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## Crónica Two: Insula

*Technology, Policy, and Other Units  
of Jordan's Isolations*

Review copy only

Every science has a beginning but no end.

—Anton Chekhov, *Love and Other Stories*

Historian Michael Bliss's *The Discovery of Insulin* moves with the pace of a science adventure story: two young men, Frederick Banting and Charles Best, toiling through a sweltering summer in 1921 in a laboratory at the University of Toronto, incidentally killing dozens of dogs as they removed parts of the animals' organs in complex surgeries focused on the pancreas. They sliced open and stitched up brown-and-white short-haired terriers, stray dogs they found or bought on the street, a few cats and rabbits, surplus organ meats from butcher shops, and calf fetuses from slaughterhouses. The experiments they conducted essentially explored one basic, urgent premise—that something in the pancreatic secretions seemed to control blood sugar.

One dog, Number 92, lived for more than three weeks after Banting and Best gave it severe diabetes by removing its pancreas. A control dog receiving no treatment after this same procedure died quickly from skyrocketing blood sugar, but Number 92 lived beyond all expectations, surviving on improvised injections of an extract from the pancreas's islet cells to control its blood sugar. The dog, a yellow collie, came to be loved as a laboratory pet; they named her Marjorie, and Dr. Banting wept when she died. Best and Banting called the serum that kept her alive for that time *Isletin*.<sup>1</sup>

In 1923, a fellow doctor wrote to a Toronto newspaper to gush about the serum's breakthrough: "No one need die today who is suffering from diabetes."<sup>2</sup>

## TYPE WHAT?

I thought about this dramatic narration of insulin's history in 2010, as I stepped off the repurposed school bus in the bright morning. The hospital stood on the edge of Dangriga, far from where the river meets the sea. I jogged across the highway and toward the hospital's entrance as part of my usual interview circuit that year, beginning the research day by asking if any patients with diabetes wanted to talk with me. The hospital's entryway usually smelled of freshly cut grass. It was roughly ninety years after Banting and Best's insulin first kept a patient alive. But in the morning bustle of Belize's regional hospital, that expanse of years and decades since insulin's development—now going on an entire century—seemed swallowed by other numbers.

When we met for the first time, I couldn't decide if Jordan looked stoic or just bored. "Insulin or no insulin . . ." That was one of the first things he said to me. Jordan paused, and I got the feeling he didn't know how to communicate what growing up between those terms was like any more than I knew how to ask. Vaguely: "It costs."

He must have felt at least as strangely audited as I did with all the other patients in the long open room. Their occasional flickering glances conveyed that our hesitant interview was a disappointing replacement for the lack of television. I wrote Jordan's words dutifully in my spiral notebook without really understanding. I hadn't yet learned to read certain bodily signs that a doctor would have recognized immediately—suggesting the particular erosions etched on a person by discontinuous or missing insulin. Jordan was wearing a diaper. His bloated ankles and feet indicated that his kidneys were unable to regulate fluid levels. He was nearly blind at age twenty-one, signaling microvascular capillaries worn out by years of high blood sugar. I saw but didn't fully understand Jordan's sunken collarbone planes, or the diabetic ulcers along his gaunt legs. It appeared his hair had fallen out only recently, with a full shape kept by the few tufts that remained.

Before insulin was discovered, doctors called a slow, shriveling-up death from severe diabetes "inanition"—to become inanimate, a process somewhere between atrophying and ossifying. Seeing it happen over time, you could understand why someone might think the condition required its own verb.

Yet while diabetes seemed to be freezing Jordan's body, our first conversation was mostly about the mechanics of motion. He wanted to



become a pilot and had worked at a garage—cars being the next best things to airplanes—while going to technical school for specialized training in engine repair. This energetic tinkering with broken systems seemed an obvious extension of his bodily and existential struggle. Yet as we spoke about such used vehicles—and the garage job Jordan had lost when no longer able to hide that he was going blind and becoming too weak to lift tools or tires—his voice kept slipping between registers and tenses, the alternating ambitions and frustrations of someone who has dreams but suspects they will not come to pass.

Was that why he wanted to talk with a stranger like me? Jordan said that he hoped our conversation that day would be the first in a series of visits. Yet it often felt like I was asking the wrong questions. For example, at one point I had blundered and asked whether Jordan had an insulin pump, coming as I did from a country where this is a basic option for many people with type 1. The majority of people with type 1 who wear these devices, sometimes referred to as “pumpers,” can expect to live a long and full life. Such machines connect the wearer’s body with a beeper-like box holding insulin in a reservoir. Small enough to be clipped on a belt or tucked in a pocket, they are connected to the blood through a vein-like plastic tube called a cannula, which is inserted under the skin for continuous subcutaneous insulin injection. In countries where pumping is prevalent, these pumps can be programmed to deliver doses in tailored intervals—in calibrated bursts or in slow, steady drips—depending on habits, blood sugar, and foods eaten. New models often come equipped with features such as micro-dose calculators and computer interfaces with blood sugar levels in real time. Some even have the ability to automatically deliver insulin based on the results and custom alarms from continuous blood glucose monitors. But Jordan explained that he didn’t have an insulin pump or continuous glucose monitoring because you couldn’t get either device in Belize. Only people able to travel out of the country might have access to the larger infrastructures necessary to set up and maintain such intricate machines.

I felt ashamed for making him explain this out loud and groped for a question that would not elicit such terrible patience.

“So, what kind of diabetes do you have?” I asked, to fill a lull. It was a kind of placeholder question—one I thought we both already knew the answer to, but that might open into a more interesting discussion. Yet Jordan surprised me again.

“I don’t know,” he said.

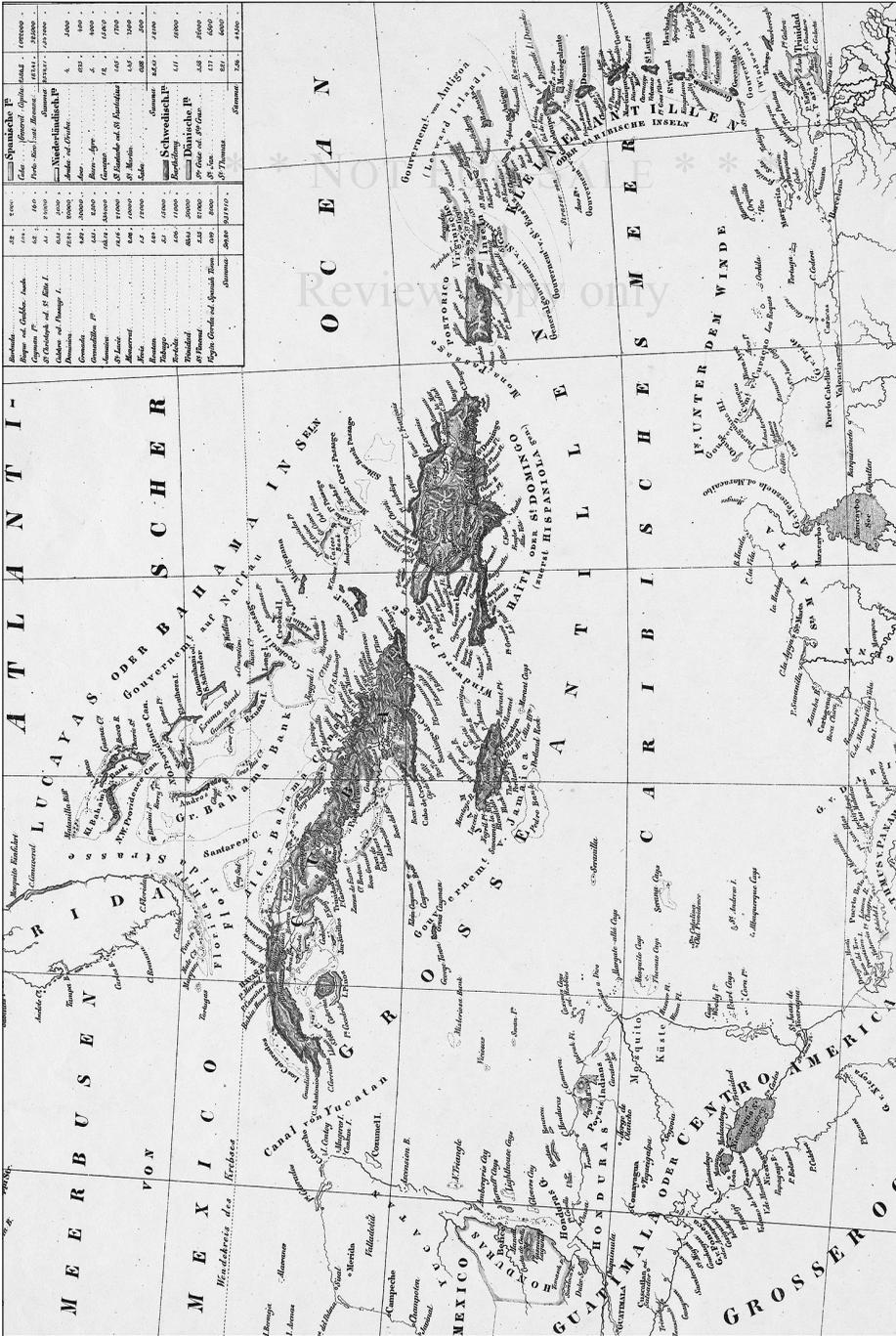
## ISLANDS AND EMPIRE

The word *insulin* comes from the Latin *insula*, meaning “island.” This crucial hormone is produced in the human body by archipelagos of cells in the pancreas, floating among other cells that produce digestive enzymes. The unique clusters are named for a nineteenth-century German medical student, Paul Langerhans, who described in his dissertation the microscopic cell groups that came to be known as islands of Langerhans. Medical textbooks now more often label this part of the pancreas as the islets of Langerhans, *islet* sounding suitably technoanatomical but still meaning “tiny island.” These islands contain four kinds of cells—alpha, beta, delta, and c, which talk to each other—though beta cells are the most plentiful.

Type 1 diabetes occurs when the islets’ beta cells stop producing insulin—the peptide hormone that allows glucose to enter cells, thereby regulating and stabilizing levels of sugar in the blood. No one fully understands the genesis of damages that cause the islet cells to malfunction this way, though there are abundant puzzle-piece insights and theories of exposure: viral triggers, various stressors, genetic inheritance, pollution, and climate, among others. But anyone with type 1 needs insulin injections several times a day, every day of their lives, to survive. This form of diabetes is an autoimmune condition that sets in quickly, classically manifesting during childhood or adolescence. Like other autoimmune diseases, rates of type 1 diabetes are now skyrocketing worldwide.<sup>3</sup>

Type 2 diabetes takes longer to set in. It occurs when someone’s pancreas used to produce enough insulin, but this function has slowly tapered off due to cellular stressors that accumulate from insulin resistance. A pattern of consuming high-carbohydrate food is the best-understood factor that can cause this effect, linking type 2 to industrial food systems and imbalanced nutrition, among other factors and exposures. Depending on long-term treatment and circumstances in type 2, the body’s ability to produce insulin might become so impaired that pills and diet aren’t enough, and insulin injections eventually become necessary.

It had taken me awhile to memorize diabetes’s multiple variations before beginning this work, and at first I was puzzled when people like Jordan told me that they did not know what kind of diabetes they had. Some patients would answer readily when I asked about type 1 or type 2—but a significant number of people like Jordan also raised their eyebrows in impatience or confusion at the question or would clarify “sugar diabetes” when pressed on the question of “what kind.” Even



Westindische Inseln, 1848, with mainland Belize mapped as an insulan (island) of the British Empire.



doctors at times have difficulty distinguishing the difference between type 1 and type 2 as they appear in the clinic<sup>4</sup>—like Cresencia, who lived for years not knowing which type she had.

Anthropologist Melanie Rock has critiqued the politics inherent in hammering down the many diseases that diabetes can represent into two neat types, terming the whole classification process “commensurating bodies of unequal experience.”<sup>5</sup> But I faced her questions of categorization from the opposite direction. I had intended to focus on type 2 diabetes, but local realities made me face the meaningful loosening of these labels at the level of actual lives: sugar diabetes, type unknown. Where did this dissolution of diabetes typologies come from, and how was it being inhabited?

Jordan told me that his mother had also lived with diabetes, dying from it in her thirties. Given this fact and his very young age at onset, I felt reasonably sure that Jordan had type 1. (Perhaps it was MODY, the rare variation most likely to be passed genetically? Did it even matter?) Yet over time, I came to see the lived murkiness between type 1 and type 2 in Belize as itself an ethnographic finding with meaningful implications. International media and public policy framings of diabetes writ large often implicitly draw on assumptions and imaginations about type 2. This includes forms of shaming (emphasizing that individuals with diabetes were simply personally responsible for their own health outcomes) that often fit poorly enough with type 2 but can be bizarrely incongruent when applied to type 1—as if patients and their families alone were morally and practically responsible for their own conditions and treatment. People with type 1 in Belize—by definition depending on treatment each day to survive—relied on technology in a way that only amplified broader struggles to reckon accountability amid medical shortages. Yet these negotiations were, in truth, part of managing *any* diabetes on the margins of an overstretched care system, and difficulty consistently accessing insulin regimens and glucometers day in and day out was also part of type 2 for many people. These kinds of struggles show how, as Claire Wendland argues, “technologies can be potent actors even when they are materially absent.”<sup>6</sup>

But how do you research the anthropology of an absence—whether of a partially missing treatment regimen or the absent lives it can imply? Stereotypes about diabetes often come alive in the blanks of missing knowledge, eclipsing actual patients with caricatures: the type 2 obese noncompliant patient; or the unfortunate type 1 child who can be saved by science, able to manage with enough hard work. In Belize, these

oversimplified tropes at times seemed animated in reality by social expectations of them, as patients moved in and out of various preset roles amid a complex cast of local characters. Nurse Norma often managed to acquire NovoLog insulin pens from a relative with diabetes in the United States (she disliked the messiness of syringes). Sometimes she arranged for Jordan to stay an extra day if there was a free bed in the hospital, which meant he could get an extra meal when he was hungry. There was no practicing endocrinologist in the public system during that time, so the homesick Cuban doctors on rotation learned more than they probably ever wanted to know about diabetes, simply from the sheer concentration of patients they tended. Many doctors focused on inspirational moments, recounting over and over such stories as the loving father who bought insulin by the crate for his three kids blind from type 1, or the diabetes camps for type 1 patients that had started being held in Belize City, where children were taught to use needles and families thickened their support networks.

In this, I saw hopeful stories move across the horizon and circuits of family care taking shape around childhood diabetes in Belize. But I also observed how the fragility of these forms excluded someone like Jordan, without a savvy parent to advocate for him. His story dramatizes the worst that patients are up against. (Happily, most children in Belize today have a much easier time managing than he had—in addition to the Ministry of Health’s ongoing efforts, a group called Insulin4Life has now partnered with the Belize Diabetes Association to try to enable fuller access.) But as a marginal figure in childhood awkwardly coming into adulthood, Jordan’s experiences at this system’s edges also show the spectrum of unequal global realities in which limits are lived out.

In 2010, the in-patient wards were well cared for, but not new. Its corridors reminded me of a story I’d read where “the hospital seemed both futuristic and worn-out, like an old starship.”<sup>7</sup> One afternoon I returned to the hospital and found Jordan’s usual spot in the room occupied by another patient. He was a banana plantation manager, young and recently revived from a coma. I wondered where Jordan had gone but chatted politely for awhile with his successor, who had just found out that morning he had type 1 diabetes. He was nervous to tell his wife.

On the way out, I saw a row of patients waiting in the hallway for appointments with a team visiting from Texas that specialized in eye surgery to correct diabetic retinopathy. Some patients even had their diabetes diagnosed by the eye care program, which was mixed news: it meant the eye care program provided a strong safety net, but it also signaled that



primary care had missed detecting these patients' diabetes at some earlier point, before their complications had progressed to blindness.

In the office, a worried-looking hospital administrator dedicated herself to calling around, hoping to find some anesthesia for the day's surgeries. One Jehovah's Witness began to pray loudly, sharing sobering pamphlets illustrated by pools of fire with others waiting on the bench. It was easy to tell who was expecting surgery by the purple Xs drawn in marker over one or both eyelids. Since Jordan was also going blind from lack of insulin, I wondered how the patients waiting on the bench had been selected. I talked with several of the women with diabetes who were waiting for surgery but also watched for Nurse Norma or another staff member passing through who might be able to tell me what had happened to Jordan.

It was weeks before I heard the news of what had unfolded: he had been returned to the hospital again a few weeks after our last interview. It was a March day when he had been brought in for the final time, drifting in and out of a coma. Jordan's stepfamily had come for this last trip to the hospital but not for the dozens or hundreds of visits that had preceded it. This upset the nurses who had been caring for him all along, who viewed it as an unearned closure on a fate that their neglect had played a role in accelerating.

Norma said that on the last day, Jordan was talking to his mother's spirit. He opened his eyes at one point and saw a woman standing by the door. He asked for two glasses of water. Somewhere in them were the last drops that Jordan would ever take into his fluid-swollen body. He died after drinking the two glasses of tap water. A long dying process often ends in aspiration; trying to wrap my mind around it, I imagined something like drowning. But ketoacidosis is actually not characterized by the excess or lack of fluid; it just looks like that from the outside because the swelling signals it's misdistributed—fluid pulled out of organs and into intercellular spaces, and into the blood.

As if searching for some proxy closure, one morning I went to find his grave near the sea: past the bridge over fishing scales and pelicans too heavy for the electric line, shops selling Nollywood DVDs and bright clothes from India, an old man sketching in charcoal sailboats of a kind that no longer exist. The cement archway leading into the cemetery read GARDEN OF GETHSEMANE in gothic script. Sinewy grass grew straight up to the sea. I searched through row after row of aboveground tombs, some brightly painted and adorned with offerings: ceramic mugs or glass bottles holding rum for the dead and wreathes with purple and



*Five Decades.* Rosary made of insulin syringe and diabetic medications.

black crepe-paper petals. Jordan's mother was probably interred there too, but I couldn't find her name either. I finally gave up looking and paused under a palm tree with ragged fronds. As a tiny Maya Air prop plane drifted over the sea, I recalled Jordan's dream of becoming a pilot.

I kept wondering to myself how I did not realize that Jordan was about to die, at least not consciously. I knew he was very sick; I knew some people my age or younger died from diabetes. But this person in front of me talking about gearshifts? It just didn't make sense in my mind. I used to think that the platitudes of our strained conversations might fall away in time. But that was all there would be now.

How does a medical cliché at times get sustained, resuscitated, lived out? I slowly and belatedly began paying closer attention to the artifacts that Jordan's life had left behind and the overwhelming complexity of his condition's material culture. Maybe that happens when someone dies: adjacent objects become supercharged with meaning, scraps and partial traces some kind of clues to interactions you never got to have and things you realize you forgot to ask and will never know.

Five years later, I sat paging through files in a New York archive where some of the early exchanges between insulin's discoverers, early prescribing physicians, and its first distributor (Eli Lilly) are stored in boxes. Many of the images have been displayed in museum exhibits,



such as the New York Historical Society's 2011 "Breakthrough: The Dramatic Story of the Discovery of Insulin." Banting and Best sold the first insulin patent to the University of Toronto in 1923 for a dollar, in hopes of making it publicly accessible, and Eli Lilly had been granted first pharmaceutical distribution rights in the United States.<sup>8</sup> I leafed through folders of old news headlines and series of before and after images of patients injecting themselves in the thighs. Did Jordan live in the before or in the after of this science?

On colonial maps, the territory of British Honduras was drawn as British *inseln*, even though Belize is part of Central America's mainland. Colonies were already conceptually rendered as islands, in the logics where remote islands have often been central to the formation of "networked empires."<sup>9</sup> Meanwhile, Spanish maps like *Insulae Americana* did not depict Belize at all, drawing its land as open ocean. In this geography, who can say for sure that diabetes is a new issue in the Caribbean? While the history of insulin is canonically told as a history of the white children who received it, it is possible that a large part of this imbalance is because type 1 was primarily diagnosed among this population. No one can provide a global map of type 1 prevalence even today—and certainly not in 1921. As William Julius Wilson observes, imagined geographies of "isolation" can reflect exclusions actively *produced* at the nexus of societal forces—frequently in the very areas deeply interconnected to global markets.<sup>10</sup> With even erasures so often obscured in histories of normalized injury, Derek Walcott once wrote from another corner of the Caribbean: "Every island is an effort of memory."<sup>11</sup>

*Insula* is also the etymological root of the word *insulate*: to make like an island, to protect something or someone through a layer of substance or distance. This place was an island in more than one sense, I thought as I sat in New York City that day. Certain standards of care had become so normalized in affluent contexts that it was easy to imagine this heartening history of insulin as a global narrative. The museum versions of this history focused heavily on where the story of insulin began but often said little or nothing about where it went globally. People like Jordan fell somewhere far outside this history's purview, missing characters only present as part of "what moves in the margin."<sup>12</sup>

Yet the discovery of insulin changed their lives profoundly as well, because it transformed people's expectations of those living with the condition. Everyone's idea of diabetes suddenly "metamorphosed," as Boston physician Elliot Joslin wrote of insulin's potential: "This limpid liquid injected under the skin twice a day can metamorphose a frail

baby, child, adult, or old man or woman to their nearly normal counterparts.”<sup>13</sup> Yet whether the drug that promised this new bodily transformation was actually available twice a day—how, and to whom, and what the compromises of “*nearly normal*” mean in reality across uneven social and medical geographies—is another question entirely.

*Insula* also refers to a puzzling bit of our emotional anatomy. Once “assigned to the brain’s netherworld,” an article in the *New York Times* noted: “According to neuroscientists who study it, the insula is a long-neglected brain region that has emerged as crucial to understanding what it feels like to be human.”

It helps give rise to moral intuition, empathy and the capacity to respond emotionally to music. . . . the insula “lights up” in brain scans when people crave drugs, feel pain, anticipate pain, empathize with others, listen to jokes, see disgust on someone’s face, are shunned in social settings. . . .

It is in the frontal insula . . . that simple body states or sensations [like hunger, temperature, touch] are recast as social emotions. . . . Intensely emotional moments can affect our sense of time. It may stand still, and that may be happening in the insula, a crossroads of time and desire. . . .

The frontal insula is where people sense love and hate, gratitude and resentment, self-confidence and embarrassment, trust and distrust, empathy and contempt, approval and disdain, pride and humiliation, truthfulness and deception, atonement and guilt.<sup>14</sup>

These associations are always in the back of my mind when I read about cutting-edge breakthroughs in diabetes research, coming largely from North American and European laboratories. There’s a steady stream of headlines: the promise of a bionic pancreas; news of islet transplants; a variety of insulin marketed for dogs, cats, and rabbits with diabetes that have fed too long on hyperprocessed American pet food; cute pancreas-shaped stuffed pillows and necklaces; an amazing variety of monitoring gadgets, iPhone apps, and care devices being invented by some with diabetes who call themselves “d-tech heads.” I always feel a mix of emotions when bumping into such news items, because I am often moved to see how community participation in such ingenuity can become part of sustaining dignified life with a chronic condition. But it can be simultaneously unsettling when the ways some cutting-edge devices get taken up by industries would strike many people in poorer parts of the world as more reminiscent of salubrious toys, flourishing in the same epoch when many people with diabetes are still struggling to obtain a century-old drug. Staring at the arrow-straight time line of diabetes science, I tried to imagine what geometry would be



needed to chart the ways those same discoveries actually reached most of the world.

#### GLOBAL POLICY GAPS

Since much of the current literature describing the global diabetes epidemic actually focuses on type 2, it is worth pausing to sketch out some basics about the global picture of type 1. Current estimates state that over five hundred million people live with diabetes worldwide, and roughly 5–10 percent of them are thought to have type 1.<sup>15</sup> But these numbers are really all just best guesses. They suggest certain global imbalances: for example, statistics show there are many more people *known* to be living with type 1 diabetes in wealthy countries (like Norway, where an estimated thirty-six per one hundred thousand people are diagnosed each year) than there are in poorer ones (like Peru, where two per one hundred thousand are diagnosed each year).

Yet these broad-stroke portraits themselves raise unsettling questions. It's unclear to what degree this hugely uneven distribution of type 1 is due to humankind's inescapable roulette of genetic and environmental risk factors, or to what extent these uneven counts suggest that children born with type 1 diabetes in poorer nations tend to die before they are ever diagnosed or counted. Many symptoms of seriously untreated diabetes—lethargy, fevers, weight loss, seizures, comas—are easily confused with malaria and other high-profile infectious diseases (the usual targets of multimillion-dollar global health campaigns favored by celebrities and donors), meaning that cryptic deaths in poor regions of the world often get tallied according to the cause du jour.

Such global health policy omissions have a history at least as old as insulin itself. In 1924, almost immediately after mass production of insulin began, the Rockefeller Institute initiated a program in which select hospitals in the United States and Canada offered insulin supplies to patients who otherwise could not afford the new drug. "This is the greatest philanthropic plum of the generation waiting to fall into your hands, and I want you to have the benefit of it," the Rockefeller Foundation's Frederick Gates—who himself lived with type 1—enthused to John D. Rockefeller in support of the program. "New Serum Dooms an Age-Old Curse," read a headline in the *Evening Telegram*.

Yet in the same archival folder as these clippings I encountered a cache of 1920s letters from people around the world—Mexico, Costa Rica, India, Norway, France, Spain, Hungary, Brazil—describing in

desperate longhand their symptoms of diabetes or those of loved ones, saying that they had somehow heard about insulin and pleading for access to it. I also found the standard reply to such requests: “[The Rockefeller’s insulin provision] activities, however, have not gone beyond this country.”<sup>16</sup>

At the time, the dynasty’s global health arm—the Rockefeller Foundation, which administered its International Health Division—was aggressively promoting numerous programs in remote corners of the world: malaria, yellow fever, tuberculosis, and its hookworm eradication campaign. Why was insulin deemed worthy of support in North America but not in other countries, when there was clearly demand for it everywhere?

In stark contrast to the pleading letters for insulin pouring in from around the world, the Rockefeller hookworm eradication campaign inspired markedly mixed sentiments—including in the part of Belize where Jordan was later born: “In southern districts, where most of the people are Caribs, it was found almost impossible to get them either to come up for examination or to construct privies,” exclaimed one Rockefeller report. Some Belizeans were so resistant to the campaign that the colonial government of British Honduras passed the Hookworm Ordinance, stating that any person “without reasonable excuse” for withholding their excrement from the Rockefeller staff could be detained in jail “as the Court orders until a sample of his feces is obtained.”<sup>17</sup> In short, hookworm testing and pharmaceutical treatment were at times being forced on people who actively resisted them, even at the risk of imprisonment. Meanwhile, with diabetes, desperate pleas for insulin therapies were arriving from around the world, without institutional recognition of any medical necessity outside the United States and Canada.

This strand of thinking persists even today. An infectious disease like hookworm is considered a pressing international priority, a “tropical” disease of poor populations and nations. But the global rise of diabetes (even when spreading much faster than infectious diseases like hookworm) has been framed as a different class of disease: a condition of *individual* responsibility—personally tragic but not collectively urgent to address as a society, or under any institution’s ethical mandate in particular.

Uneven responses like these are spliced throughout global health archives of the past century, becoming difficult to ignore even when trying to conduct contemporary research on other topics. Just before coming to Belize in 2009, for example, I found myself doing some brief comparative research about guinea worm eradication and diabetes in



Northern Ghana's capital of Tamale—a lively city echoing with prayer calls and dense with bicycles and affable goats, surrounded by expanses of West African red-earth savannah. I will never forget the morning when I started off observing the bustling program office for guinea worm eradication. Inside the office, several dozen campaign staff, Ghanaian Ministry of Health officials on laptops, and Carter Center consultants were debating how best to locate a woman with guinea worm who had run away to avoid treatment. Guinea worm hurts for several days but doesn't kill, though it appears grotesque to foreigners who are not accustomed to seeing three-foot-long parasites. These worms have been the target of major U.S.-driven eradication efforts for several decades. Later that same morning, I traveled a few minutes across town to the public hospital's weekly diabetes clinic for the Northern Region, where more than thirty patients waited outside for hours for a doctor who never arrived.

I waited awkwardly with them on the wooden benches of the hospital courtyard until they were finally sent home for the day. My collaborator in Tamale, Emmanuel, translated from Dagbani, and I took notes as people who wanted to talk approached me to describe their routines living with diabetes in a region where over half the rural population survives on less than a dollar a day. Several people described walking dirt paths by lantern light from their far-flung villages or crossing rivers by canoe to reach a road that would lead to the hospital by dawn. As was clinic policy, the first thirty patients who arrived at the Friday diabetes clinic were handed ticket-like numbers, and the rest were sent home until the following week. "I am number seventeen," offered the young woman next to me. She had arrived by *tro-tro* around 4:00 A.M. to hold a place.

When I met with the government doctor the next week, he explained he had been called away on another emergency. He spoke about the difficulty of being the only doctor assigned to treat diabetes in a region of 1.8 million people, and only on Friday mornings. "I am one man," he said. "It is just me." He told me the weekly clinic felt much different than when it first opened; many of their original patients had already died.

Outside his office door, a man with no legs was being carried toward us on the shoulders of two young men in lieu of a wheelchair. "We used to have dozens of children with type 1 diabetes here," the physician said, but there were frequent interruptions in the region's insulin supply. The emotional labor of triaging insulin often fell to pharmacists, who had to decide which of the prescriptions they would actually fill with the very limited supply. Children first. "They used to come every

Friday. But many of them lived in the villages. We lost them; they died, one by one. They are all gone now.”

“What about the Salifu girl?” asked his assistant, an attentive man in a long robe who had worked at the diabetes clinic since it first opened years ago. “We haven’t heard anything since she went back to Kampong.” The doctor nodded and smiled faintly in recognition. “That’s right, we do have one left. Her name was Safia.”

Neglected tropical disease philanthropy and global health aid become a different picture when thinking of these comparative scenes (the same city’s gutted public diabetes clinic versus its bustling guinea worm eradication program office, and countless other places like them) as *coterminous realities*, drawing from the same limited pool of healthcare workers and monies spliced into vertical programs.

An ocean away, these encounters nonetheless helped me understand that what I was seeing in Belize was part of a longtime worldwide problem. Patients, families, and other caregivers alike were struggling to achieve diabetes treatment regimens in overstrained health systems where neither type 1 nor type 2 diabetes has historically been considered high priority by foreign institutions or international communities. As is the case in most postcolonial countries, Belize’s health system has been deeply contoured by an “alphabet soup” of acronyms belonging to foreign NGOs, where piecemeal funding over the past century has inevitably come with certain priorities and strings attached.

But during the second year of my fieldwork, I saw part of a major effort to change this storyline: the rollout of a new National Health Insurance program to three of the country’s six districts, Belize’s aim to extend primary health services and a basic drug formulary to people in half the country—including insulin for those with diabetes. The hope was that this would be the pilot phase leading to an extension of the program to the entire country. But funding has been strained (largely due to Belize’s struggles with serious international debt, following structural adjustment).<sup>18</sup> Some said it was possible the national insurance program may even scale back in the future rather than expand. When I last visited Belize in 2019, the local hospital was again out of insulin.

As in many countries, receiving a diagnosis of diabetes in Belize does not automatically translate into inclusion in national statistics. In Belize, there was no statistical information available on the prevalence of type 1 diabetes at the time of my research and no specialized state program or policy yet to support children with the condition. When I interviewed the charismatic president of the Belize Diabetes Association in 2010, he



spoke about his dream of building programs to bring together local families dealing with type 1. “They are usually okay if their parents are involved,” he said carefully, when I asked. “But it would be good to have some support. We could at least get a registry of their names, of the children who have it. So we will know.”

#### OTHER ORPHANS

“AIDS orphan” is a well-known category of vulnerability in bureaucracy and activism, but there is no such thing as a “diabetes orphan” on paper or in global health policy. So when Jordan’s mother died from diabetes shortly after he turned three, that left him living in a role that lacked a recognized name.

Social scientists write a lot about the power of labels:<sup>19</sup> the reductions and politics that they inevitably entail and what it’s like for people to inhabit them. In Belize I met several young adults like Jordan who had grown up without one or both parents (the flexible definition often used to classify AIDS orphans), and I found myself wrestling with questions of how their life experiences were shaped by nonexistent techno-bureaucratic categories. Yet there was Jordan, and his stories.

His mother’s name was Tessa. She’d risked a lot to have him: “The ultimate complication of type 1 diabetes in combination with pregnancy is maternal death.”<sup>20</sup> It was once considered essentially fatal for women with type 1 diabetes to have children. Even today, having diabetes prior to pregnancy is still “a major risk factor for spontaneous abortions and congenital malformations”<sup>21</sup>—although this risk to the fetus drops to very low in a context where excellent blood sugar control is maintained by using insulin analogs (such as lispro and aspart, more often called Humalog and Novolog).<sup>22</sup> Neonatal growth often occurs during intense bursts, causing unexpected dips and spikes in the mother’s sugar, part of why one study found that “the mortality of type 1 diabetic mothers was 109 times greater than in the general population.”<sup>23</sup>

Analog treatments, now standard care in some places, were not easily available through the public system in southern Belize, where simply keeping a mother with diabetes supplied with basic insulin injections or access to a working glucometer constituted a meaningful accomplishment. Many experts recommend that pregnant women with diabetes follow an involved regimen: “Pre-conception counseling, carbohydrate counting, use of insulin analogues, continuous subcutaneous insulin infusion (insulin pump) therapy and real-time continuous glucose monitoring

with alarms for low glucose values.”<sup>24</sup> I imagine that this list would make most caregivers working in small towns or rural villages in Central America want to toss up their hands and laugh helplessly even today, let alone back in the 1980s, when Tessa was pregnant with Jordan.

The dangers of type 1 during pregnancy are greatly increased by not having access to tools like glucometers. Maternal death can be caused by ketoacidosis in cases where high blood sugar goes untreated—but in contexts of partial medical availability, maternal death is more often caused by blood sugar that crashes too low to sustain life. This puts mothers in a double bind, since “tight metabolic control of diabetes during pregnancy that is mandatory for the normal development of the fetus may expose the mother to life-threatening hypoglycemia”<sup>25</sup>—in other words, the more carefully a mother tries to control her blood sugar for the sake of her baby, the more she puts herself at risk for a potentially fatal hypoglycemic episode, particularly while sleeping. This risk peaks at night and can result in so-called dead-in-bed syndrome, which researchers estimate accounts for 6 percent of deaths in people with type 1 under the age of forty.<sup>26</sup>

Despite severe diabetes complications and incomplete medical resources, Tessa managed to survive pregnancy and give birth to Jordan. She lived for several years afterward. What it took for her to manage this double feat, I can only guess. Yet given all the mother-to-child risks that scientists are now examining during mothers’ deliveries, it is striking how childbirth with diabetes contrasts with HIV/AIDS.

Obviously, as a classic infectious disease, HIV/AIDS transmission works through very different biological mechanisms than diabetes risk. But medical care during pregnancy is crucial for both conditions. Antiretroviral drugs (ARVs) are now provided nearly worldwide for both parents and children with HIV/AIDS—however imperfectly such a program might function, even extremely poor countries at least have one. Yet there has not been analogous global consciousness or policy supporting diabetes. I struggled to understand why providing ARVs to a pregnant mother or recent orphan with HIV/AIDS is perceived as an automatic “ethical imperative,” but ensuring drug provisions for a mother or child who will die without insulin is not.

In *The Republic of Therapy*, anthropologist Vinh-Kim Nguyen describes the advent of new HIV/AIDS drugs (known as HAART, or highly active antiretroviral therapy) with an analogy that perhaps accidentally underscores this comparison: “HAART marked the advent of a therapeutic revolution akin to the discovery of insulin for the treatment



of diabetes. An illness that was previously fatal, in most cases, within a few years of diagnosis, is now treatable and has been transformed as a result into a chronic condition.”<sup>27</sup> Yet perplexingly, these drugs to treat HIV/AIDS have quickly become more accessible in many poor countries than the consistent supplies of insulin they have been likened to—even though the suite of HAART drugs only began development in the 1990s, and insulin therapy will soon celebrate its centennial birthday.

Something besides pharmacological breakthroughs alone shapes the drastic differences in global availability of seemingly comparable therapies, returning us to the imaginations driving “political will” and social movements in global health politics.

However interventions are prioritized on paper—often with an emphasis on AIDS, malaria, and tuberculosis, contagious conditions often referred to as the “Big Three”—coexisting conditions can rarely be so neatly pulled apart in practice. For example, the immunological toll of having any kind of diabetes can make patients nearly twice as susceptible to malaria and three times as likely to acquire TB. Patients who have diabetes are often less responsive to TB treatment drugs, which (like many pharmaceutical treatments for infectious conditions) can wreak havoc on blood sugar for people with diabetes.<sup>28</sup> Likewise, drugs to treat HIV/AIDS can actually *cause* insulin resistance and diabetes in up to 25 percent of patients—a poorly understood side effect now creating painful iatrogenic ricochets in many countries where AIDS medications are finally accessible. The availability of ARVs is due in large part to major international relief efforts. But these same programs do not supply insulin to HIV/AIDS patients who develop diabetes from their ARVs. “We are getting to the point now that more and more of our AIDS patients actually die of diabetes,” one doctor told me.

I met several patients who lived with both AIDS and diabetes in Belize. One man named Raul said he thought his diabetes first started after he resorted to taking expired ARVs when no other regimen was available. Another man with both AIDS and diabetes named Sammy asked me to return the following day for an interview because he was having trouble breathing at the time. I returned the next day to hear the numbing news that Sammy had died unexpectedly during the night, wearing a pair of pajamas that said over and over in tiny font *Who wears the pants?* He was thirty-six years old. It was the first time I had met somebody on the day they died, and I felt unnerved by the Cuban doctor’s exhausted laughter as he told me that his patient’s cause of death was “unknown” and that he was having trouble filling out the

paperwork. Comorbid diseases and treatments might be separated into vertical treatment programs, but people live and die in their unparsed entanglements.

The story of comorbidities can be dizzyingly untrackable even within an individual patient body, but their details become even more complicated when trying to understand how coexisting infectious and chronic conditions interface within families. I began thinking about these relational knots during conversations with a bubbly young AIDS patient named Sadie, who was also in her twenties then, just a few years older than me. She had an easy laugh and impeccable cursive handwriting with tiny spheres dotting each *i*, honed during her time spent on a 4-H scholarship program in Belmopan. As we got to know each other, she began writing little essays to give to me, explaining that she hoped I might be a conduit to people elsewhere who might find them interesting. She filled an entire notebook with longhand letters and word games and had her aunt bring it to me before I went home. Sadie called this being “pen pals” with me, although we lived just minutes apart at the time. It strikes me only now that this is the first time I am writing back.

Sadie was unable to get a steady job—in part because she couldn’t breathe some days, in part because of the stigma shadowing *Aidsi* (the Garifuna term for HIV/AIDS) there—and she survived largely through the generosity of her aunts, who often shared food with her. Yet this left Sadie in a perpetual state of indebtedness that had to be delicately managed, an obligation that weighed on her mind. She owned no stove or refrigerator, so in order to prepare food, she had to make use of her aunts’ kitchen. Eking by on a few coins’ worth of personal groceries each day therefore became impossible because if you want to prepare a meal on another person’s stove, using their fuel, in their kitchen, after they had many times shared food with you, then you had to make enough to offer the whole household—eight or nine people in all. So oftentimes Sadie would skip meals because she couldn’t cook for herself if she wasn’t able to share. Other times she would save enough to buy the cheapest foods she could to stretch for a large group, 1-2-3 oil with white flour or white rice bought by the pound.

“But my sugar is good,” Sadie would reassure me with a smile. She liked to have it checked, though casually sticking her finger to draw blood at home (the way many around the world use a glucometer at home, without gloves or biohazard supplies) was not advisable with AIDS. She often asked about my diabetes research; Sadie’s mother underwent a harrowing leg amputation because of diabetes and after-



ward had “given up” Sadie because she felt unable to care for her children. Because it had taken her mother out of the picture (leaving Sadie with the sense of being a partial orphan when she left home alone at a young age, she said), diabetes loomed large in her mind alongside the work of living with AIDS. Sadie wrote in a note dated July 2010:

The other illness killing much faster than H.I.V./A.I.D.S. [are] illness like  
Diabetes, Cancer, Heart Disease and Asthma . . . illnesses that all  
bring weight loss, and also living questions with unsure answers.

That is why I not only consider H.I.V./A.I.D.S. as Human Immune Virus  
Acquired Immune Deficiency Syndrome, I also consider it as being

H uman—what we all are

I ntimacy—closeness with our loved ones and society

V ouch—giving assurance or guarantee

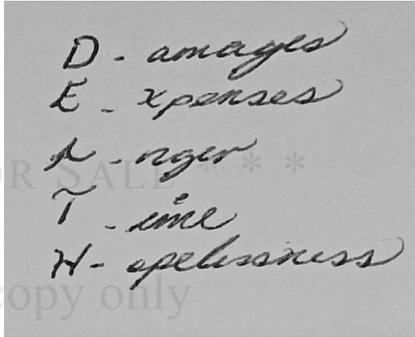
A biogenist—believing in the spontaneous generation of life

I ntercede—to plead on behalf of another

D efensive—resistant to criticism

S urvivor—to remain alive or in existence

Sadie had become accustomed to being branded in hospitals with acronyms that she found somewhat alienating, such as PLWA (an abbreviation that amused us both for being the same number of syllables as just saying “person living with AIDS”). I found her fascination with acrostics oddly meaningful, as if opening back up what Stanley Cavell once called the “non-speak or moon talk of acronyms.”<sup>29</sup> Sadie was inventing alternative definitions, spinning the acronyms’ rows of capital initials into something less like predetermined labels and more like algebra, equations full of unfixed variables. And *where*, I wondered, did she come up with *Abiogenist* as a substitution for the *A* in AIDS? I was not paying enough attention on the day she gave this text to me, and the enigmatic replacement slipped my notice until much later when I was back home reading her work more closely. It was only then that I finally noticed the wild-card term but barely recalled its meaning myself. The defunct theory of spontaneous generation stirred only vague memories for me of being a teenager in science class and learning about experiments in seventeenth-century glass jars; or biopoiesis theories, about how life sparked at the beginning of the world. But what did being an “Abiogenist” actually mean to Sadie, as she recast her condition in this spontaneous paradigm? Is that what it feels like sometimes to be any sort of orphan, trying to spark life from an interrupted generation? Did abiogenesis resonate with the feeling of trying to produce daily existence



An acrostic from Sadie's book,  
"Don't Feel It to Know It."

(let alone hope) against the dead matter of a chronic illness? Or was she evoking something else entirely? She wrote:

Grief you'll leave behind and all its  
 Responsibilities and  
 Anger—that being  
 Violence among our family instead of  
 Equality

Like Jordan, Sadie's words cryptically shuttled back and forth across the dense constellations (whether recognized in policy or not) between parents and children, as well as between diabetes and other coexisting conditions like AIDS. "Don't Feel It to Know It," Sadie wrote elegantly on her notebook's title page. Its handwritten pages were filled with terms nested with other terms in blue and black ink, her work of redefining and making legible the weight of things between lines, and page after page of acrostics that read like puzzles she could decipher but not resolve.

The end that Sadie foresaw when she wrote the acrostic pictured above did not occur for another three years, during the months of winter wind that people call "kite season," while she was imprisoned for an alleged drug possession charge. She called me before she went to prison and told me that she was going to die in there; at a total loss to respond, I found myself returning that night to her notebook. Yet her constant reworking of death's terms had extended deliberately beyond its pages.

She explained to me that one morning, when she was pregnant in the hospital, her roommate died in the bed next to her. Sadie recalled seeing the young woman's spirit fly out the window, and this made her think. When her son was born shortly afterward, she learned that he was HIV



negative and decided to name him Wasani, a Garifuna word meaning “our child.” Its plural possessive, alive with love and pain, mapped a plan that signaled an intimate sacrifice Sadie would make, as she tied her baby immediately to a larger family collective. He was taken by caring aunts to be raised in Belize City, over a hundred miles away from the place where Sadie and I later spent afternoons talking in her lonely shack. The tiny structure was rickety and stiflingly hot, with no electricity or water. When I returned in 2014 several months after Sadie’s death, it had not been converted into a new dwelling place, but instead got refashioned as a kiosk where passing tourists could stop to rent flippers and snorkels.

But during the time when she made that small place her home, Sadie spoke about her kids constantly. She was extravagantly proud from afar and wished—sometimes on the verge of tears—that she could visit them more often. It was in turn both comforting and excruciating to observe her children beginning to view other kin as their mothers. But she wanted to somehow keep distant enough to protect her kids from being irreparably shattered by her death, which she correctly understood was soon coming. Sadie was twenty-nine years old when she told me that she had designed things this way by inventing a different category of chance for her son, as if reworking the misrecognitions of bureaucracy by trying out a new label of the most intimate sort. “Our child” had never really been *hers*. Therefore, he could never be orphaned.

#### UNSTEADY UNITS

A “unit” of insulin began as an odd measurement: it was the precise liquid dose that would induce low blood sugar in a fasting rabbit.<sup>30</sup> This invented metric caused significant confusion in the early days of drug development because there were sizable differences between the plump four-pound bunnies used for insulin testing in 1920s Toronto (where the Canadian team that discovered insulin was based) and the lean two-pound rabbits in the laboratories in Indianapolis (where Eli Lilly, the U.S. pharmaceutical company licensed to mass-produce insulin, was headquartered).<sup>31</sup>

Establishing a uniform international rabbit size was only the first step on the road to standardizing marketable insulin, which at first could vary dangerously from batch to batch. The whole process was particularly complex because each drop of insulin injected into someone’s stomach or thigh first had to be literally extracted from the

pancreas of another creature. Until scientists figured out how to synthesize insulin in laboratories in the early 1960s, the drug companies manufacturing insulin inevitably created their products from vats of bloody animal pancreases in their factories' production lines, requiring over two tons of pig parts to extract eight ounces of insulin.<sup>32</sup>

Not just farms but also oceans are teaming with insulin, although it is inconveniently located inside the pancreases of swimming fish. John Macleod, the seasoned Scottish professor who would controversially come to share the Nobel Prize for insulin's discovery with Banting, envisioned harvesting the necessary islets from monkfish and stingray-like skates. One summer, his students paid a team of children to travel on an Atlantic trawler with the National Fish Company for the purpose of bottling the fish's pancreatic tissue, but they soon "learned that it was impossible to gather islets of Langerhans as fast as the fisherman gutted one catch of cod and washed the mess overboard."<sup>33</sup> For a brief time before World War II, Japanese scientists also extracted insulin from whales. Various other animal sources in vogue in their day have included pigs, clams, and water buffalo. Sensitivities to these animals could thus cause welts and other allergic reactions; for instance, Nurse Norma once recounted to me the experience of going into a coma in Belize from pork insulin, which was how she first learned she was allergic to pigs and switched back to beef-derived injections.

Another of the top experts of the 1920s, Bert Collip, contributed tremendously to stabilizing insulin's preliminary formula by adding alcohol, becoming part of the history-making Canadian team alongside doctors Banting, Best, and Macleod. But Collip later tarnished the brilliant reputation he had earned as part of Banting's team by erroneously announcing in *Nature* that he had discovered an insulin-like substance in green onions and potato peels.<sup>34</sup> These scientists' extensive searches for sources of insulin throughout nature's diversity of plants and animals also contributed to refining its formulas and mechanisms—such as when it was discovered that insulin's action could be slowed down and made "long-acting" by mixing it with fish sperm, regulating the absorption of its proteins.

"Insulin, which is both a hormone and protein, is a balled-up string of chemicals called amino acids."<sup>35</sup> Each batch is made by living organisms—which is what makes insulin a "biologic"—one of the few major modern drugs that cannot be made into a pill (though many attempts remain underway). Its amino acid chains break down in the human digestive system, which is why insulin is useless if swallowed



and still must be injected by needle or intravenously under the skin to be effective. The entire history of insulin extraction therefore would not have been possible if another milestone in medical history had not preceded it—the hypodermic syringe, dating back to the 1850s but constantly evolving, from heavy glass and stainless steel to plastic and rubber varieties like today’s specialized insulin syringes, standardized in 1949 to be uniquely marked in units of one-hundredth of one milliliter. Most insulin syringes today are disposable, made for one-time use, but they get reused constantly in homes across the world (including in Belize). Insulin syringes’ highly specialized units could also create confusion of their own: I once observed a home visit where someone had acquired a syringe marked in centiliters and almost used its numbers to administer the prescribed insulin units to her father, which would have resulted in a potentially lethal overdose. From time to time, pharmaceutical companies have also tried to market an inhalable kind of insulin, misting through a plastic-tubing apparatus that resembles some component of a college sophomore’s novelty bong. Relying on perfectly healthy lungs, it is known for uneven dosing.

A basic difficulty in calibrating doses comes from the body’s constant and intricate flux in its oscillating methods for delivering insulin, so pharmaceutical replication of the process requires an elaborate variety of offerings. In 1951, a molecular biologist finally discerned the structure of bovine insulin (just three amino acid residues different from human insulin), and the gene that made insulin was later located at the top of chromosome 11. The subsequent research breakthroughs that followed meant that each dose no longer needed to be extracted from an animal; soon, various formulas of synthetic human insulin could be made in the laboratory. By the late seventies, researchers announced they had managed to produce human insulin by splicing a rat gene into *E. coli* bacteria. Within five years, Eli Lilly brought genetically engineered insulin to market.

This paved the way for later biosynthetic recombinant insulin brands that have since become the norm. The production of Humulin, for instance, involves thawing a tube of *E. coli* from a “master cell bank” that was frozen in the 1980s, feeding the bacteria sugar and antibiotics as it doubles every twenty minutes in enormous tanks called fermenters, and then triggering the bacteria to produce insulin that soon gets harvested in a many-staged process (including being purified in electrified columns and getting turned into stable crystallized powder).<sup>36</sup> Other biotech fields have dabbled with experimental techniques such as

biofarming, in which human genes are spliced into yellow-blossoming safflower plants and grown in fields as “prairie insulin.”

Today, the average pharmacy in the U.S. will carry at least a dozen insulin varieties, each with its own peaks and valleys of efficacy: fast-acting bolus insulin to be taken with meals; slow and steady basal insulin to provide healthy background levels of glucose management; cloudy “intermediate-acting” NPH insulin, invented by European biochemists at Nordisk who toyed with crystalline zinc molecules in existing formulas; and a growing multiplicity of premixed bolus and basal blends such as Novolin 70/30 or Humalog 75/25, which require less finely calibrated precision and provide built-in convenience in the form of fewer injections. Some insulins (including Humalog) have a smell reminiscent of scotch and Band-Aids because of the cresol that helps preserve their stability. This scent was almost undetectable to me but was pungent with memory for some everyday injectors.<sup>37</sup>

In practice, even the most basic taxonomy of insulin often gets very loosely adapted in poorer countries. Some private pharmacies in Belize chose not to stock insulin at all because it was easy to fatally overdose if people did not have proper access to glucometers, and they did not want to risk the responsibility. Government posts, meanwhile, prescribed insulin widely—but at times had to change patients’ regimens from visit to visit, depending in part on what was in stock at the time.

Some patients learned to be flexible and creative in taking the kinds of insulin available to them. For example, some days only Novolin would be found locally. Maybe you would forget the name of the exact type of insulin you usually take (something I observed frequently), and no one would be able to locate its paper trail, especially if you had gotten it from another clinic or country or mission group. Or perhaps that kind wouldn’t be available at a new place where you were receiving care or wouldn’t be familiar to the caregiver there—situations that were usually negotiated by the doctor prescribing a 70/30 insulin formula, reckoned the safest bet. But all the numbers could be hard to keep track of—at times, people went home confused at the differing doses prescribed to them from various places as types of insulin changed, bringing new doses to memorize and daily regimens to reshuffle.

Yet beyond issues of differing units, the number attached to insulin that concerned Jordan most of all was its price. This began to change toward the end of his life, but when he was growing up there was no state program to provide affordable insulin to children with diabetes.



Family members occasionally bought him a vial out of pocket, or he might receive one sporadically from a nurse at the hospital or through someone's kindness, but this did not amount to anything like a constant supply. Jordan—and, I suspect, many other people like him living with type 1 diabetes in the world's margins—followed no consistent medical protocol over time. He took the insulin he could access as it became available to him, a regimen patched together from mismatched bolus and basal injections and missing doses. It only cost about ten dollars a bottle when he was a teenager, still often out of reach for a struggling family or entrepreneurial youth.

What I can tell you about Jordan at times feels generic, but the drug that shaped his story still is not. As historian Jeremy Greene and Kevin Riggs explore in their essay “Why Is There No Generic Insulin?”<sup>38</sup> this long series of formula evolutions and updated patents are key factors in the persistent issue of what some have called “insulin sticker shock.”<sup>39</sup> Insulin prices vary hugely for people depending on their resident country and insurance plans, and several pharmaceutical companies have made efforts to lower pricing in poor countries, but some prices are actually currently rising for a complex mix of reasons.<sup>40</sup>

Some attribute these price hikes to the fact that key formulas are about to come out of patent, so companies are trying to make what additional profit they can before generics flood the market;<sup>41</sup> others say that corporations rely on insulin as their “golden goose” during times when other drugs fail to create their anticipated market splash and have coordinated “shadow pricing” schemes to raise prices in unison, techniques that Jose Gomez-Marquez charts in “Insulinomics.”<sup>42</sup> In 2019, the price of insulin in U.S. contexts reached costs for some people of more than one thousand dollars per vial, leaving a growing number of patients also unable to afford basic access.<sup>43</sup> Grieving family members placed cardboard tombstones on the steps in front of the U.S. drug companies that make insulin, as tributes to loved ones who have died without it. When I saw the photos, I found myself imagining a version of their cardboard cemetery that captured the scale and duration of how widely “Living with Type 1 Diabetes When You Can't Afford Insulin”<sup>44</sup> has been happening in the world. Of the countries included in a recent survey, insulin cost the most (in relation to average incomes) for patients in Zambia.<sup>45</sup>

The social relations inflected by insulin's highly variable costs generate different personal expectations and legal norms: for example, California courts once ruled that U.S. parents whose child died from insufficient insulin treatment were accountable for second-degree murder.<sup>46</sup>

More recently, some are trying to sue companies over unaffordable insulin, dramatizing a global issue of pricing. A study in India tracked the actual cost to families for treating type 1 diabetes in a context of poverty. It found that the cost of treatment for a single type 1 patient was 16–23 percent of a family’s total income, depending on whether or not the child had to be hospitalized. In lower-income groups in India, this figure was significantly higher: it cost 59 percent of an entire family’s annual income to buy insulin for a single type 1 outpatient<sup>47</sup>—*more than half* a struggling household’s money for food, rent, and clothes for the entire family. Although these figures obviously shift a bit from country to country, they begin to show the impossible choices that many poor families face. Such quandaries raise the question of how family units—like insulin units and hospital units—collide and compound.

Trying to understand how these numerous elements had come together and inflected each other in Jordan’s specific trajectory, one day I took a bus to his village.

Jordan had described to me, in almost obsessive detail, the stretch of road that led there. Sometimes he couldn’t tell whether his blood sugar was very high or too low, but he could sense the feeling of disequilibrium that signaled he urgently needed to go to the hospital—dizzy, sweaty, itchy, thirsty, nauseous, and shaky, with flickering vision that could signal he was beginning to hallucinate—and Jordan knew that if he was unlucky, the trip might take more than a day on foot. I can only picture him as I knew him later, walking along the side of the road time and again over the years, with determined steps and uneven gait, wearing an ill-fitting polo shirt billowing on his thin frame.

He recalled counting things to make the time go faster as he walked along the sun-scorched highway trying to hitchhike: the number of cars that passed him as he walked or the exact tally of buses that might or might not allow him a free lift to the hospital out of charity on days when his former school principal (who had often dipped into her own pockets to help him) wasn’t able to give him a few dollars for the fare.

Myself, I traveled Jordan’s well-tread route in fast-forward, on board the public line of a repurposed American elementary school bus with the *S* and the *H* scratched off its original labeling (the “COOL BUS”). The driver told me that we had reached Zericote village, and I stepped down onto the highway near a stretch of empty-looking fields. I thought uneasily of the women who had been attacked or killed in recent years



along this road: a Guatemalan mother; a British medical student; a woman from the United States riding a bicycle; the Belizean woman whose body Nurse Suzanne was recently called to tend to after her son was found holding her in the high grasses, unable to speak after witnessing her rape and murder. The same kindly principal who had helped Jordan become his stopgap caregiver, too. My heartbeat quickened as I walked through weeds toward the low buildings far ahead, which I hoped and doubted made it appear that I knew what I was doing there.

The wooden houses on stilts on the edge of the village looked like sinking ships or tiny arcs in a permanent state of readiness for the next storm. I knew Jordan was not there but kept thinking I saw him anyway. As I walked deeper into the community's center, there were also active signs of construction: piles of cement blocks, metal rods jutting out of concrete foundations—meaning that many houses contained both an actual architecture and a phantom rebar superstructure outlining the contours of what someone hoped it might grow to be.

Zericote's land also had a reputation for swarming with yellow-specked “doctor flies,” so named for their painful needle-sharp bite, which feels like getting an injection. I stopped at a tiny grocery shop with an old rocking chair on the porch. They sold flour, rice, brown sugar, and white sugar from four round trash cans next to an old-fashioned double scale. The prices were listed on a black slate board hanging from the ceiling, along with the chalked prices for a few other staples sold by the pound: lard, pigtail, beans, salt, onions, and butter (lard cost only half as much as butter). When I left the store, some young children outside said they would show me where to go.

We walked past very old women playing bingo under a tree, arranging scallop-edged Belizean pennies on their boards; past a home with peeling paint and a battered sign that said *POST OFFICE*. Men called “Spanish” by local Kriol residents (mostly from Guatemala and Honduras) rode past in the back of packed trucks, headed to nearby citrus plantations—where fruits were grown and then quickly boiled down to concentrate for exported juices, making the air smell sweetly of grapefruit and oranges.

Walking through the unfamiliar terrain, I felt anxious at the thought of meeting the people who somehow both had and hadn't been Jordan's family—unsure what I was really looking for, but hoping that another perspective might help fill out some larger story that was already missing too many pieces. “Is this their house?” I asked the child leading me

along when we paused in front of a shack on the dirt road, but the little girl with seashells looped into her hair only giggled.

The children who led me there scattered at the sounds of footsteps across floorboards. I was alone on the porch when the door swung open.

\* \* \* NOT FOR SALE \* \* \*

#### MANY MACHINES

Somewhere in Belize, the electronic glucometer that Jordan once received must still exist in some form—perhaps used each morning to measure another teenager’s blood sugar; or forgotten on a kitchen shelf, awaiting a replacement batch of digital test strips; or reduced to a charred lump of microchip-studded plastic buried in the region’s land-fill, which perpetually smoldered on the edge of the highway, emitting uncannily colored flames and chemical-smelling smoke.

By the time I interviewed people years later, no one could remember the exact make or model of Jordan’s first glucose machine—some said it was an Accu-Chek, others a OneTouch. But everyone remembered the woman who gave it to him, his mother’s friend. “I call her mom,” Jordan told me of Lorel, who by then was working in Chicago. But at first, I knew Lorel only through the medical artifacts she had provided, particularly the glucometer.

Glucometers are integral to this story because they play a vital role in carefully dosing insulin. Since proper doses depend in part on how high or low blood sugar is to begin with, it matters to have relatively consistent ways to gauge that starting point. This was particularly important in a context where many people didn’t have access to other common blood sugar tests, such as hemoglobin A<sub>1c</sub> measures, which gauge a person’s three-month average glucose level to give a sense of how stable things look over time. Another missing gauge is continuous glucose monitoring, which consists of a filament inserted into bodily fluids under the skin, the sensor kept in place with a medical-grade adhesive sticker, often on the stomach or upper arms. It communicates information about the wearer’s blood sugar levels to a monitoring unit, via radio waves. This creates metrics that will sound an alarm about highs or lows (the main reason users wear them), but in turn must be calibrated against a glucometer’s finger-stick measures twice a day. While the circulation of glucose meters anywhere inevitably involves the meaningful rituals of people learning to measure and monitor their own bodies, there was also something more than textbook “biomedicalization” logic at play in the unruly ways these technologies mattered and



moved. The machines' own chemistry became part of what structured their users' stories.

Early glucometers like the 1972 Eytone had to be carried in what resembled a suitcase and plugged into the wall. From what I am able to reconstruct, most struggling patients in the era of Jordan's mother would not have had access to this first generation of machines in domestic settings at all—for a huge variety of reasons, including the fact that most villages in southern Belize were not connected to the electrical grid until several decades afterward. These bulky machines detected glucose levels in blood using reflected light, captured by a photoelectric cell that translated shades of blue color into a numerical readout using a swinging needle. Engineer Anton "Tom" Clemens at Ames Company (now part of Bayer) developed the first model that worked this way, which hit markets in 1970. Clemens later recalled the way most physicians initially balked at the idea that patients could safely perform blood testing at home, believing these machines required the expertise of a doctor's office or emergency room. According to a long trail of wary publications over the ensuing decade, North American and European medical establishments at the time heartily opposed the idea of patients self-monitoring their own blood glucose. Many considered it risky amateurship and "a dangerous practice."<sup>48</sup>

But the increasingly popular meters became more and more user-friendly over the years, and soon there was a flooded market filled with competing technologies spanning North America, Europe, and Asia. Corporate one-upmanship in the quest for new patents made machines increasingly easier to read, less expensive, smaller in size, and more accurate to use at home. Requiring larger drops of blood at first, many worked with a menacing-looking finger-stick apparatus, recalled by some patients as "the guillotine." One odd generation of meters, such as Boehringer Mannheim's Reflomap, sold in the harvest-orange hue that characterized many other fashionable appliances in the seventies, had a dial covered with tick marks like the padlock on an old gym locker. In 1980, the Dextrometer had the first digital display. A later generation of models instead had small screens and buttons, resembling credit card swipe machines used at cash registers (including the Reflolut, which later became the popular Accu-Chek series). Interestingly, Glucometer was originally the name for another model that Ames introduced in collaboration with a Japanese company called Kyoto Daiichi; but the easy-to-use machine's catchy name became so popular over time that it is now often used as a generic term for any glucose meter.<sup>49</sup>

Although they share the same general name, each glucometer can use only the strips specifically designed not just for the brand but for the model—meaning that you must pay attention not only to whether your device is made by Abbott or Bayer or Nova or Sanofi-Aventis but also to additional micro-specifications. For example, if you acquired an Accu-Chek glucose meter (made by Roche), is it an Accu-Chek Aviva or an Accu-Chek Nano or an Accu-Chek Compact? A Compact or a Compact Plus? Missing any of these details could mean your savings are spent on a jar of strips that will not work.<sup>50</sup>

Glucometers' role today in frontline diagnosis also hinges on a painful irony: such measures help to make visible an enormous population of people living with diabetes in contexts of poverty, many of whom cannot consistently access the same meters vital for day-to-day care. In Belize in 2010, glucometers—some purchased at grocery stores or local clinics, others acquired from visiting care groups or sent by relatives in the United States or elsewhere abroad—were priced around fifty to one hundred dollars. Some corporations even provided the devices for free if you bought enough test strips, which are the truly expensive component of this system. Prices for the test strips are declining today, but in 2010 they went for around fifty to seventy dollars per jar of fifty strips (which would last less than a month for someone testing twice a day, but were often stretched much further by people trying to make supplies last). A thriving gray market flourishes around them even in the national contexts they *are* specifically designed for,<sup>51</sup> a problem reflected in suspect website sales or signboards like CASH FOR DIABETIC TEST STRIPS posted along U.S. roadways.<sup>52</sup> According to a CNN report, in 2012 diabetes test strips became the number one most frequently stolen item in the United States, surpassing alcohol and cigarettes—and raising disturbing questions about the systems in place when a top target of criminalized theft is entwined with health-seeking behavior.<sup>53</sup>

I saw countless machines that were unusable or broken. For those who could acquire them, these devices commonly indexed the generosity of relatives abroad or served as artifacts of transient philanthropic interventions—networks difficult to sustain day in and out. I encountered malfunctioning meters with elaborate features such as Bluetooth compatibility, on the shelves of homes without electricity, artifacts of vast gaps between the contexts these machines' designers envisioned and the places where they have become necessary. Patients stored their



devices on kitchen shelves or carried them in weathered plastic bags, looking for ways to repair them. People's bodies and devices often seemed to be wearing out together.

Although glucometers can seem like the closest thing there is to a "solution in a box" for global diabetes management,<sup>54</sup> their upkeep entails engaging a transnational supply line of expensive, complex parts. While portable, these devices require intricate socio-technical networks of specific components to maintain: codes and calibrating fluid; lancets to draw blood from fingertips (some people substituted safety pins or sewing needles); and lithium and other specialized imported batteries, shaped like small coins.

Managing these messy assemblages often became a family affair. Certain models left people "recoding" their machine's time stamp, which might allow recently expired strips to come back into circulation. Many said a jar that expired a day or two ago could still work just as well, but no one knew exactly when a strip was too far expired to be worth consulting: a month? a year? Of course, drawing such lines returns to much larger questions about glucose meters: How bad is less than ideal care—and how are people navigating its risks against the dangers of no care? I wasn't sure what the ethics of expiry backdating were in practice, but saw many cases when refusing to fiddle with a meter would have meant no way to test at all.

But even when a glucose meter wasn't working, people often kept these little machines in prominent places. Signifying more than fragmentation alone, such devices inevitably are also (as Sherry Turkle writes) "things we think with"<sup>55</sup>—reflecting logics of the places where they originated, to be sure, but also shaping what social interactions and ethical exchanges were possible between people on the ground. They were artifacts of care and intentions over time, perhaps waiting to be replenished by a new visitor or returning intervention. Sometimes people were able to have relatives use their own health insurance to cover the test strips and send them by mail, although this strategy was just as likely to result in a new machine. Through these networks, even poorer households might accumulate one or two unusable glucometers. These circulated in intimate economies of their own, traded and loaned. Strips might also be resold or scavenged for the slivers of gold and precious metals their electrodes contain, part of what makes them so expensive. Or so I had believed, until I read a *New York Times* article about glucometer gray markets



Testing strips for a variety of glucometer models.

in 2019 estimating that they only cost around ten cents each to print.<sup>56</sup>

I heard a story, perhaps an aspirational fiction, about the early days of diabetic test strips: There were two major competing companies shaping design when the first glucometer machines came out, one in England and another in Germany. A top employee of the British company described a proposal for an open machine that would read either company's strip. He called their German counterpart with a proposal to coordinate. According to his recollections, the German company turned down the idea and did not want their strips read by any but their own machines.<sup>57</sup> Hundreds of incompatible strips circulate today in this multibillion-dollar global industry.

While this structural premise has persisted over many decades, the machines themselves have changed constantly. Today, many meters' digital memory banks function like little computers and are designed to graph the glucose highs and lows of their owners—programming that by default assumes the machine's user is one individual person, who has a laptop or iPhone to collect and centralize the glucometer's data. Some machines like the Contour Didget even synchronize with Nintendo video game consoles.

But in Belize, many glucose meters had no parent devices to report back to for data collating. If readings could be downloaded to a base station somewhere, their graphs would often compile something different than a single person's fluctuating blood sugar over time. There



would instead be the stop-and-start counts of barter and home visits, frequently charting not individual biologies but other kinds of exchanges and bodies: survey routes, mobile clinics, or sharing among families and neighbors.

Instead of a linear time line of breakthroughs, perhaps glucometers in that context could be better said to occupy a horizon where “things jump into relation but remain unglued.”<sup>58</sup> Some scenes from Belize I remember like still-life images: The man who cut his test strips in half with a fishing knife, hoping to stretch the expensive jar twice as far, not realizing he was irreparably mangling the computerized microchips he had saved for a month to buy. A well-heeled couple in Dangriga who invited me over before breakfast one day to see how they test each other every morning: tissues pressed to their bleeding fingertips, him pouring grapefruit juice afterward as she laughed, still wearing her nightgown. They had enough savings and connections to acquire four different brands of glucose meters and could usually find matching strips available for at least one of them in Belize at any given time. One Maya shrimp farmer had received a FreeStyle machine from a “mission trip” medical group from Arkansas during their visit to Belize and could not acquire replacement strips for the meter anywhere in Belize or Guatemala. I hesitantly agreed to bring a replacement vial during one trip back to Pennsylvania—unavailable at CVS but finally located at Walgreen’s. They sold for seventy dollars, which felt both too expensive not to strain our relationship and completely insufficient (since it was only a thirty-day supply anyway, thus perpetuating her initial problem). But the dilemma turned out to be moot: it ended up that she had a FreeStyle Lite, not an original FreeStyle, so even after I made the long trip down miles of dusty backcountry roads in a borrowed pickup truck, the butterfly-embossed strips didn’t work on her machine. Another woman’s glucose meter had been mailed from a donor in England, its replacement blood test strips sent as gifts but subject to heavy taxes at the post office. She had since become uncannily adept at multiplying any number by eighteen—the factor necessary to convert a European machine’s readings (in mmol/l) to units of the Americas (in mg/dL) favored in Belize, an equation specific to the molecular weight of glucose.

Looking back, I wished I had counted all the broken mechanisms for counting. The devices showed how people with diabetes were living with fragments of care, and the labor it took to transform these incoming devices into something besides a nonsystem. They indexed much more

than blood sugar. The stakes could be low or high: at its most extreme, not being able to test one's glucose could lead to miscalculating a dose of insulin. The comas caused by this so-called bottoming out could strongly resemble stroke symptoms and were common enough in Belize that one nurse I knew refused to prescribe insulin for type 2 at all, after seeing it cause numerous overdose "hypos" and deaths. In this way, glucometers at times also become part of charged mediations that occur whenever caregivers try to determine which patients could safely manage insulin.

Though glucometers at times reproduced global fragmentation, they could also become part of unlikely communication—such as the time no one could talk with an older patient with diabetes who had come to the hospital alone, speaking only Kekchi Maya. He wanted to leave and could not understand the Cuban doctor who was trying to convey in Spanish and then English that lab reports showed his sugar was still high. Finally, a Nigerian nurse was summoned to stick the Kekchi patient's finger and squeeze out a drop of blood onto the glucometer strip, so the screen could be held for him to see his count in context. As framed by the machine (the only translator available), his glucose was a language we could all understand. The patient nodded solemnly when he saw the number and lay back in bed.

Or consider what glucometer checks meant for Nancy, whose diabetes led to a doctor missing her renal cancer for several years, until it was badly metastasized. A mother in her fifties, Nancy's comorbidity with diabetes made her treatment particularly difficult—both chemo and kidney damage superadded to diabetes meant her blood sugar was constantly spiking, and her body was suddenly responding to her usual diabetes pills in unpredictable ways. On the day we had arranged for an interview at the country's first cancer center, which happened to be her birthday (her family surprised her with cake a day early to make sure she could keep it down), Nancy went into terrifying convulsions during chemo—perhaps some drug interaction with her diabetes pharmaceuticals, she would later speculate. She stopped breathing, her whole body jerking in wide arcs of motion. Following terse directions that the nurse called out, I sprinted from an adjacent building with an oxygen tank and pushed it with shaking legs down a seemingly endless hallway. The nurse grabbed the oxygen from me in the doorway of the room and expertly tended to Nancy until she stopped rocking wildly back and forth in the chemo chair, steadily smoothing her hair when it was over.

Rattled, I thought it might be better to postpone our exchange, but Nancy summoned me later and said she wanted to talk. During the inter-



view it was hard not to think of the image of her seizing in the very same chair, everything fine again but crisis hovering just offstage. But maybe that was part of why she wanted to talk right then and pass the time on that slow drip; she never looked over at the needle taped in her arm, so I tried not to look at it either. Most of our conversation sidestepped cancer and the tests and the other doctors who had missed it for all those years, focusing instead on her doting family and her glucometer. She had a OneTouch that came with a little stapled workbook, lined with calendars, to write down five glucose counts each day. It was the only such book that I ever saw in Belize, filled out fastidiously with printed numbers in pencil and pen. Unlike malignancy, when it came to blood sugar, Nancy and her husband could follow along, incremental tallies indexing each step of her body's gains and losses. Nancy called the worn glucometer pamphlet her "little book of history," as if keeping herself in time.

Nancy had stage four cancer; Jordan would have had stage four diabetes by the time we met, if that had existed (no matter how serious complications become, it isn't biomedically recognized practice to label "stages" of diabetes). It was another uninvented category of person that Jordan could not be. So there was no palliation toward the end of his life, despite the serious pain, only basic diabetes treatments that continued moving in and out of his reach. His meters circulated in intimate exchanges and leaking economies: pawned for food, only to be bought back; once stolen by an aunt, allegedly in exchange for unpaid rent; later replenished by Lorel, who promised to send replacement parts from Chicago. The machine's metrics also gauged her present absence.

One night, shortly after I had contacted Lorel's sister in Dangriga and left my phone number, I received a call on my Belize cell phone from an unfamiliar U.S. area code. It was Lorel, calling me from Chicago. I barely had time to explain my project and go through my rehearsed request for a phone interview before she began talking, as if the story had been pent up and waiting to pour out. "Let me tell you something," she said. "This was a case of pure neglect." She described seeing Jordan one afternoon in front of a game room by the river in Dangriga years ago. For some reason, the gangly teenager looked familiar to her. He had been born with an ear tucked in on one side, perhaps due to the effects of sugar in the womb. "To me, I know this child from somewhere," Lorel said. Following her instinct, she stopped to ask his name and learned he was the son of her best friend, Tessa, who had died over a decade earlier. Lorel asked if he needed anything. "Jordan told me, 'I'm hungry.'"

Lorel's voice started to break over the phone. "He was shivering, like in snow."

Suddenly, there was a new character on the scene—offering last-ditch love, trying to undo neglect, buying time. Lorel reported that at first she had tried talking to Jordan's stepfamily, even offering them money for a time and paying a high rent for Jordan's little shack in Zericote.

"His aunt promised to take care of him, then sold his diabetes machine," Lorel said of the glucometer she had bought for Jordan. "I tried to get him back." Alongside hospital appointments, she had taken him to a private clinic in Dangriga run by a charismatic Nigerian physician, who combined evangelical prayer with his medical practice. "With the diabetes, he was so far gone. When I found Jordan he was skin and bones," Lorel recalled. By then, the glucometer that she gave him was only precisely quantifying damages that they didn't know how to stop.

Increasing numbers of people share these struggles. The global explosion of type 1 diabetes (now on the rise nearly as fast as type 2) raises questions about the factors contributing to its increased prevalence. The good news is that this increase might be partially attributed to the heartening fact that more people with type 1 are living healthily into adulthood and having children themselves. However, studies show that the children of people with diabetes—even in resource-rich medical systems—may have a slightly increased chance of getting the disease (a 2 percent risk, higher than the general population's risk of 1 percent).

What do these figures look like in more unevenly resourced contexts? There is virtually no real data on this topic. But it is known that when a mother receives incomplete medical care during her pregnancy and experiences badly fluctuating blood sugar over those crucial months or during delivery, it significantly increases the chance her child will also later develop diabetes, making intergenerational risk much steeper than it needs to be. Stretched-thin primary care, in other words, is not just treating type 1 in poverty—it is also a key contributor to its rising manifestations. And similar to type 2, an abundance of population studies suggest that the uptick in type 1 is also exacerbated by exposure to pesticide runoff from agriculture and other synthetic chemicals and pollution in our food, air, and waterways. In light of these escalating risk factors, the name "diabetes machine" that Lorel used for Jordan's glucose meter made me think back to Sarah's words and about how much of the world seems to be becoming a "sugar machine," requiring many other machines to survive.



Yet the minute I started to wax philosophical, Lorel pulled me back to the minutiae of daily care, where the routine struggles of Jordan's life had been borne out. "Sometimes I would go on my bicycle to take him some oatmeal," she said. "He was my baby." She felt torn that she had to return to Chicago for work. The money she earned from home nursing in U.S. eldercare was the reason she was able to support Jordan, but distance fractures too. "If I didn't have to go back to the States, maybe he would still be alive today," she said, her voice growing soft. "I tried to leave everything for Jordan. I bought him all this food before I go. And new sneakers."

"In your documentary," Lorel repeated, "it was a case of pure neglect, you have to put that. But . . ." her voice wavered. "Maybe you could go see the barrel of groceries I send for him. My sister Jessica has it in Dangriga." For some reason, that image of the cardboard barrel with nowhere to be delivered made us both break down. Never before or since have I had the experience of being on the phone with an absolute stranger and both of us bursting into tears, which says something about how few places existed for Lorel to channel mourning for a death like Jordan's. Her absence as she worked in Chicago "to save something" to send home for him was simultaneously a tie and a disconnect, a caring relation and a break in care. In the United States, dialysis and kidney transplants—treatment options unavailable to Jordan in Belize but flat-out necessary to continue his life—have been legally provided by the federal government since 1972, as part of Medicare.<sup>59</sup> But the products Lorel purchased in Chicago to fill the barrel for Jordan (a new Accu-Chek machine, matching test strips, and diapers) were the only pieces of the healthcare infrastructure it was possible to export.

The ancient Greeks once considered diabetes to be "a melting down of the flesh and limbs into urine," according to third-century medical chronicler Aretaeus the Cappadocian. He described the humiliating dilemmas often caused by diabetes's kidney damage and resulting urination issues: "*How can shame become more potent than pain?*" For a young man struggling with self-consciousness of all kinds, the loss of urinary control is perhaps the most anxiety-producing aspect of living with advanced complications of diabetes. Lorel explained that for years, Jordan tried to avoid the daily embarrassment of wearing bulky diapers. This usually made his condition less immediately noticeable but also introduced new fallibilities. Once, he could not hold it on a taxi ride home from the hospital, and the taxi driver jeered at Jordan with a string of emasculating insults when he saw the vehicle's wet upholstery.

Lorel found Jordan crying at home in humiliated silence, unable to hide his shame. Furious, Lorel got on her bicycle and searched the streets of Dangriga until she found the taxi driver. “I yelled at him. ‘Have compassion,’ I said. ‘Don’t you *see*?’”

Since talking with Lorel across the odd telephone reversal of me in her country and her in mine, I have often thought of the question she posed. What does it take to *see*? To make sense of what we are seeing? To know what can’t be seen?

When glucose is high, a person’s urine can leave behind a subtly visible powder of sugar, like a crystalline white dust. In fact, earlier glucose tests had been based on precisely such traces. Some of the first known technoscientific testing for diabetes was conducted with urine and bits of sheep’s wool dipped in stannous chloride chemicals, which turned black to indicate the presence of sugar. Urine tests using paper steeped in alkaline indigo carmine were in vogue by 1883, when *Bedside Urine Testing* was published in England. The messy material culture of boiling your own urine was finally replaced in the 1940s by an Ames urine dipstick test for sugar, the Clinistest. Based on the major breakthroughs of dry-reagent chemistry (the technology behind litmus paper), this new type of urine testing later helped to inspire Dextrostix, the first blood glucose testing strips.

These older urine dipstick tests are now part of a new global controversy. Today’s blood glucose machines are far more accurate than urine tests because they provide real-time blood glucose levels, whereas urine (by the time it’s expelled) reflects the body’s state several hours before. This, along with other limits in precision, now makes blood glucose meters a basic standard of care for home testing in affluent contexts. But in recognition that maintaining a working glucometer at home remains utterly out of reach for many patients in huge areas of the world, one of the International Diabetes Federation’s (IDF) important policy and patient advocacy steps was to issue a position statement on glucose testing access. It boldly supported the use of urine testing at home for people with diabetes who cannot afford personal blood glucose meters. This official position statement on urine glucose testing was publicly issued by the IDF in 2005. The three-page document reads, in part:

Before the advent of blood glucose monitoring in the 1970s, urine glucose monitoring was universally used, with many people able to maintain good control. Blood glucose monitoring has now replaced urine monitoring in resource-rich settings. However, insistence on blood glucose monitoring



in economically disadvantaged settings could result in no monitoring at all. . . .

- Urine glucose monitoring should continue to be available throughout the world.
- Education about its role and appropriate use should be part of essential education about diabetes for healthcare professionals and governments.
- It can be used separately to, or in conjunction with, blood glucose monitoring in particular circumstances and settings.
- It should continue to be included on the World Health Organization Essential Drugs List.
- The major promotion by industry of blood glucose monitoring should not result in the appropriate role of urine glucose monitoring being underestimated.
- As long as results are interpreted correctly, and limitations understood, it provides valuable information in persons with type 2 diabetes treated by diet or diet and tablets, in people with type 2 who use insulin, and in people with type 1 diabetes who cannot afford blood glucose testing. . . .
- Because it is significantly cheaper than blood glucose monitoring, it has a very important role to play in settings where blood glucose monitoring is not accessible due to cost, or where blood glucose monitoring can only be done relatively infrequently. This occurs in some situations in both developing and developed countries.
- Its use should be determined by the individual healthcare professional in conjunction with the person with diabetes, taking into account all circumstances.<sup>60</sup>

The IDF confirmed to me in 2017 that they had not updated this statement, though it is not widely publicized. Perhaps this relates to diplomatic negotiations with glucometer manufacturers, key players in diabetes policy arenas today. Yet controversies about digital glucometer machines versus urine testing are also tangled up in much larger debates in global health ethics: When is outdated basic technology a stopgap measure for pragmatically addressing inequality in the meantime, and when does it risk normalizing complacency with unequal standards of care? When can the donor visions at work in the name of corporate social responsibility become a mutually beneficial situation, even if vested interests do not easily align? Are there even any other options left for shifting the current system except from the inside? We are all caught amid so many machines.

Ultimately, in Belize at least, health workers I knew did not recommend urine dipstick tests for diabetes homecare because they weren't

considered best practice. But the stark reality persisted: poorer patients often had no way to test their sugar at home at all. Once, at a local clinic, I asked how they dealt with this quandary and was surprised to find out that this simple alternative glucose test—costing pennies instead of dollars and requiring no machine—had been right there on the clinic shelves all along. It turned out that the same urine dipsticks used to check for infections measured not only leukocytes but also a row of other indicators, including nitrates, albumin protein, bilirubin, urobilinogen, pH levels, and—most important for people with diabetes—glucose and ketones, present in urine only when the body is off-balance. There were numerous cardboard boxes filled with urine test strip jars in storage, a visiting nurse added; it was one of the few things they easily kept in stock. She invited me to take a look. For a moment it felt like some sort of clue to alternative indices, which I suppose I was searching for at the time, trying to find a plot through the senselessness and predictability of Jordan's fate. "Intended for use in the U.S.A.," read the bottle's evasive label.

What would it have meant for Jordan to have had these outmoded (but actually available) urine tests at home every day during the many years he was growing up without a glucometer? I pried off the jar's plastic lid and examined its contents, but they yielded no easy answers either; just little strips of rainbow-colored patches, paper bands expiring in a jar.

#### THE LIFE OF MUERTE

"Jordan made history," his stepmother, Agnes, told me with a smile.

I had not expected the woman who answered the door and found me on the porch that day in Zericote to extend such hospitality, but to my surprise she readily agreed to participate in an interview for my research, saying that Jordan had told her about working with me. She led me past her outdoor fire hearth and a hand-crank press for making coconut oil and up the wooden steps of another raised plank-board house. I found myself sitting next to Agnes in a small kitchen belonging to a wiry old woman, who told me to call her Aunt Lil. The kitchen's plywood shelves were lined with repurposed jars. Its bright wooden shutters were tied back with string, revealing jackfruit and tamarind trees. The two women spoke about Jordan with no detectable sense of tragedy, in a tone more like the mythic flavor of a tall tale. This made it at once very easy and very difficult to talk with them.



“Once, his blood sugar was over 1,000, and he was walking around. The doctors told us, we don’t know how this was possible. He made history, *fi true*.” Lil laughed in assent, nodding at the memory. They handed me a copy of the paper from Jordan’s funeral, which Lorel had sent money from Chicago to pay for. “Jordan (aka Muerte), 1989–2010,” the program read. That was how I first learned that everyone had called Jordan by the nickname Muerte since he was a young teenager. In a place where Spanish was the third language, this was perhaps several degrees more polite than just calling him Death or Dead.<sup>61</sup>

“He is now flying God’s Plane in Heaven,” the paper said, next to a reading from Ecclesiastes 11. I looked it up later: *Rejoice, O young man, in thy youth; and let thy heart cheer thee in the days of thy youth, and walk in the ways of thine heart, and in the sight of thine eyes: but know thou, that for all these things God will bring thee into judgment.* The Xerox featured a blurry close-up photo. In the image, Jordan’s gaze is level, his eyebrows slightly raised. It is difficult to say whether his expression is stoic, skeptical, or some other countenance of waiting.

“Jordan was not careful,” Agnes repeated as I held the photocopy—never careful about what he ate, even when he didn’t have medication to cover it. Before insulin’s discovery, a so-called starvation diet was considered the best possible treatment to prolong life for children and teenagers with type 1 diabetes who otherwise would be poisoned by the carbohydrates in their food. It seemed this was related to what Agnes alluded to, in suggesting that Jordan was not “careful” by eating during times he did not have insulin coverage. “He take insulin sometimes,” she added, the present tense of Kriol verbs haunting the stories of foreclosures they animated. She reported that Jordan continuously ate all the worst things: “He would save his coins to get biscuit, even mango.” Depending on their location, fruits from some of the region’s plentiful mango trees were at times considered common property—but this readily shared and accessible source of filling food was very high in sugar.<sup>62</sup> Lil and Agnes both affirmed that by the time he became a teenager, Jordan was constantly passing out from the increasing complications of his uncontrolled diabetes.

Studying the “enculturation” of another chronic condition, anthropologist Duana Fullwiley “found that people’s ability to make-do with scant biomedical palliatives functionally filled a resource gap.”<sup>63</sup> In the face of lacking technologies, Fullwiley observed how sickle cell patients in Senegal “find ways to get by with its chronic reality,” manipulating bodily thresholds with a wide range of substances that come to stand in

as medications, such as coffee, sugar, and water.<sup>64</sup> Sidney Mintz likewise emphasized the potential for using energy-giving substances for intervention when he reframed sugar, chocolate, and caffeine as “soft drugs.”<sup>65</sup> During the years that Jordan spent stretching his insulin doses—or trying to survive until another dose could be obtained—cheap foods also became for him a way of “manipulating bodily thresholds.”

“Jordan is always buying Ideal,” Agnes told me of the dirt-cheap freezer pops, locally made of bright-colored frozen sugar water in a plastic tube or sandwich bag. Zericote village had several grocery shops with freezer and refrigeration chests. These community grocery shops are incidentally the very places where Partners in Health recommends that people with diabetes like Jordan, too poor to own a refrigerator at home, might consider storing their insulin alongside the ubiquitous cans of soda—bottled sugars and the bottled hormones needed to metabolize them chilled side by side. At around five U.S. cents, Ideals are perhaps the cheapest food available at an average grocery store. Because the liquid is frozen solid, it feels like eating food. Although adults with diabetes living in poverty were more likely to endure skipped meals by drinking sweetened coffee, Jordan became sick with diabetes as a young child. His “soft drug” of choice was popsicles.

People with uncontrolled diabetes sometimes told me that I could not understand what their cravings for sugar felt like. “Like you need it. You can’t think, you can’t think about other things.” “Your body calls for the sweet.” “Like you can’t keep going if you can’t find it.” Yet these sensations are not necessarily correlated with diabetes if it’s being managed; such extreme cravings are associated with *untreated* forms of the disease. Insulin (the hormone that people with type 1 diabetes cannot produce) is what allows the body’s cells to actually use the glucose you ingest. This means that without insulin, your cells are starving for sugar, no matter how much food you have already eaten—the body has no way to access it.

Without glucose, cells in the body face death.<sup>66</sup> The brain receives signals that something must be eaten immediately, and concentrated “simple sugars” require the least processing time for the body to access in a state of crisis. Taking this into consideration, perhaps Jordan’s habit of eating sweet, cheap food begins to appear less like a self-destructive paradox and more like twin faces of a single coin tossed up to fate: sugar as deadly risk; sugar as attempted release, in the absence of other medicine.

As they related fragments of all this to me, Agnes and Lil were not the callous people I had imagined from my conversations with Jordan.



They joked with me, fed me fruit, handed me babies to hold in rooms bustling with young children, and generally seemed to care more than I thought they would—enough to talk with a stranger about Jordan, as if they had been waiting to say out loud just what had happened. Yet at the same time, their focus on Jordan’s noncompliance with specialized diets and inaccessible medication was so pronounced that I found myself grappling with what that plotline meant to them. João Biehl has described how “the overburdened family” is today “increasingly the medical agent of the state. Illness becomes the ground on which experimentation and breaks in intimate household relations can occur. Families can dispose of their unwanted and unproductive members, sometimes without sanction, on the basis of individuals’ noncompliance with their treatment protocols.”<sup>67</sup> In Zericote, Jordan’s young age when he lived among this fragile network of stepkin almost caricatures the problem with the notion of “noncompliance”—as if a child’s choices were his alone, rather than shaped at the nexus of many state, global, and family structures.

Yet the unstable texture of Lil’s and Agnes’s comments constantly seemed to escape the framework of false consciousness that many scholars turn to in interpreting moments of family tension—most famously in Nancy Scheper-Hughes’s explanation of ruptures in family care and letting die among “angel babies” in Brazil. For all her powerful ethnography, this particular interpretive tag has never felt fully convincing to me. The Marxist diagnosis of false consciousness can seem to imply a kind of moral vacating instead of conflicted micro-practices entailed in making relations go numb, sometimes only to later be revived. Sitting in stifling kitchens as I visited Zericote numerous times throughout that year, I found myself considering the kinds of storytelling and uneasy choices within these breaks from a different direction, grappling with how Jordan’s “living death” took constant labor to normalize in this world.

Disregard also requires maintenance. Rather than a “suspension of the ethical,”<sup>68</sup> the deferrals that Agnes and Lil kept narrating were more like the innermost capillaries of some overstrained system in which participants grappled all too accurately with how lives were valued by external markets. Their accounts suggested how finite stores of care had slowly been hollowed out or replenished over time.

Instead of Engels’s master switch of false consciousness, then, I found myself returning instead to Edward Evans-Pritchard’s famous ethnographic questions stemming from divergent theories of causality:<sup>69</sup> How did different actors tell stories of cause and effect not by narrating

*how* a thing happened but *why*? Could these various starting points help to better unfurl distinct social logics and ethical fabrics, which might be better reckoned without starting from the premise that they were false? After all, everyone agreed that Jordan died from complications of his diabetes—that he had eaten foods he should not have eaten, that he did not have a regular supply of insulin. But *why* those things happened—that was the question up for grabs, and it inflected the moments we narrated to each other with undertones of responsibility and deflection.

Before I left that day, Agnes gestured toward one last place where Jordan had been found unconscious, in an adjacent wooden house. That time, she said, it was the middle of the afternoon when they found him. He had fallen still clutching a package of crackers, and there was a putrid-sweet alcoholic scent on his breath. “Drunk,” she said, sounding angry now. He must have friends and money they did not know about, she added, and gone out drinking rum with them. Lil agreed, shaking her head in disapproval: the smell on his breath was strong.

I suppose it’s not impossible that Jordan was drunk; I have no way to know for sure. But certainly, there are other probable explanations for these symptoms. In diabetes, one of the body’s most acute states of emergency is called ketoacidosis. It can cause coma and death. This state is the leading cause of injuries and mortalities among young people with diabetes. It shares many possible symptoms with other conditions—semiconsciousness, nausea and vomiting, difficult breathing—but has one unique telltale sign: a sweet, alcohol-like scent on the breath, a smell reminiscent of rotten fruit or cheap schnapps. In contexts of poverty, ketoacidosis is most often caused by missing doses of insulin.

This life-threatening state occurs in conjunction with extremely high blood sugar. Yet it signals cells starving for sugar, unable to use the glucose already consumed due to insulin deficiency. Searching for other sources of energy to keep its cells from dying, the body instead begins breaking down muscle tissues and taking apart the carbon skeletons of the amino acids they contain, in order to release the emergency energy stores they hold. This is one face of *catabolic* metabolism, or catabolism—the breakdown. Some of these amino acids are glucogenic, meaning they can be converted to glucose and allow the body to keep going. Yet catabolizing a muscle means releasing all of the chemicals it contains, including those that aren’t useful. Some amino acids are ketogenic, meaning they turn into ketones, which can be toxic at high levels. In biochemistry, this energy-or-poison difference is known as each amino acid’s “metabolic fate.”



Instead of life-sustaining glucose, the ketogenic amino acids yield harsh acetyl compounds (related to acetone, the nail-polish removing solvent). This causes the fruity alcohol smell of “acetone breath” during ketoacidosis. The major causes of death from diabetic ketoacidosis include collapse of the circulatory system, erratic potassium levels, infection, and swelling in the brain—potentially causing major organ damage for patients who survive, including neuron injuries and mental deficits. Though a relatively minor pathway, each amino acid’s distinct role in this molecular breakdown has been charted, which I found in one text labeled like a chemist’s dramatic poem: “The Fate of Carbon Skeletons.”<sup>70</sup>

When it was time to catch the bus back, Agnes offered to walk me to the highway. “It’s like Jordan is in Dangriga. That’s how I feel,” she said. A tall man approached on a child’s bicycle to ask her who I was. Agnes introduced me as Jordan’s girlfriend. There was some unkindness in this joke, I thought as they laughed, but also an eerie intimacy: according to what Agnes told me as we continued down the dirt path, I was the first “girlfriend” Jordan ever had.

I stood there wondering whether Jordan’s last coma felt different than all the other times he had slipped into unconsciousness. Maybe it felt like familiar dark, or he dreamed of flying an airplane. I have heard you can learn to sink into a ketoacidosis sugar high, a feeling I imagined like the creepy sensorium of Sixto Rodriguez’s seventies song “Sugar Man”: *You’re the answer that makes my question disappear.*

White ashes drifted down from the sky. Probably someone burning cardboard boxes, Agnes said. The disintegrating flakes looked surreally like snow falling through the heat.

I often think back to conversations with Jordan in 2010: both partly still kids in our twenties, talking about continuous glucose monitors and insulin pumps that existed in other places—never even mentioning the colossally warped inequalities behind the realities we compared, only their results surfacing in the details of the highly different technologies available in our respective worlds. But our tone during those interviews was almost absurdly casual, and so much lurked behind what was about to happen to him: global health bureaucracies that somehow blotted out the medical support and political advocacy available for other diseases; broken instruments of counting that linked together missing categories and metrics of various sorts; a local community’s precarious labor of sustaining his social death; the hope that Jordan and his adoptive mothers held out of undoing it; and the highly specific technologies and machines that were part of extending (one measure at a time) the life that was left.



*Portrait of Jordan as a Teenager, in Broken Glucometer Parts*, by James Young.

From this perspective, the history of insulin or glucometers—like any other science—was not just one of breakthroughs; there were many kinds of breaks. Amid interfacing stories—specters of his lost mother, Tessa; phone calls from faraway Lorel and edgy interviews with his stepfamily; and all the persistent comorbidities and fleeting characters and distant technological inventions bound up in his fate—I realize that



Jordan himself was a person I would never know that well. Really, I only knew him in islets, little archipelagos of connection. But maybe that is not so uncommon between people in the world.

## DESIGN ARCHIPELAGOS \* \* \* NOT FOR SALE \* \* \*

At a 2010 meeting of the Belize National Diabetes Association in Belize City, I counted cardboard boxes on a folding table, with compartments inside for nesting fragile things. The boxes held rows of glucometers. I made the trip from Dangriga to learn what was happening in the central branch of the country's most active patient support group. The glucose machines being distributed for free that day were donated by the Miami branch of the Belize Diabetes Association, and strips for them—more expensive than the machines themselves—had been donated by the Belizean Diabetes Association of New York. Its members knew how such objects at times become remote outposts of care, across the uneven terrains some anthropologists have called “medical archipelagos.”<sup>71</sup>

Since 2010, the cost of glucometers has finally decreased significantly. But the larger design quandaries remain: norms of “black box” design make delivery-oriented collaborations unnecessarily costly and prone to breakdowns. Historians of science commonly point to the way a tense politics of assigning responsibility gets materialized “between value-neutral technologies and the value-laden choices that determine how they are used.”<sup>72</sup> These divisions develop sharper edges when set in global perspective: Observing devices being used in places where they broke down in such predictable ways, one had to ask: Were these technologies really so “value neutral”? From the lack of generic insulin persisting nearly a century after its discovery, to the built-in complexity and high price of glucose meter strips that could only be used with brand-matched machines, it often felt like inequalities were built right into these therapeutics. What might it look like if diabetes care technologies were *designed*, as well as distributed, with contexts like Jordan's in mind—for example, a method of blood sugar management engineered specifically to be functional and repairable in the parts of the world where most people with diabetes actually live today?<sup>73</sup>

Some scholars have envisioned a productive “open source anarchy” at work in arenas of global health governance—hoping that private organizations and public institutions alike would collaboratively contribute to building health networks and catalyzing competition to drive technological innovation.<sup>74</sup> But the case of brand-matched strips

and proprietary glucometer parts for global diabetes care seems more representative of what Ruha Benjamin calls “discriminatory design,” technologies with foreseeable injustices built in.<sup>75</sup> And like many forms of discrimination, taken-for-granted norms and complacencies that exclude certain populations from access can produce worrisome effects without being deliberately unjust.

What is “best care” for whom? From whose perspective do we assess what a “better” technology is?<sup>76</sup> The glucometer’s historical emergence in high-income contexts sets the stage for certain kinds of innovation being constrained around industrial players’ concerns with retaining control of lucrative markets. It is an uncomfortable truth that global access to decades-old standards of basic care for diabetes treatment remains fragile enough to become life-threatening for many patients like Jordan—not just despite ongoing advances in diabetes technologies, but at least partially *because* of them.

As Madeleine Akrich observes in her classic essay “The De-Description of Technical Objects,” it is often “only in the confrontation between the real user and the projected user [that] the importance of . . . the difference between the two [comes] to light,” taking ethnographic work to “follow the device as it moves into countries that are culturally or historically distant from its place of origin.”<sup>77</sup> But when unequal design problems are identified, what happens next?

Glucose meters stand out as a boundary case example of technological design that has not been transformed by recent enthusiasm around other point-of-care diagnostics.<sup>78</sup> Why have affordable, portable tests been developed and manufactured for human African trypanosomiasis but not for blood glucose? What would it take to think about tinkering on the level of equitable design—crafting technologies to maximize robust access that include the majority of people who now need them to survive? As Akrich notes, when lived histories and “processes involved in building up the technical objects are concealed,” it can easily short-circuit our imaginations of devices’ alternative forms. “The causal links they establish are naturalized. There was, or so it seems, never any possibility that it could have been otherwise.”<sup>79</sup>

## COUNTING

Trying to give a thicker historical context to the social and medical puzzles I observed kept leading back through the infinity loops of interlacing questions that so many observers have faced: What “counts,” and



how are various scales of counting and accounting bound up with each other?<sup>80</sup> In Belize, glucose machines were just one nexus where metrics were electrified. Counting on the molecular level when meters measured light or electrochemical charges in blood became part of what shaped statistical currents on an epidemiological level and even helped animate the forms of moral accounting taking place in a hospital unit's triage or a stepfamily's rural home. These different modes of counting and accounting were each interconnected without being reducible to each other, numerologies bound up with global flows of medicine.

Even with better global numbers of diabetes cases now becoming visible, the issue often continues to be profoundly misrecognized. I once heard an Ivy League economist suggest that a particularly promising policy approach to the world's diabetes epidemic would be raising the price of glucose test strips (via higher taxes) so that poor people with diabetes "thought more carefully first" about what they were eating, knowing it would be difficult to test their sugar afterward. We had all just listened to a public health talk about death counts from diabetes escalating in contexts of scarcity. At the time, I was too taken aback to speak. The weight of our privileged surroundings in that moment seared itself into my mind: a well-appointed U.S. conference room full of white social scientists, using database statistics to discuss the assumed behavioral responses of imaginary nonwhite (and eminently misbehavior-prone) poor people to hypothetical policy scenarios. Everyone sat around the climate-controlled room over an opulent lunch platter arrayed with roasted vegetables—as if the entire world looked like this, covered with catered plates of organic grilled vegetables! And I thought of Lorel's question to the taxi driver: Don't you *see*?

In the future, some researchers predict, people will be able to wear glucometers like watches. Equipped with tiny microneedles and infrared sensors, they could tell us our blood sugar the way clocks tell time. I thought about this when I found an old glucometer in a storage box from my fieldwork. A Belizean nurse had given it to me when their clinic switched brands. Like most machines, it automatically stores hundreds of readings in its digital memory, even if they have nowhere to be downloaded. Dated now, the machine tells times already past, like some relic or last vessel.

I flipped through, wondering if one of the counts might be Jordan's reading. Amid dozens of numbers, each indexing some day and real person, a clinical encounter ending in anxiety or relief, there was also the familiar sight of scattered letters—*Err* for error or *Hi* for danger-

ously high sugars over 600—and I thought of Crescencia’s little joke to herself. She’s long gone now, interred in a family tomb labeled with only her mother’s name. Her cousin Sadie, whose birthday would have been tomorrow on the day I type this sentence, was the one who told me the news, and then she died in her thirties too. Both made it over a decade longer than Jordan, whose grave I still couldn’t find the last time I went back with a handful of red bells that wilted later on the dashboard.

But I felt closer to them bumping into the old meter than I did at the edge of the cemetery where they were unlocatable—perhaps the glucometer remembered Jordan too. I was not even sure whose blood was once measured through the electrical current of the machine in my hands, but found myself handling it like the planchette of an Ouija board. It was also a fragile archive of sorts, both anonymous and personal—one that required contextualization, but told a very different story of diabetes science than the one cataloged in North American history of medicine archives or European museum exhibits. For a moment, the monitor’s digital screen even read like the remainders of a message, as if we might squeeze a few final words into a conversation that ended without answers.



Hello.