continuously. I can only imagine that he had a flap of granulated skin which failed to adhere to the leg wound. He must have risen every morning, unbandaged the wound, cleansed it probably with alcohol which was very painful, and then repeated the procedure at night. Was he disabled? Institutionalized? Hardly! He was a farmer who worked from dawn to dusk. And if you asked him if he was healthy, I would bet that he would reply "yes!". If you asked if he had any health problems, he would probably admit to the injury on his leg, but it would not have occurred to him that he was unhealthy. Today in America, we would not put up with such an injury. We would demand that it be surgically repaired, or that drugs be used to relieve any pain. Our concept and definition of "health" has changed, and the average American no longer feels capable of truly defining his or her own health. We have been sold on the idea that only our health care professionals can truly define our health, and yet there is something profoundly unsettling about this result. Perhaps it explains why Americans visit alternative health practitioners one and a half times more each year than they visit their family physician.¹⁹

WHAT CAN WE DO?

The first way that we can begin to unravel the Gordian knot of American health care reform is for health care professionals to empower the average citizen to define their own health. This doesn't take much more than letting the patient know that he or she actually has the power, in the face of their physician, to say whether they feel healthy or not. Time and again, the very ability of the individual

¹⁹ The New England Journal of Medicine. A 1994 study found that Americans visited traditional family physicians 220 million times and alternative practitioners 336 million times. A follow on study in 1996 showed similar results: 386 million traditional visits versus 629 alternative visits.

to adopt a positive view of their own health has proved a key discriminator in that individual's ability to overcome physical or mental disability. Health professionals must teach health consumers that health is imprecise, that a normal life includes some discomfort, even pain, and that consumption of more health care will not necessarily improve the quality of one's life. We have grown up on a Western tradition of traumatic invasive intervention as the treatment of choice for health care. Health professionals and research institutes must listen to and study the "folk" remedies of alternative medicine. After all, those remedies often preceded Western medicine by thousands of years. And sometimes, we must bend our scientific hubris for just enough time to realize that we cannot always explain why a cure works - it just does.²⁰

Over twenty years ago, an American best seller "I'm OK, You're OK"²¹, informed the public that in a relationship between two human beings, one didn't have to be right while the other was wrong. Now we need to inform the public that one has the power to define their own health, despite what health professionals say. Only in this way can we regain a sane view of health in America. When we are more rational about what constitutes health, then we can define how we want to preserve health - perhaps even how we can ration our resources to best improve quality of life for every citizen. We can also identify what we are willing to pay in seeking to lead healthy lives, and thereby reshape payment mechanisms. Government can assume its proper role in medical research by encouraging research which is relevant and useful - not esoteric and expensive. And, finally, we can release ourselves from self-imposed guilt over being unable to provide perfect health to everyone.

CONCLUSION

I have presented a brief history of health care development and reform in America, looking at several patterns of success and failure along the way. We have looked at the role of medicine and health care practitioners in the health delivery system, and most importantly, I have challenged you to view "health" differently and I hope more realistically. Now the future belongs to you. Only you, each in your own way, can assist in reshaping the paradigms that have bound us for so long. Only you can make a difference in how health care proceeds, and if, in America, we can reconcile ourselves to a mentally uplifting future, secure in our health - or whether we will continue to chase the chimera of perfect health into bankruptcy. I don't think that I need to state my preference, so

²⁰ Just providing information can change behavior. A 1996 study conducted by the Automobile Industry Task Force in Flint, Michigan, found that children were delivered by Caesarian Section 23% of the time nationally and 29% of the time in Flint hospitals. Providing that information to the medical community caused C-section deliveries to drop below the national average in a few months.

²¹ I'm OK, You're OK, Thomas A. Harris, Avon, N.Y., N.Y. 1996 (reissue)

I will close simply with the classic toast: “To your Health.”