

Three Months of Distraction

By Maya Kasowski

Today I went on my first hospice visit as part of my family medicine rotation, which was also the first time I had visited a patient's home. Mr. Bloom was waiting at the door as we walked up and he opened it as a gracious host. Being pregnant, I asked if I could use his restroom. So it was that my first moments in his home I was alone, absorbing clues about his life/personhood, guarding myself a little against the uninvited intimacy of unwashed corridors that I expected to encounter (e.g., an unclean bar of soap with a wizened hair). I knew his wife had died two months earlier. Based on his layers of browning clothes and longish hair (which I later noticed was actually clean and flaxen), I was expecting little corners of moldy decay, and was surprised by the gleam of the bathroom. I joined him and the hospice nurse I was shadowing in the kitchen. It was homey – spacious open cabinets with classic cookbooks and his wife's novels, piles of paper, but nothing out of control – they were new piles, not those of a hoarder. Off to the corner (beyond Mr. Bloom's back and suggesting another life entirely) was a solarium encased in glass looking out on a copious persimmon grove, unpicked. He would offer us the persimmons as we left, dropping his arms to manifest the waste of not distributing them, hoping we – strangers to his home - would take them (an awkward obese nurse and a pregnant medical student, presumably occupying a full world) as surrogates for people in an earlier time he and his wife would have selected as favored recipients.

I expected the nurse to take charge. He had said it would be a long visit, a lot to cover. But he was idle, reading his laptop, somehow uncomfortable with me watching. He asked a few medical questions, took a blood pressure and focused on his screen. Mr. Bloom submitted, as a child would to a teacher, but in reverse. He seemed to know better, but he was old enough not to expect any gratification for showing this, and at most conveyed a subtle irony. He knew the questions were mostly pointless. The Polst was pointless – he'd just check the same boxes his wife had. He spoke about her in the present. Why adjust to the convention of past tense at this stage? We were dotting "I"s. The nurse asked if he'd like a spiritual counselor to come visit. No, the counselor had come for his wife; it hadn't helped. "We're not religious." My gaze wandered to the cookbooks. What had grounded them? I wondered if this would be the stimulation for his day, having us as visitors, finding things in his paper piles for us to consider, log.

I decided to venture some conversation since the visit was not as rushed as I had expected. In the context of the nurse's mention of anemia, I engaged him in some banter about iron-rich foods. He humored me, but was interested. He had ideas, so did I. Finally I ventured a little further, "What kind of work did you do?" "I was a synthetic chemist, an academic." "Yes, I see you're very science minded." He liked this. It was recognition of him, but not as "hospice patient". It wasn't so dreary. It was true - I could see him. I understood what this might feel like, answering silly questions, knowing better perhaps, *yet needing this*, being trapped in this present amidst a kitchen where once persimmons were thoughtfully bestowed. Having a curious fungal infection of the skin that didn't even matter. He seemed well to me, not frail. The nurse would later speak to him of "becoming weaker", needing a help- I-can't-get-up device (as I thought of them from the commercials from my childhood). I thought how cruel this forecasting was. It reminded me of Ishiguro's, *Never Let Me Go*, a novel I hated because it kept sneaking up on me at vulnerable moments when I felt my own body's decay and disappointment. A novel length poem about the dissection of our bodies and with it our souls. Ishiguro had worked with the homeless. It was about outcasts; when selfhood is outcasted from loving bonds children and lovers are left with incompleteness. An artist whose drawings are less resonant, the transcendent quality subtracted. It was a loss that couldn't be charted (the loss of art), in most cases even known to anyone other than self and intimate companion. Mr. Bloom was still living independently. The nurse told me pityingly he was too resistant to seek help, but a nice man. I thought how remarkable it was he kept himself and his house clean. He had been an organized man.

Our conversation turned to Kaiser and large-scale clinical studies. I respected our pauses; it was a conversation. I asked if he had received his care at Kaiser. He told me no, UCSD, even more arrogant than Stanford he said and laughed gently. His subtleness and quiet irony lifted. He had something to tell me that mattered, that wasn't wishy-washy like the science we had been discussing. I already knew he had gallbladder cancer. It had followed a clinical scenario I had learned for the boards: decades of ulcerative colitis → increased risk of primary sclerosing cholangitis ("something called PSC" the nurse had told me uncertainly) → gallbladder cancer. The underlying problem was autoimmunity, an inflammation of the colon and later the bile ducts,

channels that microscopically radiate throughout the liver carrying bile to the gallbladder. The chronic inflammation in these tiny canals had injured the surrounding tissue and eventually seeded cancer. I had once considered sequencing these tumors in the lab. They were rare; there wouldn't be too much competition. We had a collaborator in Japan who had samples. It would require tedious laser dissection, hours hovering over a microscope to isolate cancer nests, so we dropped it.

Although Mr. Bloom had chosen UCSD for their liver transplant program, he told me he had decided against a transplant, he was too old, past 60. He didn't know what their rules were, but this was his rule. They had discovered gallbladder polyps in July and operated in October. He had omitted the year; the months and interval between them was what mattered. "You see," he said "these polyps have a >50% chance of malignancy." This was it, his story, whittled down to the most painful nub. The nurse let out a groan-like sigh, not looking up from the screen. Was he responding to Mr. Bloom's story I wondered. How should I respond? I was trained to be skeptical of "subjective data" (especially pertaining to medical decision making in terminal illness). Patients were not always reliable narrators, a useful concept from high school English. Be empathetic, but do not affirm, was the rule. "I found that out later of course," not with reawakened bitterness, just seasoned irony (a glint in his eye meant to connect with mine), recognition that a long life had taught him he was ultimately at least partially responsible for his destiny in most circumstances (or that the details didn't matter once you'd come to accept it, or at least the reality of it). "It's a simple procedure, you see, to take out a gallbladder." I thought of the first patient I saw after returning to medical school after an accomplished student's career in genetics research, a textbook "4F" gallstone case: forty, fertile, fat, and female. It was an organ that could be removed whole with relatively small consequence.

The nurse stood up and asked if "we" (indicating me) could make a phone call from the solarium. Indifferently Mr. Bloom said yes and shuffled back to the kitchen in his fleece booties bound at the soles by duck tape. The blood rose to my cheeks. Had I gone too far in eliciting his story? Would the nurse tell me to steer clear of these deep conflicts in someone for whom "comfort" is the guiding principle of care now? No, the nurse was simply occupying his own emotions of the day, anticipating uncomfortable discussion. He had decided to call a social

worker to come tomorrow to persuade Mr. Bloom to hire a caregiver. The nurse was reluctant to engage him directly about getting more help; he struggled with assertiveness. Earlier, he had asked me “tell me about yourself” in a way that seemed practiced, his voice loud, but faltering. I had had to ask him to repeat what he had said as his tone suggested a less casual question and I wasn’t sure I had heard him correctly. I had disappointed him early when I told him it would only be a half-day. The excitement would be cut in half, rationed to just a morning, no sharing a lunch together.

When we returned to the table Mr. Bloom was fussing over popcorn in the same style of his conversation – disinterested, amused by the mundaneness of ill-fitting Tupperware. Was this all new now as he was letting go? Had his wife always set out the popcorn and he was occupying her space?

The nurse was rescued from his lecture about insidious weakness, decline and the need for a home alert by the arrival of home oxygen. The Pilipino delivery person was attentive and modest, sensitive to the intrusion and cumbersomeness of both the device and his requisite instruction session. How could someone elderly and dying be expected to navigate valves, dials with small numbers, heavy tanks, plastic tubing. He was heavily accented, used to not being understood. I paid attention – it was something I should know. We all were huddled in the corner of the master bedroom (a modest one, but that’s how Mr. Bloom referred to it). And yes, there was some grandeur. Above the weathered brown shag carpets was a wall of windows showcasing densely packed, heavily blooming persimmon trees. I said they were wonderful; he didn’t engage this; we had already sort of said our goodbyes. He looked over the device. Yes, a chemist with a lifetime of experimental expertise, he could simplify it and have it make sense well enough to hold onto the needed facts. To me, there was still much hidden architecture.

I noticed there were no pictures of grandchildren. He had talked about his two daughters; Sarah was his surrogate decision maker as the oldest, even though he thought Julia more capable. “Have to respect age,” he said resigned and again, with irony, suggestive of being at the mercy of rules beyond one’s control. It was different seeing a patient at their home. It reminded me of many years ago being bullied and how even the bully felt a surge of empathy when my parents visited, in the

presence of people who nursed me as a baby and therefore loved me with the greatest of life's passions.

How different this man was from a retired priest I saw recently in clinic who was also frail and possibly also dying. Both had lowered their trousers to show me wounds that for some would have caused shame; the priest may have accepted the decline of the body, the vessel, as not representing his personhood (or so I imagined) and Mr. Bloom saw it ironically – yes, this is what happens, here is the specimen. Gently massaging his ileostomy bag, he told me “I’ve had this since 1981.” He had been patient when the nurse asked him about his bowel movements. The withering vessel, the biological specimen, would be existentially dissected away at this stage. How much time as babies and children we spend exploring our bodies so that any subtle change we notice, momentarily shocked by the physical map not matching the exquisitely detailed mental one, the one that adjusts for every possible body position and angle.

Mr. Bloom had already begun busying himself with calling back the social worker as we left his home. The nurse would come alone on future visits. This was his dream job he had told me. There was no oversight; he had greater respect than when he had worked at a nursing home. They trusted him. He had come from Indiana for his wife's work; she left him thereafter.

We visited a skilled nursing facility together and saw the remaining two patients on his schedule for the day. They had dementia. One was skeletal, grasping at anything tactile within her reach, with the slow unfocused movements of a science fiction creature or newborn. The other was delighted, a child with an eager smile and bright eyes. She sat in a wheelchair with a belly distended from liver disease; she told me she was healthy as a horse and I didn't know whether she was ironic or forgetful. She slept most of the time. She awoke to a fresh world, for now, complementing my shirt, asking me what color it was (cranberry I offered), pinching the nurse's heavy belly as one would a small child, telling him she liked him fine because he smiles. Her husband was practiced at social talk; he had been successful in his career I thought. He asked me about medical school, Stanford. He was by her side, as they had been at dinner parties, in the household, at the clubs they frequented. Their presence transformed the outdoor patio into an

entirely different sort of space, a country club. She could still complement him socially; outgoing and dynamic, complementing those around, letting her husband provide the serious talk. The nurse told me she had recently become very angry with her husband at times; she had giggled mischievously when this was alluded to earlier.

I'm not sure it helped Mr. Bloom to tell me part of his story (his dying story) that he authored and perhaps told and retold to himself these days, cataloging signs and fitting armor from the missteps, a psychic ritual analogous to the child's game of walking on the lines avoiding cracks. It was probably a story of his youth, as easily interpreted as a Freudian dream if you knew the personal history. The universality of being helpless, knowing better. My grandmother, a woman in her late 90s, is now talking of joining her mother and sisters on a trip, telling them she's coming soon. I tear when I think of it, a sensitive child again, emotions I can't usually access. I don't have trouble letting go (I have my own children now; she has lived well for beyond all expectation, a child of the Lublin ghetto who lost a beloved older sister and her sisters' babies); rather, it is the silly primacy of childhood, the gravitational pull of being a child in the family car, parents in the front seat, sisters on both sides, begging for MacDonal'd's. "Is that all there is in the end? Parents and siblings?" my cousin, a psychiatrist, recently remarked when we talked about Grandma, distant now in her East Coast retirement community. As children she had made us crispy Matzo Brei in her Bronx home, wearing her housecoat, in constant motion back and forth the two feet from table to stove while we ate and giggled (and at 4'10' not rising much above us).

As a medical student, your patients don't really depend on you yet. You have book knowledge, but not the Cassandra-vision of those who have seen a disease manifest and know the variations of its clinical course. You can't really set expectations. As in medicine as in family relations, it is the fundamental need that defines the bond. In discussing what mattered to Mr. Bloom I met him where he was, vitamins, the benefit of coffee for bile duct disease, and eventually the story of his illness. If asked: was there relief/catharsis in telling your story to the medical student today? Yes, he would probably say, with the subtlest irony, playing along, behaving. As a first year med student (before I became a mother) we visited a nursing home and my classmates debated whether the patients were likely encouraged by their view of a public swimming

pool or disheartened by their relative captivity. It seems obvious now – it would have brought pleasure, emotion, to see the children delight in the freedom of their bodies cocooned in water. That’s how I think of our visit together. He watched me diving in the pool and it was a reminder of himself, of his own time. But I can really only attest to what the visit resonated in me.

The wonderful thing about medicine and intellectual life in general is being overruled in the court of complex, messy life; having new experience remind you life is fuller than you, you must work to keep up with the game. Last night I sat outside with my daughter looking at the stars and the moon and I thought how wondrous it continues to be, even after you’re able to conceptualize it. There are deep mysteries: our self-awareness, humankind’s ability to understand numbers and with them our mathematically idiosyncratic niche in space-time, exquisitely tuned to allow our survival (a mystery so profound that it deepens with a deepening knowledge of the math). I know patients will challenge me, inspire personal metamorphosis and hasten the lifelong pursuit of authenticity; even as a student I expect I will be able to truly help some. This visit was just the beginning of hearing his story, and sharing in his truth, wisdoms that resonate so powerfully in part because of their payloads of regret. Over time it would be important to challenge aspects of it, to open the window and bring relief. If I had more opportunity to be part of his team, knowing his story and his framework would provide us a common dialogue. He helped prepare me for this. In my mind, as I sat with him, I rehearsed the questions I had committed to memory for the visit “Do you consider yourself religious or spiritual?” and knew I’d be able to use them when I needed them (this was important). But for now it was more honest, there in his home, a stranger for a day with the luxury of time, just to talk and show simple human interest, to appreciate him. Oprah Winfrey once explained what all people desire and crave – it is *to be seen*.

With the few details I have, I think maybe the three months Mr. Bloom waited for surgery would not have affected the outcome (the large polyps that are very likely to be malignant are probably also advanced), but, psychologically it mattered deeply – for him, thinking back to all the trivialities he busied himself with during that time, conscientiously sorted out (bills, conflicts with children, etc), trusting his physical well being was being equally handled, guarded by his physicians. Perhaps on

a more visceral level he really meant to tell me that his gallbladder should have been removed even earlier, a nonessential piece of self that eventually would harbor cancerous polyps. As a college student when I had needed surgery it was scheduled expeditiously without the need for self-advocacy (a concept I didn't even know about at the time); the surgeon, a former Harvard football player as he personified himself to his patients, told me I would have the prime early morning spot. The surgery began at dawn when he was freshest, his hands most deliberate.

As we were leaving Mr. Bloom's driveway and the nurse stowed his cumbersome rolling laptop case in his trunk he told me Mr. Bloom had qualified for hospice almost two years ago (after his gallbladder surgery), but just now had finally signed up for it.