COMMENTARY

Camouflaging Informed Consent

In 1972, *Canterbury v. Spence* changed American health law, and with it, the patient-physician relationship. Some ethicists cite this as the beginning of modern medical ethics. Before a patient agreed to a surgical procedure, he was to be informed about its risks and benefits. Failure to do so was negligence. Part III of that appellate court decision gives a concise history explaining why the judges did not consider their decision revolutionary. That, however, wasn't the way doctors experienced it. A decade earlier, arguments had been advanced justifying why it was better not to tell a patient he had cancer. Not all physicians agreed with that practice, labeled therapeutic privilege. But after *Canterbury*, such paternalism was no longer acceptable (with extremely rare exceptions).

BY KEVIN T. POWELL, M.D., PH.D

Per *Canterbury*:

"The root premise is the concept, fundamental in American jurisprudence, that 'every human being of adult years and sound mind has a right to determine what shall be done with his own body.' ... True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each. The average patient has little or no understanding of the medical arts, and ordinarily has only his physician to whom he can look for enlightenment with which to reach an intelligent decision. From these almost axiomatic considerations springs the need, and in turn the requirement, of a reasonable divulgence by physician to patient to make such a decision possible."

As outlined by that court, informed consent is not a form that must be signed. It is the professional duty to communicate information to the patient. That includes overcoming cultural and language barriers, poor health literacy, and denial.

The standard for what is contained in informed consent has evolved. Not every minute risk need be discussed. In many states, the requirements went from a professional standard (What information did other physicians customarily disclose?) to a reasonable person standard (What information would a reasonable patient want to know?). Then, as with many ideas that start out with good intentions, the whole thing spun out of control. The amount of material to be disclosed expanded without bound. There can be too much of a good thing. All too often, modern medical consent forms have become like the End User License Agreement (EULA) I ignore whenever I install computer software. Don't most people just click the box that says, "I have read and accepted the terms of the EULA," without actually reading it? As if you really had a choice?

On taking my mother to the emergency department recently, I was given a binder filled with 32 pages of orientation materials, privacy notifications, descriptions of patient rights and responsibilities, and other paraphernalia, in addition to a 5-page consent form for general medical care. I read it only out of sheer boredom while waiting 6 hours for test results to come back. The 47 pages of information in the discharge packet 2 days later were never read.

But what I really wanted was a CD copy of her MRI to take to her follow-up appointment with a different doctor. That, I was told, could be obtained only from Health Information Services, which wasn't open on a Sunday.

This experience has strongly reinforced my prior belief that idolizing autonomy can become counterproductive. Some people have the notion that maximizing autonomy is achieved by increased information sharing, or more practically, adding another form. The word camouflage comes to mind. You can't see the forest for the trees. A hospital a few years ago wondered whether it should notify patients that a surgical resident might perform part of the procedure. The best advice seemed to be yes, include a sentence about that on the consent form. Almost no one will ever see it.

Medicine desperately needs its own version of the Paperwork Reduction Act of 1995 (PRA). I say this not to reduce the burden on the physician, but as a patient advocate hoping to improve the focus on important facts, thereby actually enhancing decision making rather than obfuscating it.

Having government paperwork to reduce paperwork seems a little, no, a lot, oxymoronic. However, the administrator of the OIRA appointed by President Obama is Cass R. Sunstein, one of the authors of a book called, "Nudge: Improving Decisions about Health, Wealth, and Happiness."

Advertisers have accumulated a vast science on how to influence people to buy things they don't need. "Nudge" suggests it is time to use that research in behavioral economics to nudge people to default toward making good decisions. This approach, called libertarian paternalism, may also seem like an oxymoron. But then, lately, so is the term informed consent. ■

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IMPLEMENTING HEALTH REFORM

Medical Home Demo Project to Launch

The patient-centered medical home, which has been promoted by primary care organizations for decades, is finally getting some attention under the Affordable Care Act.

The concept, which calls for greater coordination of care and a team-based approach, is one of several care delivery improvement ideas being tested under the new health law.

This summer, government officials are accepting applications from federally qualified health centers to be part of a 3-year demonstration project. The project, which will run from September 2011 through August 2014, is designed to figure out what resources health centers need to become successful medical homes that improve care and reduce costs.

Under the Federally Qualified Health Center Advanced Primary Care Practice demonstration project, the federal government will pay health centers a monthly care management fee for each eligible Medicare beneficiary who receives primary care services, on top of their regular Medicare payments. In exchange, health centers must pursue Level 3 patient-centered medical home recognition through the National Committee for Quality Assurance. The project is being run jointly by the Centers for Medicare and Medicaid Services and the Health Resources Services Administration. CMS and HRSA will spend $42 million over 3 years to fund up to 500 health centers under the project.

Whether the fee of $6 per patient per month is enough to leverage change depends on how many patients are served.

DR. GOERTZ

Dr. Roland A. Goertz, the president of the American Academy of Family Physicians, explained how this project could shape future payment policy for primary care physicians.

RHEUMATOLOGY NEWS: This project sets out to test what is needed to help health centers make the transition to patient-centered medical homes. What does the existing research tell us about the necessary ingredients?

Dr. Goertz: The five most important ingredients are a true team approach to care; clinical information systems such as e-prescribing, electronic medical records, registries for common chronic illnesses, and electronic patient access via a patient portal; training for all members of the care team in "patient self-management support" and between visit follow-up; care coordination for patients needing care outside of the medical home; and integration with community resources and the medical neighborhood.

RN: Under the project, health centers will receive a care management payment of $6 per patient per month. Is this enough?

Dr. Goertz: Federally Qualified Health Centers that participate will be paid care management fees only for the Medicare beneficiaries attributed to them. As grantees, the clinic sites will also receive free technical assistance and training resources and funds to cover survey costs.

Health centers will need to make a determination if they are ready for the transformation and whether the care management fees will cover their increased costs.

The fees will not be enough to leverage change if the Federally Qualified Health Center serves only a small number of Medicare patients.

–Interview by Mary Ellen Schneider

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