A modern-day Tuskegee
... and what’s really wrong
with U.S. Health care today?
by David Moskowitz, MD

The crime of the Tuskegee Syphilis Experiment isn’t that it was an experiment; medicine improves only through smart experiments. Dumb experiments are seldom criminal. What made Tuskegee so shameful was that a cure for syphilis had finally been discovered, but news of the cure was deliberately kept from the patients who needed it the most, patients with tertiary stage syphilis.

For the past seven years, the world has been in the midst of a situation hundreds of times worse than Tuskegee. Like the Tuskegee syphilitics, the patients affected aren’t even aware of the injustice. As in Tuskegee, patients are paying with their lives.

In 2002, I published a method to reverse diabetic and hypertensive kidney failure (1), which works for whites, blacks, and Hispanics. Dialysis, the kidney machine, claims blacks 5 times more than whites, and Hispanics about three times more than whites. My method involves higher than usual doses of a particular ACE inhibitor. Lately, other investigators have found that this approach works (2-4).

But in 2002, the media refused to take my word for it, requiring me to get an endorsement from somebody in the renal community.

I suppose that’s fair enough, but somewhat depressing: even Larry Altman MD, the medical reporter for the New York Times, confessed to me that he couldn’t evaluate a scientific paper on its own merits. Science majors learn how to do this their freshman year in college.

Since 2002, not a single medical authority has come forward to endorse my study, even though the founding Director of the US Renal Data System, Dr Lawrence Agodoa, called my data “beautiful” in a conference call in early 2004. He said the rules of the NIH, his employer, refused to let him endorse a company. That’s the same response the American Diabetes Association gave me, even though they partially funded the underlying research. It’s also what the National Kidney Foundation told me. Apparently this applies even if a company discovers a cure for the disease they’re working on, which seems a bit counterproductive, as far as the public is concerned.

Incredibly, they had no interest. Only then did it dawn on me that they’d be eliminating 90% of their own jobs along with 90% of their budget, something every bureaucrat is terrified of doing.

Neither did the NIDDK (the Kidney Institute at the NIH), the AHRQ, the American Heart Association, the American Association for Kidney Patients, the CDC, the AMA, the National Medical Association, numerous academic Nephrology Divisions, numerous kidney transplantation societies, the American Society of Nephrology (ASN), the International Society of Nephrology (ISN), the European Society of Nephrology, individual nephrologists and transplant surgeons, multiple health insurance companies, multiple health plans, all 50 state Medicaid offices, even religious leaders vocal about healthcare, et al (5).

Even the Missouri Kidney Program, which co-funded the key research along with the ADA, has had no comment.

The head of Anthem Blue Cross/Blue Shield, whom I know personally, and who is now head of Wellpoint, with over 100 million patients, told me that my 1,000 patients weren’t enough. “Come back when you have 100,000,” he said, knowing full well that it took me nine years to publish my paper on 1,000 patients. At that rate, he could safely wait 900 more years.
About 100,000 patients go on dialysis in the US every year. There are 300,000 total patients on dialysis. About 100,000 dialysis patients die every year. My method could prevent 90% of whites, and 95% of African Americans, from losing their kidney function. It’s fair to say that, had my paper received the notice it required, back in 2002, 90-95% of patients could have been kept off the kidney machine at least since 2006, and perhaps earlier. (I have to treat patients early, before they’ve lost half their kidney function, i.e. while their serum creatinine is less than 2 mg/dl. Once they’re on dialysis, it’s too late).

Conservatively speaking, 300,000 patients are currently on dialysis whom I could have kept off, had anyone at the NIH, CDC, NKF, etc. simply spoken to a reporter about my paper.

Once on dialysis, patients live only a handful of years. A 65 year old man starting dialysis has a life expectancy of 2.5 years--as opposed to decades with syphilis.

So I reckon the collective silence of the medical community, including government as well as non-profit institutions, is at least 750 times worse than their silence during the Tuskegee experiment: 400 Tuskegee patients vs. 300,000 dialysis patients. And the crime continues. Each day, another 274 patients go on dialysis for the first time, and soon die, 247 of whom GenoMed could have prevented.

This issue painfully illustrates what’s really wrong with U.S. healthcare, indeed, with hospital-based healthcare everywhere around the globe. Its business model requires disease. Patients must get sick in order for the revenues to keep flowing. A dialysis patient brings in $100,000 annually for the roughly 3 years s/he’s alive. See, for example: http://medicine.lifescienceexec.com/

So access is not the real issue; quality improvement is. Spreading manure around doesn’t change its nature. Healthcare everywhere, not just in the US, is anti-innovative and hence exploitative.

Single-payer advocates should realize that Medicare is already a single-payer for dialysis. National Health Services in other countries, e.g. Canada, Germany, Spain, France, Germany, Russia, Japan, Singapore, etc. have had no interest in my method of preventing dialysis, either. In other words, on the global scale, Medicare is not alone.

The current national debate about healthcare is dangerously uninformed without taking into account this stark example of what’s really wrong with the industry. The fix is simple: build in competition on outcomes. Start by reporting outcomes.

This simple solution is practically free: just mandate reporting of patient outcomes for any patient whose healthcare is paid with federal dollars. Post clinical outcomes for each each hospital and each physician on the web, for all to see. How many diabetic patients seen by Dr. X go on dialysis? How many in Dr. Y’s practice?

Let patients vote with their feet. This would ensure competition on outcomes, and tie economic survival of practitioners, and eventually health insurance plans, to their patients’ survival. In one neat trick, we will have inverted the current business model for healthcare, so that it actually benefits patients rather than kills them.

References

1. Moskowitz DW. From pharmacogenomics to improved patient outcomes: angiotensin I-converting enzyme as an example. Diabetes Technol Ther.2002;4(4):519-32. PMID: 12396747. (For PDF file, click on http://www.genomed.com/pdf diabetes.technology.therapeutics.pdf) – this paper reports on 1,000 white and black male veterans. An additional 350 Hispanic men and women with diabetes were treated during the period 2001-2007, and showed no progression of their normal kidney function (unpublished data).


