

REFLECTIONS & TRANSMUTATIONS

A Portrait of the *Diabetic*
as a Young Man

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I wrote this essay with the aim to highlight how society chooses to define a disease and influence the identity of those who are living with it. The PLAID Journal has a policy in limiting the use of the word “diabetic(s)” to instances of strong need, preferring to use “person (or people) living with diabetes,” and rightly so. I use “diabetic” here in essence for the exact same reason. The PLAID Journal does not—to condemn the identification, labeling, and potential segregation, of a person living with a disease. It may seem counter-intuitive, but the inclusion of “diabetic,” I hope, gives my essay teeth, forcing the reader to pay attention to WHAT I have become, a product of societal, scientific and bureaucratic appropriation, rather than WHO I should be, simply a person living with diabetes. “Diabetic” was italicized throughout in order to show that the term is inherently conceptual and intangible, and this very point is what I hope to communicate to the reader.

REFLECTIONS & TRANSMUTATIONS: A PORTRAIT OF THE DIABETIC AS A YOUNG MAN

By Hisham S. Ayoub, D.M.D.

I am a *diabetic*. I have been a *diabetic* ever since I was diagnosed by my physician at the age of 15. I cannot think of the precise moment at which I became aware of my symptoms prior to the diagnosis. But I do remember weeks, if not months, of constantly finding myself raising my hand in the middle of class to plead with my teacher for the opportunity to leave the room. I was constantly thirsty and hungry. I was constantly pelted by remarks by loved ones that I was too thin. I had found my sleep constantly interrupted by the need to go to the bathroom. It was the constancy that had finally hijacked my attention and I had slowly, but finally, become conscious of the constant abductions of my daily habituations.

It was after the second sore throat and sinus infection in less than three weeks that I had made my parents aware of the abductions. I remember that day, sitting next to my father and facing a young physician. He examined me and declared that I had a common cold, that I should just partake in the ritualistic schedule of the commonly sick; drink lots of liquids, rest, repeat. I said that I have not been feeling myself lately, that I had already been drinking lots of liquids, and had been doing so for weeks. He said, well, it was the summer and it was hot. I said I had felt very hungry and was never fully satisfied. He said, well, I was young and an athlete. I said I was always tired. He said, well, I should sleep more. I said that I tried but I kept waking up in the middle of the night to relieve the pent-up liquids that I had been drinking. He had finally succumbed to my stubborn intentions, finding himself a victim of my circular entrapment. He had realized that I was worried about something. He smiled and said, “I am sure you are fine, but if you would like,” as he was staring at my father, “we can do a blood test.”

It was a phone call first thing on a Saturday morning that had scared my mother. It was not from the doctor’s office, for it was usually closed on weekends. It was by a lab technician who had voiced her concern that my blood sugar level was quadruple the normal level, and that maybe I should make my way to the hospital just to be sure of the test result. Monday morning the young physician had verbalized his worry that I may be suffering from diabetes. My parents had looked concerned. The young physician had looked

empathetic. I, strangely, had a smile on my face. I was not concerned. I remembered thinking that I was young and an athlete. I thought I could overcome anything.

I carried that attitude, which was imbued by the hubris exemplifying the young, well through my admittance into the hospital that very same day. I was nothing less than a confident young man, no matter what the attending physician at the hospital had thought, as I laid in bed with IV tubes in my arm, relaxed, watching the television set. I was confident and strong. I was a young man, even though the physician had declared to my parents in that hospital room that I had become then, at that moment, a *diabetic*.

My life as I had known it would become what the physician and historian Chris Feudtner termed, *transmuted*. In his paper *A Disease In Motion: Diabetes History and the New Paradigm of Transmuted Disease* Feudtner argued that diabetes as a disease concept was transmuted by “medical interventions, diverting the natural history of diseases [such as diabetes] onto other, more chronic courses” [1]. Feudtner’s historical account of diabetes utilized a dynamic approach, whence he called diabetes a “disease in motion,” transformed by cycles of new medical interventions and therapeutic paradigms. Thus, he argued, diabetes as a disease concept had *transmuted*, changing over time by society’s interferences in its natural progression. “Few diabetic patients,” Feudtner remarked, “follow a natural course of the disease.” Patients’ experiences with diabetes were diverted “away from the path defined by the natural history and towards what is more accurately called a transmuted course” [1]. And so began my transmutation, as I reflect upon my life, the life of a young man as a *diabetic* whose natural progression was altered less by the disease and more by society’s attempts to define and control it.

DIABETES AS IDENTITY

What does it mean to be a *diabetic*? I do not recall ever asking that question of myself. At least, I had not during those initial years following the diagnosis. As I remarked above, I was a stubbornly confident young man. But to my physician, the healthcare staff, and society, I was a *diabetic*. I remember that upon my return to school the following week a classmate had asked me what sickness had hospitalized me. I told him of my diabetes and explained to him what it was. He then followed by a second and more profound question; was I contagious? I chuckled and replied simply with a “no!”. But the perception of my condition by others

was not lost on me. I can see now that back then in the eyes of my social circles, including my schoolmates, I was a *diabetic*.

But what exactly does it mean to be a *diabetic*? According to Kathy Charmanz, the daily responsibility of navigating one's health through the vagaries of a chronic disease imbues a sense of self that which must be reconciled with living with the disease [2]. And this is no more important, at least for one suffering from type 1 diabetes, than for a teenager such as I was at the time of my diagnosis. It is at that stage of an "emerging adulthood" which renders the reconciliation of one's self identity as a sufferer of a chronic disease ever more relevant [3]. In their profound study, Luyckx et al. argued that;

"illness self-concept predicted diabetes-related functioning and depressive symptoms, even when controlling for personality, self-esteem, and illness perceptions. These findings may have important implications. In those cases where individuals have a central illness self-concept, it may be advisable to challenge the intrusive role Type 1 diabetes plays in their self-concept" [3].

But, in my case, my *illness self-concept* was not defined by my diabetes. It was not that I simply ignored or brushed away my condition, but rather, I accepted the challenge. I was not squeamish nor scared of syringes. And I had felt a certain degree of empowerment. Through home blood glucose monitors that became commonplace during the 1970s, a period of a social revolution seen in medicine whereby patients demanded autonomy and control of their own choices, I had felt I had control over my diabetes. This control, as Luyckx et al. had argued that an illness self-concept influenced the functioning of diabetes, had

manifested itself in my results. I had sufficiently controlled the manifestations of the disease. I had not only gained weight but also strength. Both my athletic and scholastic endeavours had improved markedly. I was physically strong and mentally aware. I no longer was abducted by lethargy and feelings of motivational ineptitude. I was not "diabetic", nor a *diabetic*. I was a young man. But my endocrinologist had not agreed.

I recall at every appointment my endocrinologist would argue that I could do better in managing my blood sugar levels. My A1C results were "ok, but they could be better". Since I was already physically active and managing my diet sufficiently, he had no recourse but to always prescribe an increase in insulin dosage, and I would follow his orders. Our doctor-patient relationship became one associated with paternalism and guilt. I remember working hard to take my three insulin injections every day and test my blood sugar levels four to five times per day, not in order to improve my health, for I had already felt well, but to not disappoint him. I had not seen myself as a *diabetic* except when I was at his office, sitting in the waiting room, anxiously awaiting my name, as if I was about to be punished by the dean, or my father.

It was not the physician's fault in enforcing a certain paternalistic oversight. He had a role to play, a concerned responsibility to ensure that his patient had a long and healthy lifespan. Elliot Proctor Joslin, the prominent diabetes physician, remarking in 1955 on the call by some physicians not to make people living with diabetes feel guilty if they had less than successful blood sugar results; "I disagree. When I see a red test, I know, if uncorrected, that patient is headed for destruction." Indeed, Joslin's

I REFLECT ON MY LIFE, THE LIFE OF A YOUNG MAN AS A *DIABETIC* WHOSE NATURAL PROGRESSION WAS ALTERED LESS BY THE DISEASE AND MORE BY SOCIETY'S ATTEMPTS TO DEFINE AND CONTROL IT. ■

treatment of his patients was one of authority and paternalism, as Feudtner remarked that, “by imposing order... He [Joslin] applied this managerial strategy to all aspects of *diabetic care*.” This strategy can become overbearing for the patient, imposing moral restrictions by which one must abide [4].

That sense of the immorality of failure to control one’s own health was felt by me in those youthful years. I was an immigrant who became a naturalized Canadian, living in Toronto, and perusing a healthcare system that provided free quality care. This system was paid for through high taxes by all, including my father. His constant complaints of the government’s hands dipping into his income was heard by me succinctly. I was a teenager, yet sufficiently conscious of the immorality of not taking care of myself and burdening a system that was paid for by my father. I had a sense of moral obligation, a responsibility, to ensure my health and well-being. I had believed that the savings afforded to the government by the upkeep of my own health would allow for the care of others who were sicker than I, others who were worthier than I. I was not sick. I was not a *diabetic*. I was a young man. All I had to do was keep watch of what I ate, what I drank, what I did, and how I felt; a regimental self-awareness that any strong and able young man, one in the midst of an *emerging adulthood*, can achieve, should achieve, and *must* achieve.

It was then, in my late teenage years, that I proceeded to investigate what diabetes really is, was, and will be. I sought to protect my identity as a *young man*. Guy Rainsford, the cartoonist who had presented his daily experiences with diabetes through his sarcastic and witty cartoons, was in a sense fighting to take back his identity from the label of *diabetic*, “poking fun was part of his identity work as he fashioned his own view of what life with diabetes was, what it meant, and what it held in store” [4]. I had sought to know the life history of diabetes so that I may be able to better understand it, prepare for its future challenges, and hence, defeat it. I sought to prepare for *my* life history.

HISTORIOGRAPHICAL TRANSFORMATIONS

The history of diabetes had lived through its own transformations. It is, as Jeremy A. Greene remarked, a “disease in motion” [5]. For much of its history Diabetes Mellitus was promulgated as a disease of the kidneys, ever since ancient physicians such as Demetrius of Apameia, Areteus

of Cappadocia, and Galen [6]. This was due to the retentive deficiencies observed in those suffering from the condition, and by the subsequent emphasis on the sweetness of the urine by medieval Islamic physicians and their renaissance European counterparts. It was not until the late 17th century that Thomas Willis had extended the sweetness to the blood, which was later proven by the investigational prowess of Matthew Dobson in the 18th century. Yet, diabetes was still at that time considered a disease of kidney origin before its eventual redefinition as a liver-centered disease by Claude Bernard through his research into carbohydrate metabolism [5]. Finally, it was an endocrine disorder through the experimental investigation of the disease in the late 19th century exemplified by German laboratory medicine and the Russian commodification of dogs in medical research [6]. It was indeed the utilization of canine subjects that had played prominently in the next phase of the life history of diabetes.

I was 18 when I was rummaging through the stacks in the musty basement of an old used bookstore near the University of Toronto. The placement of the *History of Medicine* section in the balmy and dark basement of a creaky old building was a testament to the depths I must dive in order to study who I was. Among the tattered mostly 19th century books on medicine was a little book whose plastic covered dustjacket shimmered in the dim lighting; *History of Insulin* [7]. It was written by the late Michael Bliss, the prominent historian of medicine and professor at the University of Toronto. And above all, it was a first printing. I had no choice but to purchase it, being the book collector that I was from a young age.

Bliss presented the history of diabetes through its singularly most important milestone, that of the discovery of insulin. The story of how Frederick Banting and Charles Best were able to doggedly pursue the isolation of the chemical thought to be housed in the pancreas which could reverse the scourge of diabetes in many children left an overwhelming impression on me. Bliss’s account of Joslin and his heroic attempts at keeping children with diabetes alive was eye-opening, especially how they starved from the inside out the more they ate. The photographs of the young children and teenagers wasting away resonated with me. I was a teenager and was diagnosed in my teenage years. In essence, I had felt that I was cheating death. I was cheating the natural history of the disease. This was only possible thanks to the scientists and their investigational endeavors, and to hundreds of dogs.

Banting and Best experimented on over four hundred dogs in the laboratory room of a University of Toronto building before being able to isolate insulin in 1922. Four hundred dogs were subdued, anesthetized, euthanized, and dissected on metal tables in a dank room in the 1920s. The building housing the laboratory existed no more. It had been demolished. In its place a grand modern building was constructed at the historic King's Circle to house the Sciences department. It was that building that I had sat through sleepy early morning lectures and lazy afternoon laboratory sessions for four years, yet paying no attention to the personal significance of the grounds underneath my feet. Learning of the prior existence of the building in the history of insulin, that which I had been attending every day for years, had left a singular impression on me. For more than seventy years the Earth had rotated through the machinations of human history to place me on the very same plot of dirt that hosted the activities that which ultimately would allow me to survive well into my adulthood. It was a profound moment of reflection in my young life. I remember one early morning, a quickly cooling cup of coffee in hand, I stood staring at the new building before me. Images of Banting and Best, and of dogs on metallic laboratory tables abducted my vision, some tethered while others dissected, their innards exposed. I began to imagine Banting and Best working on the dogs well late on most nights, their hair matted with sweat in the poorly ventilated space.

After that morning, I began to reflect on the book, the story, and insulin. My reliance on insulin had always been an afterthought. But ever since that fateful day, that reliance bubbled up to the surface of my consciousness. I began to *feel* my life tethered to that clear liquid, that which I injected into my arms, thighs, and stomach daily. How could I have not? If I had taken insulin for granted then I would be taking all those suffering children who died a terrible torturous death, and those hundreds of dogs, for granted. I had to respect them all by being conscious of insulin, and by extension, my reliance on it.

This very reliance would eventually redefine diabetes. Insulin became a signifier of the disease itself; *insulin-dependent* diabetes. Greene remarked that the discovery of insulin had “greatly changed the diagnostic, prognostic, and therapeutic calculus of diabetes mellitus” [5]. Indeed, Feudtner argued that the discovery of insulin was a transformative period in the cyclical transmutation of the history of diabetes [1]. Of significance was the ironic increase in the prevalence of diabetes after the discovery of insulin. This had much to

do with the increased diagnoses in the adult population, giving rise to a new kind of *diabetic*, that of “late-onset,” and “overweight diabetics” [5].

A similar transformative period in the history of diabetes was through Orinase. This medication by Upjohn became a significant instrument in the reclassification of diabetes. As the company observed a failure of Orinase to have any effect on a certain group of people who were insulin-dependent, it sought to expand the potential pool of patients. Thus, “distinguishing “Orinase-sensitive” from “Orinase-responsive” diabetes would then become central to Upjohn’s promotional strategy for the drug,” and this difference in the two groups would ultimately help in the reclassification of diabetes into type I and type II [5]. Much like insulin, Orinase was a case study in the transmutation of diabetes at the hands of medical and therapeutic intervention.

Insulin, however, remained the most significant catalyst for the transformation of diabetes. Insulin allowed for those children suffering from the ravages of the disease to survive well into adulthood. But this transformation was *bittersweet*, delivering “diabetic children not from sickness into health, but rather from disease into attenuated disease with newly revealed chronic manifestations” [5]. It allowed for people with diabetes to live longer, not cured of the disease but rather with the disease. This extension of the relationship between patient and the disease brought upon a host of new challenges, that which increased the opportunity for self-reflection and *illness self-conceptualization*.

CONFESSIONS OF A DIABETIC

The story of diabetes, and particularly insulin, had stained my otherwise steadfast reflection of my identity as a young man. Questions began to infiltrate my *self-concept*. Was I an insulin-dependent young man, or an insulin-dependent *diabetic*?

I carried insulin everywhere I went in a little plastic case along with my blood sugar meter, syringe, and various auxiliaries. Our relationship, insulin and I, became ever more intertwined, ever deeper, as if a couple losing their individual identities through the years together. I could not have enough of insulin, slowly and subconsciously allowing it to define my existence. I began increasing my injections from three times per day, to four and five. I sought to model my schedule to resemble the natural mechanics of a healthy pancreas as much as possible, delivering insulin in smaller doses over many injections rather than follow the

analog-like schedule suggested by my physician. Throughout my twenties, a decade filled with the responsibilities and the time-consuming expectations of a student of higher learning, I stopped making regular visits to my physician. But I remained feeling young, strong, and confident. I had not harbored nor experienced any side effects. My blood sugar levels continued to be controlled. How well were they controlled? That I am not so sure of now as I reflect back. But, then, I was confident I had it all under control. I was a self-promoted man of science, medicine, and literature. I could overcome any challenge, methodically and emotionally.

I continued to partake in sports and intellectual pursuits throughout my thirties as a dentist. I was still a young man, albeit with the story of insulin and diabetes well-represented in the future outlook of my life story. I slowly began to ponder my shortened life expectancy at the hands of diabetes. The irony was not lost on me; insulin had increased my life expectancy, a life expectancy that remained shortened by diabetes. This very fact was a testament to my life defined by diabetes. I had cheated death and the natural course of diabetes, but for how long and to what end? Feudtner was correct when he remarked that “the ‘triumph’ of insulin had led many individuals living with diabetes to a bittersweet victory.” The disease in his view remains a “scourge, currently causing more renal failure, amputations of extremities, and blindness among adult Americans than any other disease” [1].

It was last year, at the age of thirty-eight, that I began noticing a small central patch of blurriness in my vision. I thought not much of it at first. But after a few months it had concerned me enough to push me to visit the optometrist. After a couple of tests, he suggested I visit a retinal specialist. A couple of weeks later I found myself in the waiting room of a large multi-physician retinal specialty clinic, a waiting room filled with an aging demographic. I was there for two hours, my vision sufficiently blurred by

eyedrops given to me by the nurse to render me incapable of seeing any detail, including the texts on my phone. All I was able to do was sit and stare at the rest of the patients waiting. I began to feel older than my age at that moment. I was no longer a *young man*. The well-seasoned retinal specialist finally called me into his private office. The retina in my left eye had been filling with lipids leaking from damaged vasculature due to years of oscillations between high and low sugar levels in my blood. The accumulation of the pressure changes had finally taken their toll. After a couple of open-eyed injections of steroids into my left eye over the course of a couple of months my vision improved. But not cured. The physician gave me instructions for a couple of exercises to conduct. One was to close my right eye and stare at a grid-lined paper and see if the lines were straight



or curved. Even though they were much less so since the steroid injections, nevertheless, they had remained curved.

What had left a great impression on me was not that the specialist had told me I was suffering from an eye disorder. I was not even suffering from retinopathy. Rather, I was succumbing to *diabetic* retinopathy. I feared that insulin was the cause, but not directly of course. Rather, my *diabetic* retinopathy was a long-term consequence of a prolonged life with a chronic disease. Feudtner said it best when he had warned that great medical advances and interventions cannot be left unchecked by a “greater insight” into their effects on the life experiences of those spending the entirety of their lives with them, for “patients...will wander eagerly yet blindly into a future...a future of unmeasured promise and price” [1]. For the first time I began to feel unsure of my future that I was wandering *blindly* into.

I remember standing in front of the mirror one morning staring at my reflection. I closed my right eye and looked upon my distorted image. My *self-concept* was no longer sharply defined. A worrisome feeling crept through me. I felt the urge to make a confession to that image in the mirror, a portrait framed by years of living with a transformative disease. I felt the urge to confess that I no longer believed I was a young man, nor a middle-aged man. I could not even define myself as a *sick* man, for I continued to feel just fine. But I was no longer myself, that confident and strong young man. I felt the urge to reflect upon my life history, one transmuted by a transmuted disease. I was no longer a young man, but a *diabetic*. I am a *diabetic*. ■■

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I WAS NO LONGER A YOUNG MAN,
BUT A *DIABETIC*. I AM A *DIABETIC*. ■■