

Reflections

Of Journeys and Perspectives

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The pain of a child is often only felt by its family. Toddlers are generally found in the uncomfortable position of trying to navigate a world they know nothing about and finding joy and sorrow in things they lack any degree of understanding in, yet their emotions are as real as that of any adult. Unconscious, I was taken by my mother to the emergency of a renowned hospital in Islamabad. The doctors examined me as I held on for dear life, urging my mother to prepare for anything. Ketoacidosis was the trigger and Type 1 diabetes the cause. I survived against expectation. While I cannot peer into the mind of my 18-month-old self or fully comprehend the ordeal faced by my mother, I had the immense honor of seeing her grow through it and realize how the most miniscule of things helped her come to terms with my illness. She often speaks fondly of the comfort the nurses and doctor gave her at the time of my diagnosis, "So I just shouldn't feed him any sugar? That's not very complicated". The doctor proceeded to clarify her misconceptions, foreshadowing the depths of knowledge she had to uncover and figure out on her own. She had experienced the relief of having her son back, alive and well in her arms but she was also preparing to face the challenges that lay ahead. My mother often sings praises of the counselling services for diabetics and caretakers available at the time. She had heard some truly appalling remarks, some from even the most well-intentioned of people. Stories of people who knew people losing their normal lifestyle were told and even claims about my ailment being some divine punishment were made. Amidst the noise of snarky, discouraging commentary, hearing words of encouragement from experienced professionals was akin to a breath of fresh air. My mother coming to terms with a radical lifestyle change for her son certainly merited thorough guidance. The radical was



eventually to become the new normal. The foreign to become the familiar. While the underlying cause of our ordeal was still there, the beast was not the disease as much as our perception of it. The wise sages among us will be quick to recite the cliché of our attitude towards our problems being more important than the problem itself. A lifestyle change (read: improvement) is a much easier pill to swallow than a strange chronic illness. If anything, I was lucky enough to be alive in an age of technological advancement. Long gone were the days of sharpening needles and unpredictable dosing. Vials of blood lost in tests were now drops. Insulin was now synthetic and human friendly. Knowledge of facts like these can really make the mountain seem more like a speed bump. Granted, speed bumps can often interrupt a smooth ride. Such was the case when my young, single mother decided against sending me—her immature son—to school before I gained some awareness of my condition. After facing significant backlash from even the most well

intentioned including her brothers and parents, she stood her ground and sent me to school once I turned 6. While a piece of paper does not define one's worth, I like to believe my grades and HbA1c reports gave my mother some well-deserved validation for the uncertain trajectory she went on at the time.

Regular visits to my endocrinologist were generally a pleasant experience—the process of compiling blood glucose logs and blood reports notwithstanding. As a schoolchild, I remember the doctor talking about my interests while conducting the usual examination. Chatting about cartoons and video games was a great way to distract us children while checking our reflexes. After a lengthy discussion about diet, dosage and emerging treatments, my child self was asked to raise any concerns I may have had. My concerns were often an attempt at identifying ways to cut corners. The doctor would humor me by condensing the prior discussion into a simple bite-sized list. The approach worked surprisingly well, with the additional bonus of both the doctor and myself thinking I understood most of the conversation. “Fake it 'til you make it” as they say. Having gone through the trials and tribulations of puberty and high school, I was finally ready to embark on the next stage of my academic journey. I had qualified for my field of choice in the University of my choosing to become an engineer. All those years of standing by technicians working on cars, wood, tiles, locks, TVs, computers, etc., culminated in me acquiring a piece of paper with my name and a license to tinker with expensive equipment. Funnily enough, I managed to become the one person in every class who asked the most questions. My aspirations took a major hit in my second year, however. I started noticing periodic episodes of blurred vision. On one of my regular appointments, I raised growing concerns regarding my vision despite my reasonably well controlled blood glucose. My doctor then referred me to a renowned ophthalmologist in Lahore. A hard person to get a hold of, but given the increasingly pronounced impairments in my vision, my mother and I were willing to spare no expense if it meant I would be fine. After a long wait in the ophthalmologist's office, finally came our turn. The doctor made the usual small talk as he conducted a retinal exam with the

ophthalmoscope, running through my medical history and taking notes as he asked about my classes to get a better understanding of my visual impairment. He then ordered for an OCT to be done immediately. The result was clear as day, yet unexpected. Proliferative Retinopathy with Macular Oedema. Not something you expect to find in a 21-year-old with fairly well controlled diabetes, yet the results were there, and treatment began immediately lest hemorrhaging start. The doctor assuaged our worry spending several minutes of his very valuable time explaining the recent developments in retinopathy treatment, “No need to worry, your only jobs are to take your mother's blessing and come on time”. The appointment was set for an intravitreal injection the next day and a laser some days after. Once home, we began to evaluate the issue of arranging funds on such short notice. The next day we called the clinic and asked if my appointment could be delayed, and the doctor, without hesitation, instructed the staff to tell me to come and pay whenever. There was an air of comfort in his clinic. He was calm and reassuring but also exuded experience and intellect—qualities everyone wants from someone about to insert needles into their eyes. Often, I have pointed out that the hallmark of a best doctor is one who's clinic seems less like a slaughterhouse and more like a casual conversation—even if the results of said conversation drastically change one's life. I feel profoundly lucky to have had not only some of the most competent, but also the most comforting people looking after me and treating me like their own.

The improvements brought about by my treatment were stark. I was back to driving and reading normally in very little time. All seemed well though my ophthalmologist was still on the lookout for anomalies in my results. Then two months later I was hit with another dip in vision. I was also experiencing consistently raised blood pressure, while having no prior record of such. After being recommended some blood tests, we finally stumbled upon a gaping anomaly. My white blood cell count was off the chart—thirty times the recommended upper limit. Without an appointment we rushed to my physician to share my reports. Without a formal appointment he could not expend the time of his other patients in intended including her brothers and parents

explaining the report to us and instead offered to see us at the end of the clinic and make extra time for us. Understandably so, most of the time was spent in providing reassurance and only a fraction explaining what it was and what the likely treatment would be.

He referred us to a hematologist/oncologist, and we went on our way. At the time the only people around me were my mother and old grandparents. We could not bear to tell them their grandson had acquired another condition and needed urgent treatment again. My maternal uncle was a busy man, working abroad for a multinational with long hours and hard deadlines. Seeking some catharsis, we called him up and told him the story. While we were grateful for the emotional support from a distance, the next morning he let us know he was about to board a flight and was on his way. With his laptop and suitcase in hand and office attire still on, he spared no second in getting to us. The next few days were an emotional and exhausting rollercoaster of blood tests, a bone marrow biopsy, long drives from hospitals to labs, and a report declaring the diagnosis of Chronic Myeloid Leukemia. While the taboo of cancer comes with heavy emotional and financial connotations, this was a ray of hope. “If we detect a blood disorder, this is the one we hope for” were the words uttered by one of our attending physicians. In that moment I saw my mother's face change from panic to gratitude. One sentence of comfort among the plethora of medical jargon and cancer-related vocabulary plastered all over the report files made such an impact. I am eternally grateful for my mamu's presence and help throughout this fiasco. God

knows I would have been more worried more about calming my mother than the logistics and procedures of my treatment. In a mere 2 months I had achieved complete hematological response. After 2 years, the BCR-ABL gene can no longer be found in my bone marrow biopsy report. In many textbooks, I find corollaries and conclusions often being left as an exercise for the reader. Whether this is out of a genuine desire to inspire thought or as a ploy to sell additional guides is inconclusive. During the process of writing this essay, I was stuck on identifying a reason for readers to stick through to the end, and perhaps provide some actionable insight, considering this is intended for a professional audience. How does one derive actionable insight from my anecdotal reflections? Looking back on the events that unfolded over the years, I realized that more than prescriptions, reports, and diagnoses, it was the people that made the biggest impact on my life. To this day I am baffled when people hear snippets of my conditions and go into shock as if my life had lost its meaning. It took me some time to recognize my privilege in the people I had been blessed with and the way they treated me—doctors, family, friends—as opposed to the conditions I was being treated for. Whether it was the doctor in the ER who sat my mother down to explain what diabetes was, or my physician explaining that CML was as treatable as if almost nothing had happened. A few kind words often provide a greater sense of comfort and hope. Is comfort and a sense of perspective truly that powerful? I leave that as an exercise for the reader.