

We Tricked the System for a Good Reason: A Reflection on Access to Healthcare

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“63-year-old male presents with intermittent chest pain that is worsening over the last 4 hours. Patient describes the pain as ‘pressure’ that lasts around 5 minutes. He states that he has experienced roughly 2 episodes per hour, with decreasing time between each successive episode. Patient reports of associated pain in his left arm that is radiating from his chest. He denies history of hypertension and diabetes. Patient does not speak English and does not have a primary care provider.”

That is the history of present illness that I would document if I saw my uncle while on shift as an Emergency Department scribe. I would document that the chest is tender upon palpation, while being mentally reassured that the patient is likely presenting with a musculoskeletal rather than cardiac issue. However, I would then proceed to notice that the patient has a resting tremor and is slow to respond. The mental alarms would go blaring at this point. Every physiology class I’ve taken has been sure to mention the effects of Parkinson’s disease, but it is supposed to be one of those things you hear about, not see. Or at least I thought.

My uncle and aunt came to visit their children in Texas last summer, but my uncle was running low on his medications that he had been prescribed in India six weeks prior. Considering that my family has more resources available to us, we encouraged them to visit California. We did not know what medications my uncle needed, but we were excited to see them. The tremor presented itself during lunch and almost instantaneously my mother knew what that could possibly mean. The medications he needed were not going to solve the issue but open a door that would expose the corruption, underground pathways, and crippling effects of the healthcare system that the aging and socioeconomically disadvantaged population in the United States is subjected to.

My mother is a registered nurse with the neurology department for over 30 years and she confirmed what I thought I was observing. Yet, the bigger issue was, how do we provide my uncle with medical care? He did not have medical insurance, and flying a United States citizen over to India for prescriptions was not a feasible solution. The best place to begin was a nearby clinic to help him obtain basic care. At the clinic (which will not be named) we were redirected to see a nearby neurologist without any examination by a healthcare professional. The neurologist agreed to write the prescription after a \$1500 diagnostic fee and a \$1000 prescription fee, this would not include the cost of medications. Furthermore these costs would be supplemented by a \$850 visitation fee for every following visit. The physician was willing to help my uncle outside of the healthcare system, but was tied by the financial obligation associated with practicing medicine. Astounded by these prices, my family thought it would be best to visit a doctor of the same nationality; perhaps the cultural

connection would bring about more reasonable charges.

Given the limited number of doctors available, it was increasingly difficult to find a specialist who was also Indian. We settled for a primary care provider who pulled my family aside after the exam. He informed us that the best course of action would be to take my uncle to the emergency department with a complaint of chest pain and to not waiver from the chest pain symptoms until further resources are made available. He informed us that although my uncle is two years away from retirement, as a US citizen he could qualify for MediCal and disability benefits. However, if the hospital staff discovered that my uncle was seeking care for a non-emergent medical issue such as a tremor, he would instead be directed to apply for medical insurance before being seen, which would significantly delay his access to care. The kind physician explained that presenting to the emergency department with a factitious complaint would facilitate my uncle’s work-up and access to treatment, preventing a worsening physical and emotional toll from this disease.

We then began a journey that took us approximately six months to complete. We took our uncle to the emergency department at a local government hospital where he was admitted overnight, and by the next morning issued temporary health care insurance. His chest pain labs and imaging resulted in a diagnosis of hypertension, but otherwise normal as expected. Within the next week he was assigned a primary care provider and provided with permanent insurance. Simultaneously we began to file for disability benefits. My uncle took great pride in having worked 19 years, 365 days per year and he was not about to take a loan from our family. Things seemed to be going along smoothly until we realized it would take approximately six weeks to visit a neurologist. Over the course of those six weeks the symptoms rapidly worsened, perhaps due to the daily debilitating factors of the disease in combination with the increased helplessness. When he was finally seen, the neurologist made the diagnosis of Parkinson’s disease within five minutes and then wrote out a prescription. With my uncle’s health insurance, the prescription for his symptoms costs him only \$5.

Parkinson’s disease is best characterized clinically by the presence of a tremor at rest, bradykinesia, muscle rigidity, and stooped posture.² The disease is slightly more common in men than women, with a mean age of onset of 52.7 years.³ The symptoms quickly worsen within the first decade resulting in a decreased quality of life for patients and increased difficulty for caregivers.^{4,5} It is categorized as a progressive neurodegenerative disorder, and more specifically as the second most common neurodegenerative disease after Alzheimer’s.⁶ There are very effective pharmacological and surgical options available to alleviate symptoms, but there

is no disease-modifying treatment or cure. Pharmacological intervention with dopaminergic medications targeted to alleviate the dopamine deficiency is indicated once the diagnosis is established.⁷ Deep brain stimulation is an approved therapy for patients with more advanced symptoms of intractable motor fluctuations, and is covered by health insurance.⁸ Physiologically the disease is resultant of decreased dopamine secretion from cells in the substantia nigra of the brain, which is a part of the forebrain region more widely known as the basal ganglia.⁹ It takes a loss of approximately 50-70% of substantia nigra neurons before the first tremor.¹⁰ That means my uncle had lost at least 50% of some region of his brain before he received appropriate care.

This does not mean his journey is over. The pharmacological interventions provided for Parkinson's patients target the motor manifestations of the disease.² Arguably the most debilitating effects are resultant of the behavioral, cognitive, and neuropsychiatric implications. These non-motor symptoms do not respond to dopamine therapy and therefore can go untreated.¹² Close to 90% of the Parkinson's patients experience these symptoms, and in some cases, years before the motor symptom manifestations.¹³ This makes me wonder how long my uncle dealt with this disease without the support of his family. The non-motor symptoms include depression, hallucinations, dementia, mood disorders, anxiety, and problems with decision-making.¹⁴⁻¹⁵ The occurrence of such symptoms is far from rare, for instance anxiety is reported in 1/3 of all Parkinson's patients, and up to 40 percent of all patients receiving pharmacological treatment exhibit psychosis.¹⁶ The onset of non-motor symptoms clinically is shortly followed by a change autonomic system function and sleep disturbances. This includes effects in multiple body systems, presenting itself as urinary difficulties, sexual dysfunction, fecal incontinence, sialorrhea, and dysphagia.² Furthermore, the use of medication to alleviate motor symptoms can initiate or worsen these severe non-motor symptoms. Even if this does not occur, eventually the medications aimed to treat motor symptoms will elicit physical side effects themselves. For instance, the most effective and dominantly prescribed drug, carbidopa/levodopa, can eventually lead to involuntary movements, confusion and restlessness.^{2, 17} To counter these effects, more drugs are recommended which may in turn lead to more side effects.

My uncle, or as I call him in Punjabi-thayage, has started a long journey which we were only able to travel with him for a short period of time. As someone who aspires to become a health professional one day, I should not be advocating for behavior that intentionally disregards the institution in place. However, what if that institution is flawed? Does that excuse my family's part in misusing the system? My uncle did not have chest pain, but honestly I would encourage any other family to do the same. My uncle was given a full chest pain workup over the course of 12 hours that translates to around 6000 dollars of what would eventually be billed to MediCal.¹¹ Within those 12 hours, the ED team responsible for my uncle's care could have been addressing the health needs of patient's with more

emergent complaints or improving emergency department flow. The \$6000 could have been redirected towards health initiatives such as providing vaccinations and funding mammogram screenings. However, had my uncle not used these resources he would go untreated for a chronic illness. Seeing the implications of the 6 week wait between visiting the emergency department and neurologist, I saw first hand how quickly symptoms can worsen. Thayage was no longer able to visit the Temple because the tremor was no longer localized to his arm and made him unable to walk up or down the stairs. He was no longer eating dinner with us because of his unstable gastrointestinal system or get a full nights rest because of his unstable urination frequency. He could no longer accompany my father on mundane tasks because he would quickly tire and possibly collapse. The doctors in the emergency department work to the best of their ability, re-directing patients and helping them access care that is most appropriate to them. However, this is something that needs to be addressed prior to the patients reaching Emergency Department physicians. There needs to be a revision in the health care system that provides accessible care to patients who may not have "emergent ailments." In the meantime, families like mine find themselves in a complex situation. We realize that intentionally committing nothing less of fraud is inherently wrong and potentially affects unperceivable lives. However, we also see the daily implications of the disease a loved one is dealing with. While it is undeniably unethical to lie, I would argue that many patients lack a choice in the matter and that it is equally unjust that many Americans continue to face significant barriers to accessing care. Regardless of whether our decision was ethical, I would direct any family a similar situation to do the same.

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