

Doctor and Patient May 23, 2013, 3:56 pm

# Disability and Discrimination at the Doctor's Office

By PAULINE W. CHEN, M.D.

## Doctor and Patient

Dr. Pauline Chen on medical care.

In his 60s, overweight and in a wheelchair, the patient had been seeing doctors and nurses regularly for his diabetes. Only recently had they discovered a pressure sore after someone had finally, as he put it, “wanted to examine at my backside.”

The oversight struck me as unimaginable. Until I watched another doctor try.

My colleague, a strapping man in his 30s, wrapped his arms around the man's torso to lift him onto the examining table but could hardly budge the patient. A few members of the clinic staff came in to help, each taking a limb. Several minutes later, one of the nurses called for security. Two burly men in dark blue uniforms joined the fray, grunting as they finally extricated the patient from his chair.

A nurse lunged forward to unbuckle the patient's belt while a medical student began yanking on his sneakers, but with each tug and jerk, the guards' grip on the patient's torso loosened. Feeling himself slipping, the patient grabbed at the shirt of one of the guards to break his fall. The

guard lost his balance and reached for the wheelchair, but its brake was not engaged. The wheelchair spun, hitting the medical student and nurse and knocking over the other guard as the patient, pants half off and one shoe missing, collapsed back into its seat.

No one was hurt. But when my colleague leaned down to ask the patient how he was, he stopped himself midquestion. Though the patient's black baseball cap now partly obscured his face, it was clear to all of us what his expression conveyed: utter humiliation.

No doubt the patient is far from the only one suffering such embarrassment, as a recent study published in *Annals of Internal Medicine* on why people with disabilities still receive such subpar care makes clear.

It's been nearly 23 years since the Americans With Disabilities Act, a federal law prohibiting discrimination against people with disabilities, went into effect. Despite its unequivocal language, studies in recent years have revealed that disabled patients tend not only to be in poorer health, but also to receive inadequate preventive care and to experience worse outcomes. One study even uncovered significant disparities in the diagnosis and treatment of breast cancer in women with disabilities.

But it's been difficult to pinpoint exactly why. Just as there are disparities in health care for people with disabilities, financing for disability studies also falls short, so many experts and advocates have had to rely on small surveys, anecdotal samplings and their best "guesstimates."

Now Dr. Tara Lagu, a physician-researcher at the Center for Quality of Care Research at Baystate Medical Center in Springfield, Mass., and the lead investigator of the latest report, has identified some of the root reasons her own patients with disabilities were receiving such substandard care. With no external support or research grants, she and her co-

investigators first created a fictional patient based on many of Dr. Lagu's real cases. The "patient" was partly paralyzed as a result of a stroke, could not get out of a wheelchair without significant assistance, weighed roughly 200 pounds and needed additional, specialized medical evaluation.

The researchers then called more than 250 doctors' offices in four major cities across the country that offered care in areas like gynecology, urology, psychiatry, endocrinology and orthopedic surgery. The researchers presented themselves as the doctors that they were, and tried to make an appointment for the fictional patient.

One out of five offices refused to even book an appointment. Some explained that their buildings were inaccessible to people in wheelchairs, but most refused simply because they had no equipment like height-adjustable examining tables and chairs, specially designed weight scales or trained staff members to help move the patient out of the wheelchair.

But even the offices that agreed to see the patient were not necessarily offering appropriate care. When pressed, some acknowledged that they had no plans or equipment for moving the patient. Others said that they would complete only the parts of the exam that they could — and forgo the rest. Fewer than 10 percent of these offices had appropriate equipment or employees trained to help patients with disabilities.

"People assume that just because we are health care providers, we are accessible to patients," Dr. Lagu said. "But in fact, the vast majority of practices are probably doing things that if I were disabled, I would not want to have done."

Many of the doctors' practices were eager to explain why they refused to see the patient, unaware, it seemed, of the legal implications of their refusal. Some said the patient was "too heavy." Others brought up the potential litigation risk if the patient or a staff member was hurt during a transfer.

Dr. Lagu also suspects that time and financial constraints are important obstacles. Height-adjustable exam tables, for example, can cost \$4,000 or more, at least four times as much as a standard table. And even with federal tax credits and deductions for disability-related equipment, the additional work of transferring can take up more office time, none of which is reimbursed.

“Health care is really one of the last bastions of this kind of discrimination,” said Dr. Lisa I. Iezzoni, author of an editorial accompanying the study and a leading expert on disability who directs the Mongan Institute for Health Policy at Massachusetts General Hospital in Boston. “But it’s curious because we’re talking about health *care*.”

The situation may improve over the next few years. While the Americans With Disabilities Act has improved accessibility, it lacks detailed requirements for medical equipment and furnishings. Under new provisions in the Affordable Care Act, a panel of specialists is convening to discuss specific guidelines and will present a list of recommendations to several federal agencies this summer, recommendations that Dr. Lagu believes could help address the problems uncovered by her study.

“Any one of us could become disabled,” Dr. Lagu said. “But none of us should have to face these kinds of disadvantages.”