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Twenty Years

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A writing teacher once told me that he'd written (and sold) a half-dozen articles—all different—about the same event. A teenaged girl had been injured in a car accident and had lain comatose in the hospital for several months before recovering. Too much time has elapsed, now, for me to remember which of his articles went to which magazine, but most of them were magazines I knew. The story of the accident itself went to the local paper. The story of her treatment and dramatic re-awakening went to its Sunday supplement, *Parade* or something like it. The story of her return to school and attendance at that spring's junior prom went to *Seventeen*, and somewhere along the way there was a made-for-television movie and an article in either *People* or *Reader's Digest* and then a new set of articles about the family's sudden fame and the parents' resulting divorce and the girl's dependence on pain-killing drugs—some of these for the same magazines that had published the earlier, more inspiring versions.

But were all of those different stories *true*? I asked my teacher.

Every word, he replied.

And while I didn't (and still don't) believe him, I've come to believe his point.

An event is not a story. Neither is a series of events—a car accident and the series of accidents or non-accidents that follow it. A story requires a teller, a point of view with a stated or implied set of values. These values determine its conflict, rising action, climax, and resolution, and each of those changes every time the teller and his or her values are changed. So, to tell the story of my infection with Hepatitis C, I must decide how to tell not one story, but several, because I was, during my twenty years with the virus, different people with different values and, therefore, different ways of putting things together.

The facts are these.

In April of 1985, while a third year medical student at Case Western Reserve University in Cleveland, Ohio, I was doing a clinical rotation in surgery at the Wade Park V.A. hospital and stuck myself with a contaminated needle. I don't remember the needle-stick itself, as there were several that year, and such events were (until the 1990s and universal blood precautions) largely ignored. I do remember that the symptoms began – probably a day or two after the stick – on Easter Sunday while I was on-call with a surgery resident, who was initially reluctant to let me leave. Surgeons *never* allow students to abandon call, not on a Sunday, not on a Sunday that was also a holiday,

one my resident wasn't getting. But I was periodically doubled over in pain, and there was little he could do. I was suffering the first stage of my illness, one I mistook for a twenty-four hour flu until several weeks later, when, at the start of my obstetrics rotation, I turned yellow. I went to the campus health service and was diagnosed with "Non-A, Non-B Hepatitis," the designation for the yet-to-be-discovered form of hepatitis I actually had. I was sent to a faculty hepatologist who told me that my liver would recover and that I'd most likely be fine, although I could never again donate blood. Relieved, I went back to obstetrics and my fourth year of medical school and my years of internship and residency, only occasionally remembering the whole thing until, in 1990, having completed my training, I began to use the episode in teaching.

After seeing a patient in the outpatient clinic, students would come to me frustrated.

"This guy's all over the map," they'd complain. "He says his chest hurts but he can't tell me for how long, and he says his vision in one eye is going bad and that it's somehow related to his chest pain, but he can't tell me how. And then he starts talking about his knees. I don't know what he wants or why he's here or what he expects me to do for him."

They'd finish by telling me that the patient was a "poor historian," and I'd tell them that everyone who's sick is a "poor historian." I'd tell them that I was sick, once, as if the whole thing were over. I'd tell them about my hepatitis and share the fact

that I ignored both yellow skin and brown urine until they were noticed by somebody else. I'd tell the students that, yes, some patients are limited, whether educationally or intellectually, but a nonsensical history can sometimes act as a sign, something like smoke in a house not yet known to be burning. I'd tell them that to be sick, really sick, is to be afraid, and that people can only share those parts of their history they're ready to face. Hence the chest pain that might be knee pain. Hence the indigestion that might be what the patient ate a day ago or a week ago, or maybe didn't eat at all.

And hence the first story of my hepatitis.

However frustrating they may be, patients are lost in a hall of mirrors (remembering this but not that, remembering only the information we least need), and our job is not to hate them for being lost, but to extend a hand and lead them out.

One day, I told a medical student this, and she asked if I'd heard about the new test.

"What test?"

"The one for Hepatitis C," she replied, which I had heard of but had chosen to ignore.

When the results came back positive, my story—my first story—failed, and I found myself with a new one, with a new teller and a new point of view and a new set of values and a new everything. No longer the scarred but triumphant survivor of medical training, I was the victim, the failed Samaritan, the poor guy who'd worked so hard to get into and through medical school and then residency and board certification just to find that he hadn't made it after all. I wept. I screamed

and pounded the steering wheel while driving home that night. When I repeated the test and it was still positive, I wanted the alternative, second-generation test, and when that too was positive, I went to see a hepatologist, a new one, a “smarter” one, I thought—one more likely to tell me what I wanted to hear, but who gently confirmed most of what I feared. With the new test, a new population of patients was being identified, and the early conclusions about their fate were pretty bad. Although Hepatitis C is less severe than Hepatitis A or B, it’s much more often chronic, and many cases seemed to progress over twenty or thirty years to cirrhosis and death, unless the patient was lucky enough to receive and survive a liver transplant.

Left with no treatment, nothing but the promise that one might someday be available, I re-entered the hall of mirrors I thought I’d escaped. I would first convince myself that I was fine—that the information about Hepatitis C was coming from academic centres, where the patients were sicker and would fare worse than young, healthy people like me—and then I’d convince myself of the opposite. With perfect illogic, I’d switch from terror to devil-may-care, sometimes several times a day, but was never without *some* story, *some* logic, *some* sense of progress, whether forward or back. I needed a narrative that could act as a shelter, and having two, I ran from one to the other depending on where the Big Bad Wolf was and how terribly he was puffing.

And before long, I’d started work on a third: an angry, if toothless, *j’accuse!*

Things like this don't *just happen*, I thought, once my defences were ready to re-form. They're somebody's fault. Somebody was supposed to be watching, keeping me safe, keeping us tuition-paying medical students from wandering out onto the wards and falling into the traps any truly caring system would have spotted and removed. I focused on the surgical resident who'd been reluctant to let me leave that long ago Easter Sunday. I replayed my interactions with the hepatologists, the first one especially. Abrupt, I decided. Uncaring, or at least, insufficiently sympathetic. I remembered the first of my third year rotations, medicine, where a nurse told the new students the rules of the ward. She'd made a particular point about drawing blood. She'd said that she disliked students who drew blood and then put the syringe and the needle, still attached, in the one needle disposal bucket that served the whole floor. The syringes were large and weren't dangerous and took up much needed space and should be detached and put in the regular trash. But there was something even worse, she said: students who walked from a patient's room to the needle bucket with their used needles "uncapped" posed a hazard to whomever they passed in the hall. After pulling a needle from a patient, we were expected to replace the plastic, protective cover. This practice was subsequently discovered to be the point at which accidents like mine most frequently occurred.

This story, my attempt to absolve myself by blaming everyone I could think of, was the weakest of the three and, generally, the least useful.

After all, the nurse had told me nothing that wasn't correct at the time. My hepatologists had been of little help, but there was little help they or anyone could have given. However disgusted, the surgical resident had let me go that Sunday, even though it meant he'd had to do all the ward chores and write all the Sunday admission notes himself, a considerable annoyance. And he hadn't known. Neither had I.

As soon as hospitals saw what was happening, they changed their blood drawing procedures and apparatus and put one or more needle buckets in every room rather than one on every floor. And anyway, what should any of my residents or the nurses or any of my other teachers have done to protect me better than they had?

“Now, Bob. This is a needle. You're supposed to stick it in the patient. Don't stick it in yourself.”

In any case, this story was quickly replaced by a fourth—of all things, a love story.

The medical student who suggested the test for Hepatitis C was a woman I was dating. It was the first and last time I had a relationship with a student, and she is now my wife and the mother of my two children. Our relationship was, if technically unethical, otherwise virtuous. It had to be. The risk of breaking the medical school's code on sexual harassment was dwarfed by the risk we were taking with my infection. Although the risk of transmission between a monogamous, long-married couple is low (a few percentage points over a lifetime), in the early 1990s, the figure was yet to be established and the estimates then were

much higher. From the first, we had to talk to each other in full, honest sentences about who we were, what we wanted, what we had to offer in return, and which things were likely to change and which to stay the same. We had to discuss what intimacies we enjoyed and how much, and which we could delay, until suddenly, we were comparing the risk of co-infection to the other risks spouses inflict on one another. Divorce. Substance abuse. Spousal and child abuse. Even the risk of being a bad driver and killing your spouse in an automobile accident or having different interests and boring him or her to death. By the time we were married, my infirmity was such a part of our relationship that my successful treatment in 2005 brought an odd sense of loss. Yes, I was and still am delighted. Yes, I no longer feel a kick in the stomach every time I drive past a V.A. hospital, anywhere in the country, all of which look unfortunately similar. But my wife and I are no longer Rodolfo and Mimi singing our way through *La Bohème*. We're no longer Pyramus and Thisbe trying to spot each other through a wall of CDC-mandated bodily fluid precautions. We're just another middle-aged couple trying not to overeat. And then there are all the other things I didn't notice when I was sick: the spread of HIV, the rise of terror, global hunger, global warming, not to mention not-so-global problems like leaky gutters and broken windows and doors that squeak or don't close and kids that need to get to school and then to soccer and baseball practice and skating and piano and dance lessons.

Imagine my pleasure when, in 2007, more than a year after treatment, I found all my old needles, the ones I had used to give myself a total of forty-eight weekly doses of Interferon.

Aha! I said.

Another story. One last narrative. A final chapter, or maybe epilogue.

I had missed a required flu vaccination at work, so I brought a dose home and administered it myself and, afterward, wondered what to do with the syringe. This is when I suddenly remembered that sharps container, the personal one I'd been given by the mail-order pharmacy that had supplied my Interferon injections. After each one, I would put the needle in the bucket and close it and put it back in the unmarked cardboard box it had come in and put the box high on a shelf in a corner of the attic. The idea was to hide the needles from my children but, apparently, also to hide them from myself. Embarrassed, I called the pharmacy and asked what to do. I couldn't put the bucket in the trash, I thought, not when I knew the needles to be infected. What if a trash collector found it? What if he dropped it and the bucket fell open on the street? The pharmacy told me to bring it to a hospital or, if I preferred, to any fire station. I thought this was odd, but I stopped at the station on the corner anyway and asked.

No! The fireman on duty replied, as if, in his line of work, he heard a lot of crazy questions but mine was about the craziest. So I called my hepatologist—my third and, hopefully, last hepatologist—but his nurse said that she couldn't help either. She

said (incredibly) that she'd never had a patient ask, and suggested that I call a local pharmacy, which I did, but they too said they couldn't help. The trash should be fine, they said. But to me, it still wasn't. Having been injured myself, I couldn't be casual about the risk of injuring someone else. So I asked my boss if I could bring the needles to work and dispose of them by whatever means our clinic disposed of needles, and he agreed. He said I could bring my bucket to the clinic and simply empty it into the bucket in one of the exam rooms, and I almost did. Unfortunately, my bucket had only a narrow opening, too narrow for me to simply invert the bucket and expect the tangle of needles and syringes to slide out. I'd have to reach in and fish them out, which meant that I'd have to risk sticking myself again, which I couldn't because I knew that my infection with Hepatitis C in no way protected me from another infection with Hepatitis C, even from *my own* Hepatitis C infection. That's why it's so often chronic: it generates an indicator antibody but no curative or protective antibodies—none that could be used, for example, to create a vaccine.

Was it a sign? I wondered. Was the risk of handling my old needles telling me something about the risk of handling my old stories? Are stories told and re-told until the teller, rather than the story, is complete?

Was it time to move on?

I now live in Boston and was informed by the Massachusetts Department of Public Health that, yes, so long as needles are in a puncture-proof con-

tainer, the curbside trash is an acceptable means of disposal. The next morning, I took my needle bucket and sealed it with duct tape and put it out with the rest of our trash and went back in the house and got to work on some writing—this remembrance, among other things. Several times I heard the roar of a truck in the street and went to the window, only to be disappointed until, about noon, I looked out and saw the trash truck. A stocky man with short white hair took one bin and dumped it in the truck, while a younger, taller man in a baseball cap took the bucket of needles and dumped it in, and then our old Christmas tree, and then, after the white haired man had pulled a lever that crushed the trash, the truck roared on, down the street and was gone.

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