Socioeconomic perspectives on interactions with the health care system: A collection of three fictional short stories

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The Underserved

I’ve always prided myself on my work ethic. In a world that moves so fast and changes so slow, it’s usually the only thing in my control. This lesson was one of the few things my parents were able to gift me. It’s served all three of us well enough to get by.

Working two jobs has been my norm for a while now. I started serving as a teenager to afford to do things with my friends on weekends. When I graduated high school, I figured serving full time would make me enough money to move out of my parents’ place. Unfortunately, no restaurant wants to hire me full time and dish me some benefits, but I’ve found that spending my mornings slinging eggs and my evenings behind a bar gets the job done. Mild sleep deprivation aside, I’ve got clothes on my back, my landlord off my back, and a MyPlate that my health teacher would be proud of. Pair financial adequacy with a library card and a walkable city and any self-respecting 20-something would be living the dream. Like I said, I get by.

When the world gifts me a day to do nothing, I like to sit around and think about who I am. To be honest, I’ve yet to find a good answer. The only thing I’m sure of is that I’ve yet to be completed. Maybe nobody ever gets completed. I get the sense that my role is to find the balance between becoming as complete as I want to be while becoming as complete as the world wants me to be. It’s hard to deny that the two judgements are codependent. The way those I interact with view and treat me affects the way I view and treat myself, which feeds back into the way others view and treat me. Sometimes I wish my identity were as in my control as my work ethic. Other times I realize that my identity wouldn’t be nearly as unique if
it didn’t have to exist within the confines of the world. Mostly I come back to reality and realize
I’m just a pawn in this silly little game of life. So who cares? It’s time for bed.

Just woke up. I guess my stomach hurts today. Not too badly, but it’s hard to ignore. I
still do.

Breakfast is unremarkable. Lots of eggs. Nice to see my Saturday regulars. They usually
tip pretty well. I guess my stomach still hurts, but it should go away. Naptime.

Waking up for dinner is never easy, but it’s a little more difficult when it feels like you’re
being stabbed in the belly with every motion. Oh well. Saturday night to Sunday brunch is the
best 14 hours of my week; it’s literally the only reason I can afford to live. Whatever ails me, it
must wait. Naproxen is my friend.

Going to work was definitely the right move. Might even be able to afford to take one of
my unpaid vacation days in a few weeks. Good job me. Time to grab a few hours of sleep before
brunch.

Holy shit this hurts. It woke me up before my alarm. More naproxen. Not sure I can walk
to work right now. I bet my coworker can pick me up on their way. They can. We’ll be alright.
Just have to make it through the day. Then I’ll go to urgent care. I promise. I’m young. I’ll be
fine.

An unfamiliar voice wakes me up. ‘Why didn’t you come in when it started hurting? You
could have died. If you’d have come in 2 days ago this would have cost so much less and you’d
have to be here for much less time.’
Yeah, I guess that’s on me.

My coworker happens to be there. Cool. They tell me I passed out walking to their car. They called 911 and an ambulance brought me to the hospital. This was reflexive to them, and I guess I’m thankful they were there. Unfortunately, all I can think of is numbers, bills I can imagine but can’t afford. Now I’m lying in a bed in a room in a building I’ve walked by hundreds of times but hadn’t considered going into on my own accord. Go figure they’ve got comfier beds than I do.

A tall person I identify as a doctor comes in and tells me my appendix burst. They’ve already cleaned out my abdomen in surgery. They say I’m lucky, that usually people who wait as long as I did to get medical care after it burst get a blood infection with a high chance of death. Nobody’s ever called me lucky before. I certainly don’t feel lucky.

Someone tells me they expect me to be in the hospital for a week. It’s recommended that I don’t go back to work for a month. Somebody else says ‘I hope you enjoy the time off.’ Personally, I hope I don’t get evicted and fired.

I get the sense that nobody at the hospital understands my situation. Sure, they get that my appendix burst. They have even seen people go through this physical pain before. Do they understand that this pain hits me deeper than my appendix? Do they know who I am?

On the other hand, how could I expect them to? I can’t even afford to know myself.

*The Blueprint*
I’ve always been the astute type. Quiet, observant, with only as much intensity as I deem necessary. It took a long time to come out of my shell as a kid; finding the right life path for me was really difficult as I came into myself. Thankfully I had parents who facilitated the search for my place in this world. Currently I work a decent job as a teacher, own a decent home, and overall, live decently. My life partner works the same decent job as I do. We’ve been at the same school for 23 years now. Stability has served me well.

Though I am first and foremost a teacher and most who know me would say that I fit the ‘teacher’ archetype, I wouldn’t say that being a teacher is my identity. I’ve been blessed with the health and wealth necessary to explore the parts of society that intrigue me. My identity has been shaped more by external forces than anything I’ve done for anyone else; there’s so much more to learn from others than I could ever teach a child.

Lately a sense of discomfort has been creeping in. Which is weird. Comfort has been my status for so long. Why would I feel discomfort in comfort? I guess after 23 years at a job even the most growing and fluid person would be left wondering what their next step is. What can I learn next?

Maybe I can learn how to deal with these headaches. They’ve also been creeping in lately. They’re worst in the morning. As if God puts a brick on my head for me to wake up with.

A few weeks in I’m starting to lose hope about lifting the brick myself. Time to see a doctor. It’s about time for my yearly checkup anyway. I’ve been with my doctor so long they almost certainly know me better than I do. Even though I haven’t really ever needed medical help, I feel even more comfort in my life due to their continuous guidance. Shoutout to my job’s
insurance for covering me for so long. I might not make six figures, but teacher health insurance is quite nice.

The doctor looks uncomfortable as I speak about my headaches. Not sure what to make of that. They say I should get some blood tests and an MRI. ‘Just to be sure it’s nothing serious.’ That reassures me. They also assure me the tests won’t hurt my body or my wallet. Works for me. I even get to take a paid sick day.

The next day I wake up to a call from my doctor. They want me to come in again to talk about the scan results. I’m feeling the discomfort they felt. Probably my fault for complaining about being too comfortable.

I’m shown a black and white picture of a blob I assume to be my brain. My doctor points to a smaller white blob on the top edge of my brain which apparently has been causing my headaches. The doctor calls it a meningioma. Men-in-gi-o-ma. I call it Jeff.

Supposedly Jeff has already been shown to a surgeon who says it’s easily removable. I have an ‘excellent prognosis.’ They thank me for coming in so soon after my headaches started. Of course, I say. That’s what patients are supposed to do.

My surgery is scheduled for the next Wednesday. If everything goes well, I’ll only have to spend about 3 days in the hospital. I could be back at work the next week if I want, though my principal says I can take a few weeks. After all, I am having brain surgery. Everyone’s been so sweet and accommodating. I feel scared but supported.
I spend the next few days reading articles about tumors like Jeff. I learn about the arachnoid cap cells that have decided to grow really fast in my head. I guess not all growth is good growth.

Surgery is ‘uncomplicated’, though I wake up with a splitting headache. Go figure that. I’m told it should go away in a few days. If it doesn’t, I should give them a call. It goes away.

My follow-up MRI shows my Jeff-less brain. Kind of boring honestly. He was probably the most rogue thing about me. Maybe I miss him. I sure don’t miss those headaches though.

Through all this I’ve felt that the health care system is made for those like me. I’ve got a doctor who seems to care about me and my health on a personal level. I have easy access to people who are thoroughly trained to cut my head open for health reasons, should I need them to. My job even pays for all of this. I feel blessed.

My experiences were even able to validate my identity as a learner and, in a way, facilitate my growth by removing one.

What a life.

*The VIP*

People tend to cater to me. I don’t mean that in a malicious or exploitative way, but it’s clear that the financial resources I’ve had access to since birth have allowed me to influence others in my best interests. If I ever had needs, I didn’t have them for very long. What can I say? I’ve been lucky.
My parents were proud when I got into the same prestigious college they met at. They were even happier to give me a job at the same firm they founded together. Though I had some connections, I still worked myself to the bone to make my way to where I am now at the top of their company. Those who know me personally can attest to my go-getterness. My mentality in work and life has always centered around being a dreamer, a risk-taker, and a grinder. At this point it’s what defines me.

I discovered in my late 20s that throwing money at the things I’m passionate about nearly always pays off. If I yearned for vacation, it happened. If an entry-level employee at my firm had an idea that lit their eyes up, I made sure it had legs. This strategy paid off financially and made sure I didn’t get burned out. 30 years later I’m looking back with admiration at the foresight I had.

I could use some of that foresight right now. No food has stayed in my stomach in a few days. Fever, chills, back and stomach pain, and vomiting all at the same time feels like I’ve been hit by a truck. My heart rate won’t go down. I think I need to see a doctor.

A few years ago, a few friends and I decided it would be a good idea to pay a doctor to be on retainer for us in case we needed emergent or personalized home care; I’d hate to have to go to a hospital without excessive need. I call the doctor and they come to my house straight away. They bring me to the hospital they have access to so I can get bloodwork and supportive care. I’m told my symptoms and labs are consistent with acute pancreatitis, which is usually caused by excessive alcohol use. Weird. I don’t drink. My doctor recommends an MRI, as it’s
the best test available to rule out anything potentially bad. Sounds fine to me. I wouldn’t want
my doctor to miss anything.

I get a call about an hour later from someone who introduces themself as ‘The
Radiologist’. They saw nodules on my pancreas on the MRI. Likely pancreatic cancer. Allegedly
the worst cancer. They’ve already talked to the in-house surgeon, who, based on the imaging,
doesn’t feel comfortable taking my cancer out. The cancer is ‘borderline resectable’, and
they’re not an expert. I guess they’re not my surgeon then.

Several hours and calls later I speak with a person from Johns Hopkins who says they are
willing to consider trying to operate. Given the high chance of complications, they’re wary. I tell
them I’d sign a no-sue agreement. That seems to ease their concern.

They’re considered the foremost expert on the Whipple Procedure, which is supposedly
my best shot. They say the Whipple put years back on Steve Jobs’ life after his diagnosis. My
doctor agrees. I arrange for a flight to Baltimore.

On the way to the operating room I’m told that there’s about a 10% chance I don’t live
through the procedure. Finally, the gravity of the situation I’m in catches up with me. My
thoughts are dizzying. I take a moment to think of who I am. If this is the end of the road for
me, did I live the life I should have? Should I have had children? Am I defined by anyone or
anything other than myself? Am I even human? I guess it’s too late to change it now.

I wake up to the calm face of a nurse who presumably has been assigned to my care. I
guess I lived. Hopefully that makes me human.
The nurse retrieves the surgeon. They explain that the procedure went as well as they could have hoped. The head of my pancreas is gone, as well as part of my stomach, gall bladder, and liver. I’ll have to stay in the hospital for likely another week or so, and I’ll have to receive intravenous chemotherapy for several months to kill any of the cancer cells that they weren’t able to remove. Either the chemo or the cancer will still likely kill me at some point, but I’m in the best situation possible for someone with this diagnosis.

As I rest, I reflect on my circumstance. I’d be a damn fool to not recognize that the average human does not have access to this care. The care team must recognize this too. I wonder if they resent me; the opportunity cost of emergently operating on me is as high as someone else’s life. My monetary worth is likely higher than that person’s, but the haunting truth is that my human worth is not. Yet I received the care instead.

How can medicine reconcile with the fact that, within their system, humans are stratified by their monetary worth? It seems plainly wrong that a profession that publishes ubiquitous research on mitigating inequity, discrimination, and disparity significantly manipulates the literal livelihood of citizens in ways that are beneficial to medicine’s wallet.

References


https://www.ncbi.nlm.nih.gov/books/NBK560538/


https://www.ncbi.nlm.nih.gov/books/NBK518996/