My Uncle and His Struggle with COPD

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Constricted

As he rounds the corner onto 81st street, the familiar feeling of dread fills his stomach. He parks the family's navy-blue Jeep and braces himself for the worst. He grabs his stuff and opens the door. He grasps the handle above the door and pivots himself in his seat. He begins to lift himself up out of his chair, place his feet on the pavement below, and lower himself completely out of the car. By the time he is done, he is gasping for air, exhausted.

After pausing to catch his breath, he proceeds to the front entrance, unlocking first the glass door and then the wooden one. Behind it, his wife and three children wait inside, the oldest fourteen, the youngest only seven. He steps inside and situates himself. His breathing is heavy, audible, and concerning to a point.

While the kids play in the above-ground pool in the back, he stands by the barbecue, watching the burgers, hot dogs, and vegetables roast above the flames. He flips them every so often, but even something as simple as turning a cob of corn is enough to leave him depleted. If you listen close enough, you can hear faint turbulence every time his chest rises and falls. Aware of his nearly constant panting, his wife approaches from behind, asking him – as always – how he feels, if he needs anything, if there is anything she can do to help.

He finishes cooking dinner, eats, and lowers himself onto the couch, nodding off as he often does; his condition causes sleep apnea, making it nearly impossible to get a decent night's rest, leaving him perpetually exhausted. As his wife leaves to work the night shift as a nurse at New York Presbyterian and the kids climb into bed, he lifts himself off the couch. As he recalibrates and gains his balance, he suddenly feels sore, lightheaded, and as if he is drowning. By the time he makes it up the flight of stairs linking the living room to the second floor, his chest feels like it is going to implode. Upon entering the master bedroom, he turns on the air conditioner – the cool air soothes him – and pulls the covers over himself, his whole body aching with the strain he felt at work, in the car and on the subway, at home – all day. He turns off the lamp to finally shut his eyes, but before he does, he glances at the gray apparatus lying in the corner across the room. Although he can barely sleep without the CPAP machine, he cannot at all with it. He prays that he makes it through the night safely. The lamp goes out.

This is the reality that my uncle, JZ, lives every day. My uncle suffers from chronic obstructive pulmonary disease (COPD) but to say that his condition is the result simply of general COPD or that his only symptom is difficulty breathing is an injustice to him, to the 15 million other Americans who struggle with COPD, and to the 150,000 Americans who die annually from COPD and its complications.

Chronic obstructive pulmonary disease, also sometimes knows as chronic obstructive lung disease (COLD) and chronic obstructive airway disease (COAD), is a type of degenerative lung disease. This means that it progressively worsens over time and exists on a spectrum, from

mild trauma and symptoms to severe, life-threatening conditions. The two most common variants of COPD are emphysema, in which the alveoli are enlarged and their walls are compromised, resulting in permanent lung damage, and chronic bronchitis, in which the bronchi become inflamed and thus constricted. Although the main symptoms of COPD are coughing and shortness of breath, the disease can affect the body in other ways, resulting in other conditions and symptoms, as we will see with my uncle.

Similar to many others with COPD, JZ's case is not the result of one single acute factor – rather, it is the culmination of long-term exposure to many potential risk factors over an extended period of time. First, JZ suffered from asthma long before he was diagnosed with COPD. This means that even from a young age, his lungs were already compromised and hypersensitive to risk factors for COPD and other illnesses. Moving past asthma, the most decisive factor by far in the development of my uncle's COPD is smoking. JZ is part of a very large statistic – it is estimated that 85 to 90 percent of all COPD cases are a result of smoking tobacco and long-term exposure to secondhand smoke. Although he quit in 2017, JZ began smoking in 1996 after taking his first puff at the age of 17 at a rate of about a pack per day, which translates to 25 years' worth of tobacco smoke in his lungs and even more years of exposure to secondhand smoke.

Although the coupling of asthma and smoking is probably the basis from which my uncle's COPD sprouted, proximity to other risk factors certainly accentuated and catalyzed its development. As an ironworker, JZ is often exposed to potentially harmful particulate airborne matter when on job sites and within their vicinities. Moreover, he works almost exclusively in Manhattan, where air pollution levels are significantly higher thanks to constant automotive traffic. Considering the fact that JZ has worked in the ironworking industry for well over twenty years, it is easy to see how exposure to irritating air pollution on a daily basis could easily have an impact on the development of his COPD, which was diagnosed in 2017, shortly before he quit smoking. To make matters even worse, JZ contracted coronavirus in 2020, causing further lung damage due to prolonged inflammation and autoimmune response.

With regard to the COPD itself, JZ experiences a specific type of ailment called bronchiectasis. Bronchiectasis is similar to emphysema in that the airways become larger in diameter. However, in bronchiectasis, the cough that results from the widened airways causes blood vessels in the walls of the airways to pop. Consequently, the subject experiences hemoptysis – the coughing up of blood – and thick, tough scar tissue forms in the lungs. As a result, the lungs are no longer able to drain normal mucosal secretions and become more vulnerable to infection, which creates nearly constant conditions for inflammation. Thus, the lungs lose function over time.

Although JZ experiences a variety of symptoms, the ones he experiences most often are those most directly related to his COPD. Coughing, dyspnea (difficulty breathing), hemoptysis, and sleep apnea (periodic lapses of breathing while sleeping) are among the most debilitating symptoms he exhibits on a day-to-day basis. However, it is suspected that other health complications of his – and thus, their symptoms – are connected to or even potentially caused by his COPD. An electrocardiogram revealed that the left side of JZ's heart was enlarged. Further examination showed abnormal ventricular relaxation on the left side, which means that his heart's left ventricle pumps irregularly. After wearing a cardiac monitor for a month, it was also found that JZ suffers from non-sustained ventricular tachycardia – in other words, his heart beats at an irregularly fast rate for short periods of time. These are both early indicators of heart failure, meaning JZ has to take extra care when it comes to his activities and his diet.

It is a typical Saturday morning, the sky scattered with high, wispy clouds. As per usual, JZ clambers out of bed exhausted because he could not fall asleep for more than an hour at a time. He heads

downstairs and treats himself to breakfast. He waits for the kids to get ready, helping the youngest one dress into his soccer uniform. Then, they are off.

En route to the soccer game, everything is very normal. Traffic jams and lousy drivers clog the roads. They arrive, and the kids pile out of the car. He follows, much more slowly and deliberately. Again, as he gets up, the pounding in his chest ensues, and it is sustained as he walks across the patchy soccer fields behind the enormous Con Edison plant and dilapidated halal butchery to get to the field on which his boys will be playing. However, while the boys play, his consciousness begins to lapse. Because he is too tired, he cannot resist nodding off no matter how hard he tries. The pseudo-narcolepsy plagues him everywhere – at his sons' soccer games, at work, and while running errands.

After the games, they beg him to stay and kick the ball around with them. As always, he acts hesitant, but both he and the boys know that the answer is always yes. But there's a catch, an unwritten rule. Each and every time the ball goes past his reach, one of the boys has to get it for him. The boys don't think much of it, but it haunts JZ. It pains him immensely that he cannot spend his limited time with his children as he would like. And it is his greatest lament that his boys must see him, their greatest role model, in a position of such helplessness.

This is perhaps what JZ, as well as others with COPD and related illnesses, finds most debilitating about the disease – the impact it has on his relationships with those close to him. In an interview with JZ, he stated that there are two ways to deal with the effects of COPD, the first being to do half the work you normally would, and the second to work twice as hard and do the same amount of work you used to. JZ explains that this affects his productivity and his relationships with those both at work and at home. In the domestic sphere, he is responsible for doing work on the house (he is in construction, after all) but tends to back away from most other physical things like cleaning, for example. As a result, his wife (who has her own set of debilitating health issues, including herniation) and children assume a good chunk of domestic labor.

JZ also finds that COPD presents obstacles to his productivity at work. In the workplace, JZ is the foreman in his squad of ironworkers. Consequently, he still does a decent amount of physical labor, but not nearly as much as he used to. Regardless, he still feels suffocated whenever he does any hands-on tasks. If JZ were not a foreman, however, he would have to complete much more physical work than he currently does, which of course means he would be subject to even more respiratory strain. Moreover, JZ has a very supportive network of coworkers, who know what sorts of barriers he faces and are always more than ready to assist him when he needs something done.

In retrospect, JZ is quite lucky when it comes to his circumstances, despite his horrible illness. He can find support from his immediate and extended family and from his coworkers, and he can be accommodated if need be. However, he concedes that for others who may not be as fortunate, the case could be radically different. For those who lack supportive family – or any family at all, for that matter – it may be difficult to complete certain tasks around the house, resulting in an overall lower quality of life. It may also be hard or impossible for them to afford domestic assistants or caretakers who could assume some of the responsibilities which COPD makes difficult to complete. For those who do not have supportive networks or are not in positions of power in the workplace but nevertheless have physically demanding jobs, productivity might be greatly reduced, making staying employed or even finding employment difficult in the first place.

This being said, those battling COPD – and any illness, in reality – actually often find themselves embarking on two separate expeditions. The first journey is, of course, combatting whichever illness they unfortunately have. The second, however, is effectively navigating the very mechanism that tries to help them – the healthcare system.

In his experience with the healthcare, JZ has two overarching gripes with the system. The first is lack of comfortable treatment options and lack of patient autonomy. With regard to the treatment options, he is rather unsatisfied with the therapies available. For his bronchiectasis and asthma, there is little he can do but lead a healthier lifestyle and take medicine, respectively. Unfortunately, that is just the nature of his condition, and there are few other treatments available. For his sleep apnea, he had a choice between only two possible treatment options. He quickly became disillusioned with the CPAP machine, the option he ended up with. He finds it incredibly uncomfortable and impossible to sleep with, describing the feeling of exhaling with it as "burning your whole sinuses." Thus, the machine does nothing but worsen his inability to sleep soundly through the whole night. He also finds maintaining the machine cumbersome and logistically impractical. He thinks the nature of the machine is unnecessarily complex and often struggles to thoroughly clean the device.

When at the specialist for his sleep apnea, he was presented with his two options, the CPAP machine and Inspire sleep apnea therapy, which involves the insertion of a device into the respiratory tract. Although JZ had tried a CPAP machine some years before and was willing to participate in another sleep study for clearance to use the Inspire device, the doctor ultimately overruled his request and put him on the CPAP machine again even though JZ would have met all the criteria necessary to use the Inspire device. JZ was disappointed with this outcome, and in his eyes, rightfully so. JZ acknowledges that doctors are trying to help, but he believes that patients should have the final say in how they want to be treated. After all, it is the patient who suffers from their illness – not the doctor. However, despite his issues with his treatment, JZ understands that developing effective, safe, and efficient treatments for any illness requires years upon years of research and immense monetary and human resources. In that vein, he hopes that in the future, more treatment options for COPD and other common illnesses will be developed that are more comfortable and logistically simpler. He also hopes that patients will be awarded more autonomy when it comes to picking treatment options.

JZ's second issue with healthcare is lack of availability on part of the doctors. Because JZ has many conditions beyond COPD, including those aforementioned heart problems as well as hypertension, he goes to see specialists quite often. When making appointments, one thing he notices is that doctors are very rarely available. For example, he is still waiting to book an appointment with a stroke specialist he was referred to after reporting a case of vision loss in well over six months ago. There are very few vacant time slots which anyone seeking help can book, making it hard to receive medical assistance. Although this issue has certainly been exacerbated by the recent coronavirus pandemic, it is really part of a wider, much older trend; over the past two decades, the number of physicians in the United States has been shrinking, even as the population as a whole has been increasing. By 2033, it is estimated that the United States will have a shortage of as many as 139,000 physicians, meaning that it will be even harder for people to receive medical help of any sort. This is an incredibly significant statistic that those in medicine need to be aware of. Does more need to be done to encourage young people to pursue medicine as a career? Should the financial barriers to a medical degree be reevaluated in order to get the most talented and dedicated individuals into the industry?

Moreover, JZ notes that the geographic distribution of doctors is widely skewed. Even though he lives in Queens, New York, an area that is somewhere between urban and suburban, he frequently has to commute for more than an hour each way to see any specialist, as most of them are concentrated in wealthier but less populated Manhattan. For people who live in areas further from places with high concentrations of doctors, seeing a physician who may save their life may be beyond difficult. It is for this reason that JZ hopes

one day the medical community will integrate more fully into areas lacking specialty medical care to tend to those whose geography may be a fatal disadvantage.

As of now, JZ's future is uncertain. He will sadly struggle with the consequences of COPD and other complications for the foreseeable future, which leaves his health up in the air. COPD is not curable, but it is treatable and preventable. There is much that can be done to increase awareness around prevention to lower communities' risks of developing respiratory issues. Abstaining from smoking tobacco or other substances and minimizing exposure to air pollution and harmful particulates takes care of the most prominent risk factors. In the future, it is critical that we listen to patient experiences like JZ's and try to incorporate feedback when we can to improve the healthcare system and to make it more equitable, accessible, and convenient for those that use it.

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