

I'm Not Talking to Anybody

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Turning the Tables

One of the basic tropes of doctor-writing is the physician forced all unwilling into being a patient. I have rung this bell myself, over and over (yes, never send; it tolls for thee), starting with my wise-ass second-year medical student self, writing to the editor of the *New York Times Magazine* to say, here I am, pregnant and in medical school, and what they teach us in my reproductive pathophysiology class does not overlap in any way with what I learn in my birthing class, and wouldn't that make an interesting article?

I've done it again and again, and we all do it, all of us who write the sensitive stories of doctoring. I have day surgery and argue with the protocols, or insist on staying awake to have my wisdom teeth extracted, and I learn something about power and powerlessness, or about pain and stupid stoicism. I experience the pediatric ward as a parent, and I learn a different way of understanding the parents who during my on-call resident nights on that same ward insisted on interrupting my admission workups or hanging over me, judgmental, as I started IVs and struggled to draw blood.

This turning of the tables is both truth and trope; you learn something profound by being the object, rather than the subject, of the delivery of care. You understand yourself differently by looking from that putative other's perspective, and you gain some understanding of the others.¹ But as you can probably tell, I've come to be a tiny bit suspicious of this experience and what it teaches us. There are physician-writers who have told some amazing and

¹ It's a little bit precious, perhaps, to think that you are actually gaining the patient's perspective. You may be gaining some hybrid over-intellectualized and perhaps occasionally self-congratulatory pedagogical patient perspective—but it will have to do until the real thing comes along.

moving stories out of being on the wrong end of the doctor-patient relationship,² either because of their own illnesses or those of their children, or their parents. I might cite, for example, the piece by Dr. Jerald Winakur in *Health Affairs*, “What Are We Going To Do With Dad?”³ in which a geriatrician reflected with heartbreaking honesty on the realities of aging and of caring for an “old old” parent. Yes, the familiar tropes are there—the empty value of all your hard-won medical knowledge, the tragic difference when the rules, this time, apply to you and yours. But there is a kind of fierce truth in this particular story which transcends the genre; the anger is not easily resolved; the geriatrician, correctly, rails not only at a crazy medical system, a reimbursement structure out of whack, but also adds in some of the underlying howl of Lear on the desert heath: it is not fair that it should come to this, and all our puny efforts to mitigate, codify, and medicalize are only chicken scratches on a vast darkness.

At the Bedside, 2014

I am sitting in a lovely private room, easily the nicest hospital room we have been in during this current journey through the New York City hospital system,⁴ looking out the window over the

2 I don’t mean to suggest that there truly is a “right end” and a “wrong end” in the doctor-patient relationship. I know—really, I know—that it’s a privilege to care for people, that there are elements of partnership in all healing relationships—but I also know that if you have to choose between being the doctor or the patient when it comes to being sick, you should go for the earpiece end of the stethoscope.

3 This 2005 essay, the single most downloaded essay ever published in the Narrative Matters column of the journal *Health Affairs*, later grew into a book, *Memory Lessons: A Doctor’s Story*. Dr. Winakur wrote poignantly about the moment of joy when he was able to present his now confused father with the news of a book that would be all about him—and, of course, about his decline.

4 Nicer than the double room at Hospital A where she recuperated after the hip surgery; nicer than the ICU room at Hospital A; nicer than the double room at Hospital B where I took such comfort in the academic stroke team;

upper reaches of Central Park,⁵ and sometimes when I stand up to approach the bed, looking down at the people walking, scooting, hailing cabs, and thinking, as one does, about all the hundreds and thousands and millions of people going on with their lives and not in this hospital room.⁶

And in the bed is my mother, my dear mother, my mother whom I have helped walk all over Trinidad in 2003, all over India in 2005, and more recently, all over New York City, my still-teaching professor writer mother who had, she said, the most exciting day of her life last November, when the *New York Times* ran her “New Old Age” column and she got hundreds of online responses, my mother who was ecstatic at the Globe “Twelfth Night” just three months ago—now lying on her left side in a light blue hospital johnny with her mouth open in a rictus of agony and despair.

nicer than the rooms at Rehab C where she groaned and moaned—but occasionally took comfort, ate yogurt, and listened to music; nicer than the single room at Rehab D that we were so proud to achieve, where no one ever came in, no matter what.

5 To be fair, Hospital E is charging us more than \$500 a day to be in this private room, though as soon as they ordered stool samples for *C. diff*, she was automatically on contact precautions, so maybe we should go and try to make them give us back our money—but I suspect that has never happened in the history of the world.

6 No accident that this week in the personal essay writing course that I teach in the NYU journalism department, I assigned, for a class on “travel essays,” the David Foster Wallace essay “Shipping Out” (so you can see what inspired all these footnotes, including this particularly self-referential one), and the David Sedaris essay, “Journey Into Night,” which includes a reflection on precisely this subject: “I could feel him watching as I cut into my herb-encrusted chicken, most likely wondering how anyone could carry on at a time like this. That’s how I felt when my mother died. The funeral took place on a Saturday afternoon in November. It was unseasonably warm that day, even for Raleigh, and returning from the church we passed people working on their lawns as if nothing had happened. One guy even had his shirt off. ‘Can you beat that?’ I said to my sister Lisa, not thinking of all the funeral processions that had passed me over the years—me laughing, me throwing stones at signs, me trying to stand on my bicycle seat.”

“Please help me!” she cries. “Help me! Help me! Please! Help me!” Her eyes are closed as she says this over and over. Sometimes she weeps. Occasionally she slips into what looks like sleep, but after a few minutes, she stirs. Her right hand claws the air, and then it comes again: “Help! Help! Help! Oh, God! Please God! Somebody help me!”

She cries, “Ow, ow, ow, ow!” though when I ask her whether she has any pain, she says no. When I say, “I love you, Mama,” she replies obediently, “And I love you.” When I try to give her an ice chip, she calls me a bastard.

I have been here since 7:30 a.m., and it is now 3:30 in the afternoon. She has been crying out like this all day. I have asked the resident to come and assess her at least three times (and he has come). I have had them give her Haldol and Dilaudid and more Haldol and more Dilaudid. I have asked the resident to call the geriatrics team and see if they have any more ideas (they don’t). I have stood in the room at the bedside and sobbed hysterically. I have stood out in the hallway to get a break from the agony of my mother. I have conducted departmental business on my cell phone with tears running down my cheeks.

The resident says to me, “I can just imagine... if this were my mother...” And I understand this to be the equivalent of spitting to ward off the evil eye. The younger, less convincing intern, who was here on the night I stayed over, said the same thing when I asked him to assess her pain. “If this were my mother, I wouldn’t want her feeling like this...” and he gave her more Dilaudid. Perhaps they use this particular trope because I am a doctor. I confess that I wear my Bellevue badge on its Bellevue lanyard round my neck, when I walk into Hospital E, so everyone who deals with me can see the MD on my chest.⁷ Perhaps that helps

7 In this odyssey through the NYC medical world, I have worn that ID in and out of every facility; the only place where I was ever given a second look was at Rehab D, a place that was not a good place for Mama, a place where she deteriorated, unwatched; they may not have paid much attention to her pain, but they were vigilant about my ID, and the first time I tried to walk past the

them identify. Perhaps that helps them be kind, as each of them thinks: *here is a doctor watching her mother deteriorate; I, too, am a doctor, and I, too, have a mother.*

Checking Messages

I kept on working, while my mother was so sick, but everything came back to her. When I taught my graduate class on travel essays, I found that I was really teaching about my mother, telling my students about how the two of us had traveled together and then written about it, but then finding myself in that discussion of life as a journey—and where that journey takes us all.⁸ When the editor at the *New York Times* asked me to write a column about a new study coming out in *Pediatrics*, guess what—it turned out to be about my mother. The study looked at adults’ use of mobile devices as they sat in restaurants with young children.⁹ In other words, the *Times* was interested in whether cellphones were distracting parents from their children just as the *Wall Street Journal* wrote about how the

security desk there, the man behind the desk scrutinized me and asked, are you a family member or are you here professionally—but no one at Hospital A or Hospital B or Rehab C or Hospital E has ever looked, let alone asked.

8 I pointed out to my students that many narratives use travel as a metaphor for the journey of life itself, and that in particular, the essays by David Foster Wallace and David Sedaris make reference to the great cold surrounding darkness through which the airplane flies (yes, yes, the journey into night), or the danger-filled cold and hungry depths over which the self-deceiving luxury cruise ship sails (yes, yes, the shipping out). So much for the glossy photos in magazines devoted to scenery, spas, and sight-seeing. The gods of travel writing, you might have thought, were Kierkegaard (“The most painful state of being is remembering the future, particularly the one you’ll never have”) and Schopenhauer (“Life without pain has no meaning”).

9 Actually, these are anthropological techniques, and my father was a cultural anthropologist, so at first it seemed to me that the column was a little bit about my father, and I thought I might use the term “anthropological,” as a kind of secret tribute to him—my parents wrote, together, an article about having a baby (me) in Trinidad on a field trip, “Birthing in the Bush: Participant Observation in Trinidad,” for a collection entitled *Children in the Field*.

phenomenon of parents texting instead of watching their children was increasing the injury rate.

So I wrote the piece, about how children can feel hurt, neglected, overlooked, when they can't get a parent's attention. Yes, the experts confirmed that face-to-face interaction is the most important thing. I clucked over the parents who can't put down their devices, but I also commented on the long and boring periods of supervising young children, and on the hazards of judging parents by every new rubric. But what I was really thinking about the whole time that I was writing this, was how I would stand at my mother's bedside in the hospital, clutching my cell phone. I would feed her some yogurt and then tap in my 4-digit password. I would tell her how I loved her and then I would check my voicemail. I would tell her she was going to get better and then I would scan my email.

And it wasn't just me. The doctors taking care of my mother took cell phone calls, excusing themselves and stepping out of the room.¹⁰ The nurses were glued to their computers-on-wheels, scanning my mother's ID bracelet, entering all meds on the screen. Oh, you could see why these actions might make sense as safety measures, but the upshot was that even nurses didn't actually look at the patient. They scanned, typed, tapped and documented ferociously, but they remained focused on the screen until they pushed the portable computer station out of the room and on to the next bar coded bracelet, summoned by messages on their voice-pagers.

All of us at the sickbed were constantly sending and receiving messages. It was yet another twist on parents and children and mobile devices, I would think, looking at my mother, who refused

10 I want to be clear here that I am not accusing them of insensitivity or even, really, of bad manners. What they were doing, for the most part, was using their cell phones as beepers, responding to hospital inquiries. And after all, I am as susceptible as the next highly educated, highly entitled, family member to the irritation which comes when what you get back from the nurses is, "I paged the team. They didn't answer." If the team is going to answer, someone somewhere has to step away from a bedside to talk on a cell phone.

to use a cell phone. She was cut off from the world and we were all of us—even me—checking messages and sending messages. The revolution will be televised. The social protest will be twittered. The deathbed will be attended by smart phones; everyone standing round the bed will be instant messaging, tweeting, checking Facebook. A ringtone will interrupt the proceedings every few minutes, and people will clutch their pockets.

The geriatrics team was as nice as could be. They were sane, humane, good at talking to patients—even difficult patients—respectful of the humanity of those who are voyaging off into dementia, I'm sure. But as we sat down in the family room for a conference, to be conducted with all due interpersonal skills, the attending kept stepping out to answer his cell phone,¹¹ and the fellow was tapping messages into her cell phone all through the discussion, looking up at every turn to let me know that this was all clinically relevant. She was sending messages to the resident to order the special cushion, get the new ointment for the sacral ulcer, to be sure to include all that in the discharge notes for Rehab F.¹²

But I couldn't be too self-righteous since I, after all, took calls myself at my mother's bedside. I would be cheering her on—you're better and stronger than you were a week ago—which was somewhat true—and my cell phone would ring, and I would say,

11 And when I say, stepping out to answer his cell phone, I mean that he got apologetically to his feet, in his long white coat, putting the phone to his ear, identifying himself: *Dr. X, yes?* But I know that trick; it's how I answer my cell phone when there are people around me, *this is Dr. Klass*, even though I can tell from the caller ID that it's one of my kids, or maybe a friend—it makes for a better exit line, as I hustle apologetically and yet importantly out of the room.

12 At the moment I was upset that the ulcer was notably worse, so I wanted to tell her to put down the damn cell phone and look at the patient! But no, message after message tapped in, and really, wasn't it good that all these imperatives were being relayed immediately, not scrawled on a clipboard and forgotten? And yet, it was hard not to feel sometimes, as I watched my mother's decline, that the buffed electronic charts with every field filled in and every checkbox checked, showed that the documentation by the team was thorough and rigorous—but that all their care, like all my caring, was unable to push the darkness back.

excuse me, Mama, I have to answer a call about getting you out of here—which was also true—and I would step outside the room with real relief. The outside world was on the line.

At the Bedside, 2014

About this oxygen nonsense. Let's just be clear, here and now. If I were traveling on an airplane with a small child and the cabin experienced a sudden loss of pressure and those trusty oxygen masks dropped from the ceiling, I would put the child's oxygen mask on first. I don't know if there are any people out there who have been so warped by the years of repeated exposure to the I'm-a-reasonably-friendly-machine voices of recorded airline announcements that they would actually leave the child straining for breath in the depressurized cabin. Probably not, but you never know—they're probably the same people who would go on administering the shocks in that famous experiment that we learned about in our college course on moral dilemmas in a repressive society. The recorded voice, someone who cares nothing about you, or your child, tells you to put your own mask on first.

Since my mother has been sick, several good friends have brought up the oxygen mask metaphor with me. Take care of yourself. Give yourself a break. The very kind geriatrics attending just gave me the same advice. It had been a long morning with my mother, during which my brother and I had tried what he calls "tough love," telling her over and over that she wasn't allowed to cry "help help," that she had to eat. We got maybe 7 or 8 spoonfuls of a thickened cranberry-flavored drink into her—I kept calling it pudding, and once or twice she said it was good, but mostly she said it was terrible. Anyway, the attending came in and sat with her and took her hand, the way that a geriatrics attending should, looking at her, touching her, listening to her—and I sat on the other side of the room. He told me that he thought I needed a day out of the hospital—to take care of myself so I could take care of her. So of course, I teared right up. As you might expect. Nothing like a little sympathy to make you cry for yourself.

But I don't need taking care of, not in that way. I need a good

strong drink in the evening. Which I get. I make excuses to myself for ordering fattening food—I really need this, don't I? My mother may be dying, but I've been in the hospital all day so I need a donut. Now. Or a foie gras taco as the case may be¹³—but let's face it, I'm not the sick one, I'm not the one in pain, I'm not the one whose left arm is so edematous that she can hardly move it. I am a family member, strong as a horse, and appropriately sad. The patient is the one with the disease, as they say in *The House of God*. And if I want to do something to make myself feel better, I can do it without needing to claim medical necessity. I don't need a doctor's note to have that donut. And I'm here at the bedside because it feels better—in the sense of less bad—than being anywhere else.

My mother is in a reclining chair now, asleep sitting up. It's good for her to be sitting up for so many reasons—makes it safer to feed her, though that hasn't been a dramatic success. It takes some of the pressure off her sacral ulcer. Probably helps her digestive tract and her urinary tract do their jobs. I am in a chair over by the window, my feet up on her special air bed (arrived too late to prevent the ulcer). And to tell you the truth, I have been enjoying the last hour, as she has been sleeping relatively peacefully. Not fighting her way out to cry and scream. But even as I type that, I hear the quiet moaning begin, and soon the full force comes again. She is crying now and saying something in a tearful way. When I ask her, "What, my darling?" she says, "I'm not talking to anybody," and I decide to let her talk to herself in peace.¹⁴

13 A few blocks over from Hospital E, there is a hipster restaurant, where they make the foie gras taco, or foicco; I have been there twice in the eight days that my mother has been in this hospital, and have eaten the foicco, and the spicy tomato soup, and the grilled cheddar with pork belly, and the grilled blue cheese with fig jam and french fries—stoner food in the middle of the day because why not, I deserve it.

14 There have been a few odd exchanges today, including one in which she called me a lentil—she was angry at the time—and one in which she asked if there were any prayerbooks, at which the resident—thrilled to have something to offer, said, "We have a wonderful chaplain!" When my father's father—an

A few minutes later, she suddenly seems to be awake and responding, so I spoon two more plastic tablespoons of mauve cranberry liquid into her mouth, and she says it's good, actually (at least it's cold), but then just as suddenly she doesn't want any more.¹⁵ I ask if she wants me to talk to her or to let her rest, and she says to let her rest, but as soon as I'm back in my seat, typing this, she begins to cry, "Help help help help help me." I try to take some tiny satisfaction in the idea that maybe she's gotten 50 calories today. True, this is an achievement; they're the first 50 calories by mouth in a week—but how tiny is that tiny satisfaction.

I wonder about the idea of the physician who becomes a patient, who crosses that essential divide and learns those essential lessons. Does it really have anything at all to do with being a physician? Sure, medical training maybe gives us a couple more illusions than the average person about what we can control, or about the benign efficiencies of the hospital. But those illusions

avowed atheist socialist who had rejected his orthodox Litvak childhood—lay dying in a hospital, a passing priest asked my grandmother if she wanted a mass said for his recovery. She enthusiastically agreed, because how could it hurt? I guess I felt the same way.

15 We've been engaged in some kind of parody of dietary modification—my mother was made NPO when she first came in to Hospital E, both because they were initially worried about her abdomen and because she was getting narcotics and they were afraid she would aspirate—but there were apparently several different people writing in the chart, from the internal medicine team to the geriatrics team to the speech and swallow team to the nutritionist who showed up to evaluate her calories (none). So a woman would come in with a tray and look worriedly at the NPO sign on the door, then recheck her orders, then put the tray down, then come rushing back in to say, *don't give her the liquids, she isn't supposed to have the liquids*, then go out again, then come back to say, *she's supposed to have pureed food, I don't understand why they sent up this other stuff*—but it was all pretty academic since she wasn't eating anything at all. The speech and swallow lady provided us with one juicebox full of honeythick cranberry stuff and one of nectar cranberry stuff. We have also been given little canisters of calories, basically, 300 calories in each, which we should theoretically be folding into everything she eats. But she doesn't want to eat—truly and consistently. She doesn't want to eat.

may just be our own gloss on the most basic essential human illusions. The world only exists for any of us because we see it, hear it, smell it, taste it, feel it, and until we are most harshly forced to learn otherwise, we cannot believe that it will exist without us. Or maybe, better, we do not truly believe that we will stop being here to make this world exist.

The great divide is not between physician and non-physician, or between patient and family member, but rather between the heedlessly happily healthy and the breaking-down. The experience of illness and caretaking wrenches you out from your place among the autonomically functional and teaches you what there is to lose. More than that, it forces upon you the unwelcome lesson that you will someday lose it all.

But you haven't lost it yet. In my sadness and my dullness and my perseveration, I have moments of what can only be described as smug joy in the performance of certain bodily functions—so *this* is what it feels like to empty a full bladder, to gobble down food that you are craving, to sprint across the street to snag a taxi and end up winded, and yes, to have sex. I can do this. My body works. Having started to feel this, I instantly believe that everyone who has watched at a parent's sickbed has also felt it in some variety, shamefaced or defiant, proudly straightforward or twistedly ashamed...or miserably confused. But if you've been there, I bet you've felt it. You know you have. Because you've finally understood what those smart residents and interns just don't understand: that all bodies, eventually, stop working. They just stop.

There is a shelf life, a limit to how long you will be able to do any of these things. These functions are small physiological points of light in that great darkness which you newly sense hovering. And so, the triumphant bowel movement. The resonant thrill of the belch. Maybe you shake your head because the young doctors don't understand this. They work in the hospital among the sick and the dying, but they don't believe in their own mortality. They wall themselves off from the inevitable. But the truth is that when you exult in your function, you are also making

a gesture of nonbelief. You are rejoicing in powers that you have seen someone else lose, but secretly believe you will keep forever, because how, really, could your own precious body ever stumble and fail? But you don't say anything about this, because you are not talking to anybody. ∞