

FIELD NOTES | SPRING 2014

Love and Medicine

By Jennifer Stella

Stably sick. Many patients, many families, might not appreciate our divisions between "sick" and "not sick." It's common enough to be in the hospital, yes, but "not sick." The sick ones take more time. The crashing ones—*crumping* is more common in parlance, but I still prefer the latter—take more time. More time in the room, more time on the phone or face-to-face with the family and with other providers, more time on documentation and reading old records. I've worked in places where people were poor. Yet somehow, in the Bronx, so many are that—and so many are sicker (than in other parts of the US). I'm not in the ICU, but I may as well be. Many of them should be.

But this means so many of my patients are tied to their beds, literally and/or figuratively. Lines and tubes. The breath capacity to cross just half a room before collapsing. Amputated toes and feet and legs. Should-be-amputated limbs. So it's hospital gowns, oxygen prongs or masks, IVs, feeding tubes, breathing tubes, continuous electrodes (and the stickers we absentmindedly leave on), sequential compression devices to prevent blood clots, fluorescent 'FALL RISK' bracelets. An isolation room for whatever infection or risk of infection. They are bedbound, identically dressed, tired, covered in stuck-on gauze for infinitessimal blood draws, barcoded by bracelets. The nurses identify them by room number. I forget those and identify them by name. And because of our ordering system's algorithm, I automatically combine first initial, last initial, age, and sex. The sicker you are, the better I know how old you are. A descriptor, for lack of a more meaningful one to standardize. (The sick-not-sick patient this morning, with biting wit in his jokes, couldn't remember what his birthday was. Or his last name).

The patients who've had strokes and now can't talk, who've contracted illness-after-illness for years and are now defined by a sick role, wasted away limbs, and a nighttime cry, who are literally being kept alive by machines, or who can now do nothing but breathe and cough—I don't know them. I haven't met them, and I never will. So I define those patients by the people who love them, and how.

Today, Ms. M, one of my stably-sick (and completely non-responsive) patients began to actively die. Die actively. It has been a long, passive process for her. Every night, I've drawn labs from a central line (one of my favorite activities, every night. It was the one thing I was

sure to get right). I greet her—it's habit—it's 3 am, and it's like I'm miming a conversation, out loud. Blood out, chemicals back in to balance it. The mathematics of medicine. Eyes open or closed, light always on, a soothing channel on the TV, a sporadic and strong cough to prove a will to live, arms so full of extravasated fluid that the thought of regaining IV access after removing the central line seemed impossible. She caught a cold, it infected her heart, her heart's rhythm mimicked experimental jazz rather than a metronome, a clot snaked or flew up to her brain, she had a stroke and was okay but then there was bleeding after and that pushed part of her brain down into her skull…etc. Etc. But she could still open her eyes (but not follow anything with them, not track like greyhounds on a cheetah track), she could still breath, and she could still spit and cough. She remained. Last night, running in to check oxygen levels in her blood, again (the fingertip monitor), I ran into her sister. And I asked—not just because I cared, partly to make small talk, and partly to make myself care—who my patient was. Who she had been, "before." Someone who helped her twin sons study for the SATs…and then took the test herself, for the first time. Someone who was almost a national track star. Whose first grandson was just born.

And today, Ms. M began to actively die. She had a fever, all of a sudden. She was breathing twice as fast, all of a sudden. Her oxygen was going down. And her heart had tripled its speed. We knew that her family had decided—for sure—to not intubate her. No machines were going to breathe for her (not again). No chest compressions. But "everything else." I tripped over my words as I called her oldest daughter (now next of kin. Husband died ten years ago). "I'll be there in half an hour," she said. I paused. "Good. We'll talk when you get here." And when she did, I presented the options for testing—why test if the decision will be to not treat—in an unsensitive list, trying to just remember what to say and to be factually correct. She was horrified. Why was testing a question? "Aren't you here to save people's lives??" Pause. "We want to make sure we respect your wishes." "Why aren't you helping her??"

I am. I will. And as I sat to draw blood for bacterial cultures from her right radial artery, turning over her wrist and watching her arm, full of fluid, settle in place, I had a few minutes to ask who she is. or was. or is. How and why she'd moved to the neighborhood at sixteen, inflating her age on IDs, picking up part-time jobs at the zoo for her to-be-first husband. How she practically collected three-legged cats. The daughter rummaged through receipts in her wallet. "Here. and here." Her mother—my patient—on her own wedding day. And then the daughter, twenty years later, in the same dress. What she looked like. The face they see and that I would never recognize. Later, a large family is hunched in prayer around a breathing-with-difficulty body in a bed. How much love can fit, cliched, in a fluorescent-lit room.

Another patient's wife. "I know you can't get too attached. You have too many patients. I know. If you cared too much, it would be too hard, you wouldn't be able to stand it. I know.

You can't care too much." Right and wrong. But unusual, because for others, *their* patient is (should be) *our* only. The partner. "One in a million. Forty years. There aren't any others like her..." paranoia, crippling illness, weakness and dependency. In the hospital, they renewed their vows. (The only other person I know who's done that? One of my clinic patients). The best friend who paused. "This...isn't her. This sick. This wasted. After the last time, she went right back to work." "What was her job?" "Dental assistant. She practically ran the place." I consider the patient I've never seen sit up. We wore the same thing to work, but I can picture her scrubs, the stereotype, brightly colored and pastel. She must have closets-ful. Here, she's surrounded by the same clothes, but more uniform. I'm overwhelmed by the trust people put in me, every day, and I'm overwhelmed by the devotion others show. The son who stayed up all night, every single night, by his father's bed. The daughters with endless containers of chicken soup. The niece of the visibly-dying woman who arrived with purple nail polish and hairspray. When there's little else to go on, when the patients are dressed drably and identically in drab and identical rooms, they become distinguishable by visitors and visiting patterns.

When I walked into Ms. M's room this morning, I had a nagging thought that something was wrong. There's little to go on. I rechecked. Oxygen, perfect. Lungs, fine. Or rather, the same. Every reaction. The same. I managed to convince myself that I was wrong, using data. Later in the day, as she transitioned from passively to actively dying, I sinkingly remembered the morning. It was something. I had known. A slight color change, a slight grimace, maybe. I was developing an instinct, morbid or not, practical or not, to trust. Had I said so to the team, nothing would have been different. Nothing would have been done differently. She would have started to die at exactly the same rate. That, Ms. M could tell me herself.

I've written reams about K, my first patient who died. I have two pictures of her in my head. The emaciated body sinking back into the bed that I encountered upon opening the door to room 782. And the one I found when I looked for her obituary. I never met her family or any friends. Somewhere in the gulf between those pictures, the volume she used to take up, was a life, I like to imagine, well-lived. And loved. I wish every chart was emblazoned with a "before." I was too afraid of K's pain, death, and slow dying to ask enough about who she was—I didn't admit her to the hospital, and I didn't think of asking until she really was too tired for questions. I counted her platelets. I got mad at her oncologists. Back then, I was younger than her. Now, I'm older than she'll ever be. My job includes more counting of more platelets/ particles and chemicals of blood than I might have understood, then. If that was most of what mattered, medicine would be a science. It isn't.

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