MEDICINE AND SOCIETY

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The Best Medical Care in the World

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The first few days he was here, they didn't know about his defibrillator. That would seem shocking in a palliative care hospital where people come to die, but to one who knows Kenneth's story, it's no surprise. He didn't tell them about the ICD, and the doctors didn't ask. (Why would they? Do you ask your patients if they happen to have an implanted cardioverter–defibrillator?) They've seen the computer disk that accompanied Kenneth here in the ambulance, but there's no way they've read the 5000 digitized pages of medical records from the 19 inpatient institutions where he spent the past 18 months. And even if they did, they might easily miss that one-liner buried in his "past" medical history: "S/P CABG and AICD, 2015." Remarkably, in every one of those institutions — seven acute care hospitals, two psychiatric centers, five acute rehab facilities, and five nursing homes — Kenneth's ischemic, arrhythmic cardiomyopathy has been the least of his problems. Now, with his defibrillator discovered (and deactivated), it will be part of the solution.[1]

On the bedside table is a photograph of a handsome young man with his beautiful blonde wife. Kenneth's friends wince when they see it: his aging is not the work of time alone. With his snow-white beard and twinkly blue eyes, he'd make a fine Santa Claus if he hadn't lost a hundred pounds. Instead, at 68, he's a dead ringer for his father when the old man was dying at 91. Kenneth's siblings don't know that this "mortality gap" is the national mean for people with severe mental illness, though another brother, also "touched with fire," died in his 40s.[2,3] But like Kenneth's big heart, 50 years of mania and depression aren't why he's here.

He asks me to reposition his legs. His instructions are detailed, precise, experienced: first the right leg, then the left, hands on the midcalf, not the ankle or knee, don't lift it, please, just slide it, no, not there, a bit more, there, yes, there. Even this passive activity fatigues him, makes him thirsty. I hold the cup, the straw, so he can drink. "Ah!" he says, licking his lips, so grateful, so *cheerful.* Hemingway's "grace under pressure" doesn't begin to describe it. When a friend comes to visit and play the flute — tunes from *West Side Story* are his favorite — Kenneth sings along loudly, joyfully, too moved by the music to just lie there and listen. He didn't sing before he lost the use of his arms and legs. Now, quadriplegic, he sings.

For months, Kenneth had declined to file a malpractice claim. A graduate of a top-tier law school — Kenneth was a senior executive administrator at a major university before he turned 30 — he knows whereof he speaks. But it's not his legal knowledge that makes him less litigious; it's his empathy for his caregivers, his capacity to forgive. *I'm not an easy case, you know? They did the best they could.* He reconsidered only when a friend mentioned Kenneth's kids, so young years ago when he went off the rails for good. *Wouldn't you like to leave them something after you're gone?* Bankrupted by medical bills, Kenneth said with a hitch in his voice: *Yes. Yes, I would.*

The negligence is indisputable. The only dilemma will be whom to blame; the suspect list is long and libelous. Is it the first hospital, where the police brought him, incoherent and incontinent, after his fender-bender? (Kenneth complained of neck and arm pain a few days later, but his transfer to the psych hospital had been approved, not an opportunity to miss.) For the next month, Kenneth, still in pain, was confined to a wheelchair; the psych hospital's putative purpose was patient safety. Is that where they missed it? Or was it the rehab facility where he

went next, "weak and deconditioned, in need of intensive physical therapy"? The staff there heard his pain: they obtained a cervical spine x-ray ("mild degenerative changes") and prescriptions from the doctor who "saw" Kenneth. Combined with his four psychotropic medications, those opioids and sedatives had the desired effect. But whenever relatives telephoned him, day or night, the staff would answer. *He's asleep. Do you want us to wake him?* Kenneth's sister, his legal guardian, flew west to visit him. Inexperienced in medical matters but alarmed by Kenneth's stillness, his "refusal" even to hold a spoon, she asked about his arms and legs. *Yes,* Kenneth's nurse reassured her, *isn't it remarkable what the mind can do? It's like his head isn't connected to the rest of his body!*

Hard to believe? The next three institutions missed his quadriplegia, too. When he was transferred from the rehab facility to a local hospital (a different one) for "suspected bowel obstruction and renal failure," Kenneth's quietude from the neck down elicited no curiosity. Unnerved by Kenneth's persistent "refusal" to answer the telephone, a brother who lived far away asked his nurse: *Has he had a neurological examination?* The nurse was righteous: *That's not why he's here. He's here for a GI workup.* This mission was accomplished — the workup comprised a plain film of his abdomen plus "careful observation" — his discharge diagnosis read "acute *paralytic* ileus and urinary retention" (my italics, but I kid you not). After transfer to an acute rehab facility (a different one), Kenneth's new bladder catheter worked but the high-fiber diet didn't. Soon he was back in the hospital (a different one) where, at his brother's insistence, someone examined Kenneth's limbs. Sure enough, there seemed to be a problem. This discovery prompted a consultation — by a psychiatrist.

Kenneth was depressed, the consultant concluded, his "psychomotor retardation" likely to benefit from a change in his psychopharmacology. On the telephone with Kenneth's brother, the psychiatrist conceded that he might be depressed too if he couldn't move his arms or legs. Largely to appease the brother, the psychiatrist recommended a neurology consult. The neurologist wanted STAT imaging of Kenneth's cervical spine — his neuro exam was "clearly myelopathic" — but the defibrillator nixed the MRI. After plans were initiated to transfer him urgently to a tertiary care center, Kenneth's brother called again. *He hasn't been moved yet? What's the delay?* On the phone, a voice whispered frantically in the background: *No, no! That's the doctor brother! We can't talk to him!*

The lawyers, of course, will want to know the rest of the story. (Legally, it's not the negligence that matters, it's the loss incurred, the damage done.) Given the delay in diagnosis — CT myelography showed "multiple disc herniations with severe cord compression at C3-C5" — Kenneth's neurosurgeon predicted postoperative results no better than "improvement of neck pain and possible return of some upper extremity function." And indeed, 6 months later, Kenneth's neck felt better and he could wiggle fingers on one hand. But the neurosurgeon never heard the rest of the story. Months of drug-induced stupor and delirium. Repeated hospitalizations for "urosepsis" (never documented), each time treated with weeks of broad-spectrum antibiotics. Intractable colicky diarrhea (refractory *C. difficile*). And finally, that Stage 4 sacral decubitus the size and smell of a large rotten pizza. Surely, this saga would satisfy the lawyers' need for "pain and suffering." They will want to depose Kenneth soon, get it all on video before he dies, especially that bedsore.

It's hard to know how much of this debacle to blame on the "passivity driven by pernicious bias" against patients with psychiatric disease.[2] Kenneth described this phenomenon decades ago. *Once they find out you have a mental illness,* he said, *it's like the lights go out.* In her incisive essays about medical care for the mentally ill, Rosenbaum highlights the larger problem: "Care integration is an attitude."[2] But this "attitude problem" affects countless U.S. patients, not just those with mental illness (or severe physical disabilities, like quadriplegia).[3,4] Whose attitude, then, needs adjustment?[5] Many doctors and nurses seethe about the profit-driven dis-integration of our health care "market" yet insist they can't fix this mess themselves. Kenneth, no stranger to cognitive dissonance, said, *Well, if they can't fix it, who the hell can?*

This question becomes more urgent as our health care system's balkanization becomes increasingly "normalized." Consider, for example, Kenneth's transfer from his fifth acute care hospital to his fourth rehab facility. There, finally, the specter of care integration seemed to mate-

rialize; the rehab facility shared a building with both the hospital and an inpatient psychiatric center. Surely here Kenneth could receive all needed care. The admitting rehab doctor noticed that Kenneth was severely anemic. Iron-deficient with heme-positive stool, Kenneth needed a "real" GI workup. Never mind why this problem hadn't been addressed in the hospital or why no one knew about Kenneth's subtotal colectomy years ago for a large premalignant villous adenoma (or his brother's death from colon cancer). No harm, no foul, right? The hospital's GI endoscopy suite was about 30 paces from Kenneth's rehab room.

Unfortunately, the rehab facility was a "separate institution" from the hospital; it merely rented space in the building. So wheeling Kenneth down the hall to the hospital's endoscopy suite would require discharging him from the rehab facility and "readmitting" him to the hospital, a punishable offense.[6] Instead, Kenneth required transportation in a specially equipped ambulance to an outpatient endoscopy center across town, first for his preprocedure visit and then again for the procedure. Weeks later, Kenneth had been transfused with red cells and treated with parenteral iron, but the endoscopy center refused to do the procedure, concerned that Kenneth wouldn't tolerate conscious sedation (though he'd been consciously sedated for months). Entreaties to perform the procedure at the hospital down the hall were rebuffed because Kenneth's problem did not meet criteria for "emergent hospitalization."

The absurdity upset even Kenneth's equanimity. He became anxious, couldn't sleep, needed psychiatric help. That couldn't be arranged, either. The psychiatric center, one floor above Kenneth's room, was a separate institution, too.

Ultimately, his family brought him home. A private "angel" air transport service flew him east for half price, only $15,000. (Read the fine print before trying to fly a quadriplegic person on a commercial airliner.) Kenneth was admitted to the best hospital in his hometown, where he'd received all his care before he went west several years ago. There, finally, it was all sorted out: not one cancer but two, both still technically curable but, in the big picture, untouchable. Kenneth died peacefully at the palliative care hospital shortly thereafter, surrounded by loved ones (and undisturbed by his defibrillator).

He never heard about his lawsuit. A big-league personal injury attorney concluded that Kenneth's case had "obvious merit" but no potential for compensatory remuneration. In the state where all this happened, medical malpractice law caps awards for "noneconomic" damages at such a low level that a successful suit wouldn't cover attorney expenses, much less leave Kenneth's kids anything. Had Kenneth known that the law valued his future (poverty-level) income more than his pain and suffering, he would have said this was just another example of our attitude problem.

At the funeral, folks reminisced about Kenneth's mischievous grin and big laugh, so easy to love, such fun to be around. When Kenneth's sister thanked the doctor-brother who "made sure Kenneth got the best medical care in the world," people nodded knowingly, confident they would get the best when their time came, too. The only one there who knew the real story didn't speak, resting silently on the altar in an urn. But the doctor-brother says Kenneth's been speaking to him every day now, and he says Kenneth wants you to know the real story, too.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

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