

Section Editor
Michael H. Brooke, MD

Steven P. Ringel, MD

Address correspondence and reprint requests to Dr. Steven P. Ringel, 12631 E. 17th Ave (B185), Aurora, CO 80045 steven.ringel@ucdenver.edu

RESTRAINTS AND CONSTRAINTS

Javier's* wrists and ankles were bound in iron bands and attached to a chain that circled his waist. He shuffled into my office wearing an orange jumpsuit and shoes without laces under the watchful eyes of 2 armed prison guards. Having treated Javier for myasthenia gravis for 15 years, I had grown accustomed to the shackles that were necessary when a convicted criminal serving a lifetime sentence in our state Department of Corrections is transported 100 miles to see me. But these visible reminders of his incarceration were relatively insignificant compared to the other constraints in my longstanding doctor-patient relationship with prisoner number 32267.

The first time I examined Javier is etched vividly in my memory. He couldn't walk, his eyelids were drooping, and he couldn't smile or hold up his head without support. More ominously, his speech was slurred and his breathing was shallow. It only took me a few minutes to decide that I had to admit him to our intensive care unit to support his breathing, to prevent aspiration, and to do a few quick tests to confirm my suspicion of myasthenia gravis.

I was amazed that Javier hadn't been sent to me sooner since his symptoms had been progressing over many months. As it turned out, the guards and prison doctors had concluded that he was malingering. Years earlier, Javier's spleen and part of his bowel had been removed following an accident. The surgery left him with digestive problems and chronic abdominal pain so Javier was constantly asking for a special diet and narcotics to alleviate his abdominal pain. The prison staff felt manipulated and grew increasingly deaf to his requests for medical care. Although their attitude seemed shocking at first, over time I begin to appreciate the complexities of prison culture and why staff was so distrustful of Javier.

The picture I remember of Javier in the intensive care unit was also far from ordinary. He was totally unable to move and was tethered to a ventilator, yet 2 guards chained him to the bed and stood a few steps away day and night. Fortunately, the diagnosis of

myasthenia gravis was correct, and our aggressive treatment rapidly reversed his weakness. Before long, he was talking and eating and we prepared to transfer him with his armed guards back to prison.

I had started Javier on several medications to counteract his overactive immune system and scheduled his return in a few weeks for surgical removal of the thymus gland in his chest. Unfortunately, he didn't fully comprehend much of what I tried to explain to him about his illness and treatment. I wasn't certain if he was even capable of understanding the clinical issues related to managing his myasthenia. Complicating his management further, his prison doctors and guards had never cared for someone with myasthenia gravis. Having treated other patients with "brittle" myasthenia, I needed close monitoring and a partnership with my patient and his caregivers to be successful. As it turned out, the gap in medical knowledge of Javier and his doctors was not the only constraint I would face in providing him care.

Getting to know Javier proved to be quite a challenge. He was literally and figuratively guarded. He had no family or friends who I could turn to for help. His previous medical records included social worker reports that painted a bleak picture of his childhood. He had been a disciplinary problem at home and had been arrested on several occasions for shoplifting and assault. His mother was an alcoholic whose only response to his poor behavior was to beat him physically, after which Javier would run away. He never knew his father, and his 2 older brothers were in jail. He had failed special education classes, dropped out of school, and served time in the state's juvenile correctional facility. As a young adult, he was arrested for drug possession, robbery, and assault, followed by repeated incarcerations. Eventually, he was sentenced to life in prison under our state's habitual offender statute. At age 36, when I began to treat him, although he had never committed a violent crime, Javier had been in the state penitentiary most of his adult life and was unlikely ever to be released.

Six months after his thymus was removed, I received a call from Marilyn, a pro bono defense attor-

*Names and other details have been changed to protect identity.

ney who was investigating a civil rights claim that Javier had filed against prison staff. He accused them of being poorly responsive to his requests for help before his diagnosis and for continuing to provide him substandard care. Strange as it sounds, I welcomed the opportunities I had over the next year to talk with Marilyn to learn more about Javier. She was the one person outside the penal system I could talk to about his management. I didn't understand why Javier was moved so often between prisons, why I had to deal with new doctors all the time, and why he didn't come to many of his scheduled appointments. When I wanted to write letters to his physicians describing my recommendations, I always had to ask the guards and Javier where to write. His doctors made no effort to contact me and were difficult to reach by phone. I subsequently learned that many of the doctors worked part time at a prison and didn't stay in the position very long. I couldn't imagine that it was easy or rewarding to deal with the clinical realities of correctional health care and assumed that recruiting suitably qualified and trained physicians to work in prisons was difficult.

Marilyn also explained why Javier seemed to move so often and missed scheduled visits with me. He would intermittently act out and would be moved to a more secure environment. I began to learn the coded language of the penal system. If he was disruptive, Javier would be placed in a "diversion program" designed as an alternative to "long-term administrative segregation." There were 5 levels of security, with the most dangerous and disruptive prisoners housed in level 5 facilities. When Javier was in level 4 or 5, he was not allowed to make the trip to see me. If he and others in like circumstances behaved, then they were allowed a "progressive reintegration opportunity" and more privileges. Although physicians learn to rely heavily on direct communication with patients, their families and friends, and their health care providers, I was constantly meeting roadblocks, if not dead ends, with all those well-established approaches.

A year after I began my conversations with Marilyn, I received a subpoena to testify in the US District Court regarding Javier's civil rights claim. I was quite ambivalent about my impending testimony. Although Javier's initial diagnosis was excessively delayed because of inattention, I had witnessed first hand his manipulative behavior. Every visit, he would spend most of the time urging "medical prescriptions" that would allow him special privileges. His requests had little to do with treating myasthenia gravis and were really intended to break up the monotony of his day and ease the severity of prison life.

Despite my conflict over his motives, he ultimately prevailed, and the settlement contract included training for the Department of Corrections staff, an individualized plan of medical care, and regularly scheduled calls between me and the prison physician overseeing his care. I was optimistic that this intervention would help both him and me in managing Javier's myasthenia, but with time I increasingly saw the futility of the contract. Javier continued to miss many of his appointments, and many of the scheduled calls never took place. As I continued to see Javier over the next decade, my physician-to-physician exchanges were with a dozen different physicians who serially were assigned prisoner number 32267.

Javier required high-dose corticosteroids as well as additional immunosuppressive medications for many years. Not surprisingly, his medical complications began to multiply. He gained weight, and developed recurrent infections, a peptic ulcer, mood swings, and alterations in sleep. Over time, his spine progressively collapsed, causing him intractable back and leg pain. Because of widespread changes, spine surgery was ruled out as an option and medications prescribed to control pain were met with skepticism by his prison doctors. They were convinced that Javier was manipulating me so he could receive narcotics. Admittedly, I was also uncertain of Javier's motives, since every time I saw him he wanted stronger pain medications and urged me to tell the prison doctors to extend him some new medically indicated privilege that made his day-to-day existence slightly easier.

Javier's visits continue to occur unpredictably. The guards who accompany him to my office are reluctant to leave me alone with him, so we never have a confidential conversation. Treating him is certainly not the same as caring for most of my patients. But, surprisingly, I've come to appreciate that the restraints and constraints I face with Javier are mere exaggerations of the barriers physicians encounter in the care of any patient. There are many people in need of medical care who have poor environmental support, little money, overwhelming psychosocial stresses, or limited education. As doctors, we see those people every day. As a prisoner, Javier has decreased independence, choice, and access to care, and he confronts a certain amount of abuse and coercion. Despite these limitations, his survival outside the prison walls is unlikely given his complex medical needs.

Although recent health care reform debates emphasize that physicians should provide "standard" health care to all individuals, the complex reality of imprisonment highlights the many barriers we

face in achieving that goal. In treating Javier, I've learned to adjust to the rigid and punitive views that are acculturated in a prison environment. I've faced my own biases and emotional reactions in caring for someone who does not share my values, who has committed crimes, and who is manipula-

tive. It is a constant challenge for me to remain nonjudgmental and to be an ally to him. I keep trying to understand what he wants, thinks, feels, and experiences, and to remind myself that our system failed him as a child. I try not to add to that breakdown.

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Reflections for July: RESTRAINTS AND CONSTRAINTS

Steven P. Ringel

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