Hearing voices

John H. Stone, MD, MPH

The author is associate professor of Medicine in the Division of Rheumatology at Johns Hopkins University School of Medicine. He directs the Johns Hopkins Vasculitis Center and serves as the deputy director for Clinical Research at the Johns Hopkins Bayview Medical Center. Dr. Stone is a Hugh and Renna Cosner Scholar in the Center for Innovative Medicine at the Johns Hopkins Bayview Medical Center.

ight years after hanging up with the transferring doctor, I still remember thinking as the receiver clicked down: This is going to be complicated. Felicia, a 26-year-old city jail clerk, had lupus. Diagnosed several months before in some other place, Felicia had "fallen through the cracks," coming to rest that Friday afternoon at my hospital. Details of her medical history, though sketchy, were worrisome: low platelets, falling hematocrit, rising creatinine, altered mental status. And one other challenging but fuzzy detail: a history of possible "psychosis." The discharge summary faxed from the other hospital shed no more light. This was going to be complicated, indeed.

When I met Felicia, her hair was matted, the edges of her mouth crusted, her teeth unbrushed, her gown in disarray. Though she was "oriented to person, place and time," her thought processes seemed profoundly disturbed. As I watched, Felicia mostly peered straight ahead as though afraid to look to either side. She spoke curtly, but only when spoken to.

If her mental status was disturbing, her bloodwork looked even worse. Felicia's daily platelet count had been sinking fast—132,000 ... 115,000 ... 39,000 ... 22,000—and despite several blood transfusions, her hematocrit hovered around 20 percent. Her peripheral blood smear told the tale: bizarre, irregularly-shaped red cells and fragments littered the slide. Felicia had thrombotic thrombocytopenic purpura, known more often by its sleek but sinister initials, TTP.

As a second-year student struggling to remember the causes of anemia, TTP had captured my imagination through its unforgettable mechanism of destroying red cells. Within the small blood vessels of patients with TTP, strands of fibrin stretched themselves across the walls of blood vessels like tiny razor blades. These strands—as we were taught then—guillotined the innocent red cells percolating through the small vasculature, converting healthy, oxygen-carrying cells to schistocytes (the Greek root, skhistos, means "to split"). Skhistos also forms part of the word schizophrenia, or "split mind." As I pondered how to treat her TTP, I also wondered



if Felicia's alleged psychosis figured into her current mental state. It wasn't clear.

Desperate to combat the lupus flare that we assumed to be the trigger of her condition, we gave Felicia more huge doses of steroids on top of those she had already received. And after a long conversation with her family about the urgent need for plasmapheresis to remove "toxins" from her blood, the surgeons inserted a large-bore catheter in her neck so that we could begin treatment. With a platelet count that was still grimly low, her line insertion site oozed blood all night.

Despite plasmapheresis, Felicia's mental status declined. At first she was just less responsive—somnolent, but still following commands. Later, she struggled mightily in bed, calling for her father who had died some years before, and for her Bible. She tried to pull out her plasmapheresis line, and to bite anyone attempting to touch her. Examining her for signs of bleeding, changing her catheter dressing, and drawing blood to monitor treatment became major ordeals not only for her, but for her nurses and house officers, who prepared

The Pharos/Spring 2006

like a SWAT team. Felicia had delusions of nosebleeds and often cried hysterically "something is on my face." At other times, she erupted in salvos of gospel singing; the intern once opened her door to find "the patient singing like a banshee in her room." She required a sitter in the room at all times to protect her from herself. Periods of outbursts required heavy sedation. And over her hospital gown, around her torso and tied in the back was a restraining vest with heavy cloth ties, for use when all else failed. To help keep her calm, the lights in her room were kept low, the door closed.

After about 10 days of plasmapheresis and prednisone, her blood profile improved. Her platelet count stabilized and began to inch its way up. Her need for red cell transfusions diminished. Oddly, though, as we seemed to gain the upper hand on some aspects of her TTP, her altered mental status assumed a new twist. She began to hear voices. The nurses were the first to detect this. They noted that Felicia seldom interacted at all unless belligerent, but during long plasmapheresis sessions she occasionally responded fearfully to input from beyond the room. "No!" she would mutter. "No!" Pressed for details about these voices—"Are they frightening to you?" (Pause. No response.) "Are they telling you to harm yourself?"—Felicia usually looked confused and grew quiet. But eventually she acknowledged that the voices were there.

Generally, I didn't see Felicia by myself. Whenever I was in her room, I was part of a team of caregivers: on rounds with medical students, social workers, interns, and residents; talking with the hematologists in low tones; standing at the foot of her bed near the plasmapheresis nurse. Never alone. In part, this was due to the intensive care of a sick patient in a busy hospital. There was always someone at work in the room: the nurse, the sitter, the cafeteria worker picking up Felicia's tray, the maintenance staff. But I also knew there was another reason that I had spent little time with Felicia alone: avoidance. Felicia's capacity for violence, for lashing out, biting, and attacking, was frightening. Safety in numbers was reassuring.

One Saturday afternoon when the hospital was quiet and the house staff had already finished rounds, I entered Felicia's room alone. As I knocked and pushed the door open, I remembered that the sitter had been dismissed as Felicia's outbursts had grown fewer. I paused at the door, peering through the dimness to see if she was awake. She was. I greeted her softly and smiled, but realized that she probably had trouble seeing my face, backlit from the bright yellow hall lights. Closing the door but leaving the room lights low, I slowly approached her bed. She lay as she had lain for three hospital weeks. I wondered if she had interacted with any human the entire day.

When talking with patients, doctors-in-training are taught to come close: "Take your hand off the doorknob . . . Go in and sit down . . . Sit at eye level . . . Touch the patient in a nonthreatening way . . . Hold the patient's hand." Judging Felicia to be calm, I eased my way down to sit on the foot of her bed. My extended hand rested on her knee through the blankets, still far enough away for plucking to safety if necessary. My heart sank for a brief moment at the thought of how little Felicia had changed since her first hospital day. Because of her combativeness, bathing in the hospital had been intermittent; her hair remained unkempt, her

teeth unbrushed. In response to my warm-up questions, designed to soothe, she uttered only a few unintelligible words. "Pardon me?" I said gently, and leaned closer. There were long pauses in our conversation as I searched for what to say next. Was there any way of getting through to her? Was a human communication possible today? Maybe not. If not, how to extricate myself gracefully, without making her feel alarmed or deserted? Long seconds ticked by. I fell back on summarizing for her the progress we had made. "Your platelet count—have you heard the doctors mention that term?—is better. You are still in the hospital and have been very sick, but we have been making some important strides. . . ."

As I rambled, Felicia stirred and struggled to sit up in bed. Her movement was restricted partly by her own weakness, her tangled IV, her bulky plasmapheresis catheter and its dressing, the soft eggcrate mattress, and the thick straps of her restraint vest. Only then did I think to notice the condition of her restraints: untied. Uncertain of her intentions, my own inner voices awoke: Leave. Just say goodbye and step out before she gets close. I was frozen. Slowly she rose from the pillow, staring wildly and grimacing at the effort to hoist herself by the bedrail. The thick wooden door was closed firmly. Even if it had been open, we were at the end of the hall, beyond earshot of the nurse's station. The next level of anxiety arose in me: Get off the bed! Call for help! Shout! Get OUT of here! But something held me there as she drew nearer. She mumbled as she rose, reached out determinedly, and then lurched toward my side, bringing her head uncomfortably close to my ear. Through a tangle of sheets, blankets, layered gowns, hospital tape, and an IV, I realized only then that she was hugging me. Startled, relieved, I hugged her back, welcoming her warm tears on my cheek and white coat.

Epilogue

"It's the steroids," pronounced the psychiatrist, whom we had asked to consult on Felicia's mental health and auditory hallucinations. The prednisone, he maintained, had caused Felicia's symptoms of psychosis—not the TTP, not lupus, and definitely not schizophrenia. "Taper them if you can." In the end, thankfully, he was right. We tapered Felicia's prednisone. Her platelet count, hematocrit, and kidney function remained stable. And her inner voices fell quiet.

Eight years later, Felicia still works at the jail. I've gotten to know her much better than the chaotic circumstances of her hospitalization allowed. We marvel together at her transformation from those days. She doesn't remember the inner voices, but believes me when I say she heard them. Her voices have not returned, but fortunately some of mine have remained. They are not voices of alarm, but reminders of the lesson that human contact—being there for talking, touching, and even hugging (sometimes particularly hugging)—are essential for people who are critically ill. And for those who provide care.

The author's address is:

The Johns Hopkins Vasculitis Center 5501 Hopkins Bayview Circle, 1B.23 Baltimore, Maryland 21224 E-mail: jstone@jhmi.edu