

PART ONE

Contexts

Approach

Emergency in Slow Motion

Sugar . . . has been one of the massive demographic forces in world history.

—Sidney Mintz, *Sweetness and Power*

A lot of people, countrywide, in the whole entire world, here in Belize and Dangriga, are traveling with sugar.

Diabetic is a dangerous thing . . . It's like cancer . . . It makes you get weak, it makes you get blind, because of the sugar in your eyes and the pressure . . . It makes you get slim, especially if you don't know . . .

That is the most [serious] thing that is hampering the whole entire world. The diabetic sugar . . .

The whole of your family can get the diabetic. You have to look out [even] if you don't catch it—maybe your children later on to come . . .

—Anne, expanding on living with diabetic sugar in Belize

I have never seen a good stand-alone picture of “diabetes.” If not for Mr. P's storytelling, I might never have glimpsed it at all. He was paging through a family album on the kitchen table in his home on Belize's south coast, showing me pictures of his wife. He smiled back at the old photos of her as a Garifuna teacher standing firm beside a rural schoolhouse. We watched as on the pages she became a mother, then a grandmother. The next time Mrs. P appeared in the album, she was suddenly on crutches. “Sugar,” Mr. P said simply as he paged forward in time, the

photographs sharpening in color and filling with grandchildren. In a family Christmas picture his wife's entire right foot was missing. At one wedding, both of Mrs. P's legs were gone below the knee. We watched her disappear a piece at a time from the pictures, until she was absent altogether.

Later, that scene kept looping in my memory: Mr. P turning the album's pages carefully so as not to crinkle its plastic sleeves, the photographic record of loss a surreal counterpoint to the stories he told about raising a family and caring for the generations to come. About the harrowing parts, he only ever repeated, "Sugar." Back then, I didn't know about the dozens of different cellular pathways and blood capillary injuries by which you can lose a limb to diabetic sugar's wears. But I could never forget how he narrated a series of slow losses that somehow had come to feel inevitable.

At the time, I thought I would be writing about another health topic altogether. Early in graduate school, I went for a preliminary visit to Belize to lay foundations for what I thought would become an anthropology project about people's perspectives on worm control programs. Mr. P had obligingly shown me the apazote leaves in his garden, which could be added to a pot of stew beans for worm treatment. But clearly, intestinal parasites seemed a minor footnote to him, in contrast to the pink housedress still floating on a hanger near their kitchen window. The more people I talked with, the more it appeared that the pressing health issue on many people's minds was not parasites, but rather the shape-shifting disease of diabetes.

The worms I had initially planned to write about are so easy to visualize. Public health campaigns focused on parasites often put cartoons of their targets on T-shirts and sponsor museum exhibits that display worms in glass bottles of formaldehyde. Fascinated viewers frequently do not read the captions; they just stare at the grotesque-looking specimens. Diabetes, in contrast, is strangely ineffable. You can't show it to anyone in a jar. It has no totem: no insect vector to put on letterhead like malaria-bearing mosquitoes, no virus to blow up under a microscope and target like Ebola, no tumor to visualize fighting like cancer, no clot to bust like a stroke. It eludes any single, self-evident image.

As Mr. P showed me, in order for most pictures of diabetic sugar to mean much at all, you need to know something about their before and after in time and place. Yet traces of diabetes were everywhere in Belize, once people taught me to pay attention to the quiet, constant presences that so many lived with. I began to glimpse the negative spaces of what

was missing: Bodies that sometimes slowly stopped healing. Potent medicines and devices that sometimes slowly stopped working. Specters of lifesaving technologies that existed somewhere else in the world. Memories of former vegetable gardens and lost homelands. Loved ones changing in photograph albums. Missing limbs, failing organs. An empty dress left hanging to outline an absence.

I didn't know how to read those signs when I first walked Belize's southern coast, observing what washed up along the tideline. But like my interviews about the health of people and places, the tide arriving from the deep ocean presented a knot of entwined lives I didn't know how to untangle: the last nylon strings of "ghost nets" that now make up half of the ocean's plastic debris, long abandoned by fishermen but still catching life until they unravel; curds of broken Styrofoam in clotted algae; hunks of dying coral from the heat-bleached reef; thin gleaming strips of brown seaweed that looked as if they'd been unspooled from the reels of an old cassette tape. Odds were that most of the bright microplastic shards had once been food containers, perhaps ejected from passing cruise ships decades ago in order to be worn down to such confetti-sized slivers. I watched as local women deftly swept the day's debris from their stretch of beach, treating the sand underfoot like the floor of a well-tended kitchen.

SHORELINES

These are some of the shorelines of sugar to which the stories ahead will keep returning.¹ On a nearby wooden porch worn gray by brooms and sand, I used to sit sometimes with Cresencia and her Aunt Dee in the afternoon when it was too hot to walk anywhere. They would laugh about how I looked even whiter when sweating out beads of sunblock and invite me to stretch with them along the steps, trying to catch a little breeze from the sea. Dee liked to show me the latest foil punch card of tablets from her small bucket of "sugar pills"—an old joke that stayed funny both because they were pills for her sugar, and because she honestly could never tell whether the clinic's diabetes medications were working better than a placebo. Cresencia had stopped taking insulin injections for carefully weighed reasons after the hospital had last given her up for dead. But from the porch, you could see the tree where a meal of lavish Garifuna dishes had once been buried in the sand as part of an emergency *chugú*, offerings for the ancestral spirits who had revived her from what her physicians were certain would be an irreversible coma.

Not far from there, on a sunny overgrown highway parallel to the coast, a teenager with type 1 diabetes named Jordan used to walk in a determined half delirium, trying to reach the hospital before diabetic ketoacidosis set in. It was also along this coastline that a legendary healer with diabetes named Arreini used to send me with a tub to hang her sopping laundry after we finished at the washboard, little chores that were part of the daily test and price of being an old midwife's student. If I didn't use enough extra clothespins for her heaviest shirts to stay on the line in the stiff sea wind, she would snap at me, "*Merigan!*" (American), and I was not allowed to ask her any more questions for the night.

Somewhere far across this water lay the sugar islands from which her ancestors had come, and toward which this story will slowly wend back in trying to understand the sugar now rising in her family's bodies. It was also in Arreini's seaside kitchen where I met her daughter Guillerma when she was hoping to receive dialysis to clean her blood—even though such intricate technologies from abroad were nearly impossible to procure at that time, much less maintain. Some of these friends have thrived for many years past medical predictions. Other people I knew dealt with limbs that eroded from diabetic sugar and eventually required amputation. Many of their heaviest losses happened between my irregular trips back, although over the past decade I have also known many people whose injuries were painstakingly mended.

Most everyone in Belize had somehow witnessed the long list of strange ravages caused by diabetes: blindness, renal failure, bone disease, deadened nerves and numb limbs, pain shooting through limbs or stinging like needles, hunger that did not stop when you ate, thirst that lasted no matter how much water you drank. Whenever I thought I finally knew what diabetic injuries looked like, it seemed I would encounter some new manifestation. Like a dream or a nightmare that kept revealing more images. Once, a friend called me to come over after midnight, but there was nothing either of us could do. We stood watching her mother, Sulma, running through the house as it got harder to catch her breath or even breathe, after years of diabetes complications had contributed to organ failure. Her children had saved up to buy her an oxygen tank, but it cost one hundred dollars and had already run out. Sulma thrashed through the kitchen like someone trying to claw toward the surface, only there was no water. It looked like someone drowning in the open air.

"Far from being a disease of higher income nations, diabetes is very much a disease associated with poverty," Jean Claude Mbanya of Cam-

eroon has argued, writing as president of the International Diabetes Federation. “The global community still has not fully appreciated the urgent need to increase funding for non-communicable diseases (NCDs), to make essential NCD medicines available for all and to include the treatment of diabetes and other NCDs into strengthened primary healthcare systems. The evidence for the need to act will soon be overwhelming.”²

The president of the Belize Diabetes Association, Anthony Castillo, once told me how strangers often tell him he doesn’t *look* like he has diabetes. He laughed about this: “Well, how are you supposed to look? Is there a look?” And it’s true that if you went by the pictures that tend to show up in international papers, it would be easy to mistake globally rising diabetes for a well-understood, generally mild affliction simply linked to excess. When international media coverage of diabetes appears at all, it often implies individual misbehavior—as if people with diabetes simply cause their own conditions—like the upsettingly typical *Economist* headline “Eating Themselves to Death.”³

These commonplace news stories and assumptions probably would not upset me so much now, if I had not once accepted some version of them myself.

A GLOBAL EPIDEMIC AS SEEN FROM BELIZE

Although it took me awhile to realize, I was one in a long line of outsiders who traveled to places like Belize assuming that infectious diseases must be the country’s key health issues. Contagious conditions could be serious matters too—the Stann Creek District, where most of this book is anchored, was experiencing one of the highest HIV/AIDS rates in Belize, and Belize had the highest rate in Central America.⁴ Yet as Garifuna anthropologist Joseph Palacio observed of HIV/AIDS in Belize: “It is a disease that is killing our people. But there are other diseases that are not receiving as much attention. They are diabetes, hypertension, and glaucoma. There is hardly one of us over 40 years of age, who does not have one or more of these public health problems.”⁵

During my initial visit to Dangriga, I asked a prominent Garifuna physician for feedback on my proposed project. He urged me to focus on diabetes and its many chronic complications instead of parasitic worms. He also offered to mentor the project if I came back to spend a year in Belize, getting to know people who were interested in being interviewed about their experiences and trying to learn something about the ways they were making sense of what was happening.

Many doctors worldwide are also confused by the ways diabetes is now changing. Type 1 (about 5 percent of the world's cases) used to be commonly called "juvenile diabetes," while more gradually developing type 2 was labeled "adult onset diabetes" (about 95 percent of cases). They are both rising steeply. Over one million children and teenagers worldwide are now estimated to have type 1 alone.⁶ But today, more children are also developing type 2, and more adults type 1. In untreated versions of either type, high or low blood sugar wears on the blood vessels carrying it. These vascular complications can accrue into severe injuries over time, including organ damage and limbs with circulation so limited that even tiny ulcers might end in amputation. Some researchers today propose to frame types of diabetes instead more like gradations on a spectrum, offering new labels: severe autoimmune diabetes; severe insulin-deficient diabetes; severe insulin-resistant diabetes; mild obesity-related diabetes; and mild age-related diabetes.⁷ Many of the first people I met in Belize, though, simply called it all *sugar*. I framed this project's scope accordingly.

By the time I returned to live for a year in southern Belize in 2009–10, I had read everything I could find about diabetes. There was an odd dissonance between the tenor of U.S. public health conversations at the time, where the topic was still often assumed to be minor background noise, and statistics I could not really fathom. For instance, the International Diabetes Federation estimated that diabetes annually killed more people worldwide than HIV/AIDS and breast cancer combined.⁸ Somehow, I typed abstract numbers over and over into research proposals back then without grasping the implication that a significant number of the people I was getting to know were going to face untimely deaths.

This book is set in Belize, but it also signals a global story. Diabetes takes specific shape in each life, family, and nation—but it's also spreading and causing unevenly patterned injuries and deaths in nearly all countries in the world today. Belize was dealing with the situation about as well as a very small country with limited resources initially could manage. Most health workers and policy makers I encountered in Belize cared greatly about trying to address the rising issue of diabetes. The uneasy scenes in this book show just how complicated a global problem diabetes is—even for a small country labeled "middle income" by the World Bank's relative standards, where so many community leaders and caregivers are working hard to respond. Many health officials and doctors in Belize actively encouraged critical dialogue, and were trying to expand discussions about the next steps against a growing epidemic in which their offices and many others have some role to play in future

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NO. 2448 BELIZE CITY, SUNDAY, AUGUST 8, 2010 (60 PAGES) \$1.35

Diabetes #1 killer in Belize

Violence is #1 killer among Belizean males

Each day, thousands of Belizeans must test their

133 BABIES DIED BEFORE REACHING THE AGE OF 1

by Adele Ramos
adelescribe@gmail.com

BELIZE CITY, Wed. Aug. 4, 2010

The number of diabetes deaths in Belize in 2009 hit 130, up from 103 reported cases in 2008, according to official health statistics from the Government of Belize. This makes diabetes the leading cause of death in Belize. In 2008, diabetes tied with murder for the #1 spot, as a record

reaching the age of 1. They died mostly from hypoxia (deficiency in oxygen to the tissues), birth asphyxia (deficiency of oxygen in the blood along with an increase in the amount of carbon dioxide), and other respiratory conditions, congenital abnormalities as well as intestinal infectious diseases.

Of note is that among males in Belize, homicides and purposely inflicted injuries were blamed for the most deaths. This was especially true for youth ages 15 to 29, among whom violence is the leading cause of death. In fact, the death rate of males in this age group was more than double that of females their own age.

National headline, August 2010.

policies. But the fact is that the food systems and agricultural toxicities contributing to diabetes are domains far beyond the purview of any Ministry of Health alone. Even the wealthiest governments in the world have not managed to bring diabetes under control.

Belize is so beautiful that its reputation as a vacation spot for Europeans and North Americans can saturate even academic visions and distract from serious life struggles. The country's name often brings cruise ship brochures to mind. But many citizens, of course, also struggle with material constraints and social issues similar to those in neighboring countries, as much careful anthropology in Belize has shown.⁹ Still, I have received enough questions over the years from audiences who have not taken social struggles in Belize seriously that it is worth reprising a thumbnail sketch of resource context: Belize is somewhere toward the lower economic range of countries in Latin America and the Caribbean. It is among the countries where the average income is more than four thousand dollars but less than five thousand dollars, according to World Bank estimates of GDP per capita in 2016. For a sense of regional reference, the other five countries listed in that income range include Jamaica, Guyana, El Salvador, Guatemala, and Paraguay.¹⁰

The Stann Creek District has the highest rate of diabetes in the country, nearly double the national average.¹¹ I talked with all kinds of people across Belize's tiny and diverse population. But as I began to be introduced to families dealing with diabetes, I ended up meeting a disproportionate number of Garifuna people (more properly, in plural, Garinagu). Both Black and Indigenous,¹² Garinagu make up some 5 percent of Belize's overall population but represent the majority of residents in Dangriga. They number among the world's surviving speakers of a Carib-Arawak Kalinago language and widely consider themselves a "nation across borders," as Joseph Palacio puts it,¹³ with thriving communities across Guatemala, Honduras, Belize, Nicaragua, and U.S. cities from New York and Los Angeles to Chicago. "Certain diseases are known to have high incidence among the Garinagu relative to the wider population," the National Garifuna Council (NGC) of Belize wrote in its statement on health. "These include diabetes, hypertension, hepatitis, cataracts, and glaucoma. There is urgent need for studies to be carried out as well as the provision of treatment."¹⁴

Wading with patients across washed-out roads knee deep in mud to keep doctor's appointments, or traveling by canoe alongside everyone else when Tropical Storm Arthur washed out Kendall Bridge (which cut off the single road that linked southern Belize to the rest of the country and its only tertiary care hospital), I saw how realities often labeled "environmental" in the keywords of an academic journal were already part of the terrain that people with diabetes were negotiating in life. Nurse Suzanne recalled floating from rooftop to rooftop a few days after Hurricane Iris to deliver diabetic pills and insulin. The rough boat ride through floodwaters made her seasick, but she had heard how many families—on nearly every rooftop—had at least one person going into a coma or other diabetic emergency on top of their houses.

Once, I rode through the Maya Mountains in the back of a slow-moving ambulance with Paulo and his young daughter Elisa, wondering about tipping points. Elisa's pharmaceutically induced high blood sugar was a secondary concern to the fact that her skin was "coming unglued," which may also have been a side effect of the steroid medicines. We never knew for sure. There was no IV rack, so Paulo and I took turns holding the bag until our arms shook. None of us had been inside an ambulance before. We had imagined speeding to Belize City, but instead we told each other jokes about wishing bus drivers would travel this slowly along the precipitous highway.

Years later I followed behind Paulo as he chopped dense jungle plants away to clear Elisa's grave, the surrounding vegetation's growth a ruthless account of the years I had been gone. I have never felt more responsibility than when I learned that her mother, Angeline, had waited three years for me, and together we made the trip to see her daughter's grave for the first time. Afterward, Angeline handed me a photo of herself kneeling with open arms as Elisa took her first baby steps. The fact that the picture's chemical exposures had outlasted Elisa's seemed to dissolve all the words we tried to say. I gave them an image in return, an ornament engraved at a Pennsylvania Christmas shop. They cut the ribbon off and nailed it to the dash of their pickup truck.

Elisa's real name is written on that ornament, but not in this book. One difficult decision in finalizing this project was that most of its contributors requested that I use their actual names. "But then it wouldn't be true," one research contributor protested, when I asked for her input choosing a pseudonym. Others did prefer to create new names, as Belize is such a small place.¹⁵ For this reason, I have mostly stuck with typical anthropological conventions of changing people's names unless they are public figures whose names have been previously published, changing place names except for district capitals, and at times blurring particular identifying details. Still I remain uneasy about these trade-offs, wanting to recognize people's intellectual contributions to this project.

On the other hand, most everyone I met in Belize has more than one name. When Antonia later told me to call her Beh, she said that when I first arrived at her door with a nurse asking for her by her legal name, she knew we had not been sent by friends. Her neighbor Kara had not even known her own legal name until she went to vote for the first time and discovered that in the state's eyes her name was Roseanne. Her mother had chosen to call her children by one set of names in real life and to write another name on official documents for them to claim one day or not as they saw fit. I offer this book's names in something of that spirit, an extra name that could be opted into or plausibly denied by each of these individuals as lives change over time. It also remains a way of asking readers to engage with the larger health and social issues being described, but to respect the privacy of individuals unless they have reached out first.¹⁶

The slow time-lapse stories unfolding in Mr. P's album were also shaped by a gradually changing landscape. Erosion touched human bodies as well as their environs, atmospheres, and infrastructures. They all wore down in ways that were materially connected. In fact, Mr. P

and I first started up our conversation while standing in the doorway of a stranger's barn, watching the broken-down yellow school bus we'd been traveling on get pulled up a hill backward by another school bus. That road strained many engines, and bad weather chronically worsened already rough terrain. That particular afternoon, the hours sitting around the farm where our bus broke down felt like the opposite of a crisis. But that same trip for someone urgently needing medical care would have been a very different matter. One woman recalled how her surgeon planned to cut below the knee, but the vehicle carrying two necessary bags of blood sent by a loved one got stuck in flooded roads after a storm. The infection moved faster than the ambulance. By the time the blood delivery arrived, the surgeon had to cut above.

TRAVELING WITH SUGAR

One of the first expressions I heard for diabetes when I arrived in Dangriga was “traveling with sugar.” *Sugar* is a very common phrase for diabetes—though “traveling with sugar” is not a set label, just one possible translation. In Belize's English Kriol, to “travel with” has long been a term for living with chronic disease.¹⁷ This striking turn of phrase stayed with me as I saw how trips in search of care were a significant part of how many people with diabetes spent time, often traveling by slow public transportation to far-flung clinics, hospitals, temples, or other destinations in search of materials “to maintain” themselves and support their family members. “Traveling with sugar” also echoed common reflections that living with diabetes could feel like being on a strange trip or a very long road, chronic routes that people had to navigate for themselves without knowing where it all might end up.

In Garifuna idiom, one could also “travel” in a spiritual sense, through forms of inner reflective work or metaphysical communication with visiting ancestors. That is why expressions like “to take a trip” or “to get a passport” can double as Garifuna euphemisms for death.¹⁸ I remember stopping by Ára's house on the night before she died, its familiar rooms suddenly filled with children who had made the trip from Chicago when they heard the news. They told the nurse I was accompanying not to worry about checking Ára's sugar unless she woke up again. “She is traveling now.”

If some of the people I met were traveling with sugar, I was trying to travel part of the way with them: to be worthy company in moments when people invited me somewhere, to write down what they offered

up, to ground my questions, and to learn what I could from faraway libraries or locations abroad that might fill in some blanks about the deep divides between us and the uneven conundrums people faced. Foods, technologies, and medicines were also traveling. Like the movement of people, objects' mobility could be capacitated or curtailed by larger infrastructures. Some of the most profound "travels with sugar" were the first journey across a room on a new prosthetic leg or learning to travel on one's hands, people teaching each other to move again as bodies and worlds change.

An ambulatory anthropology of sugar draws attention to how differently we each circulated through the same infrastructures, and how my own comings and goings contrasted so starkly with the mobility of others. Sometimes, but not always, I could borrow a pickup truck and offer rides to the hospital for emergencies. I accompanied hitchhiking friends to doctors and glimpsed the terrible frustration along certain junctures as air-conditioned resort vehicles sped by, but I have also been a passenger in precisely such private vehicles that passed by good friends. There was no eschewing the tourist infrastructures I moved through and no avoiding their troubled histories and ongoing implications they carried. And, of course, traveling with sugar can mean all of this too, trailing charged colonial legacies: travel with money, pleasure, illicit gains.

Tourists were hardly the only ones coming and going. "Garifuna people, *we travel*," Antonia told me emphatically. "We traveled from Africa." For many proud members of the Garifuna diaspora, traveling is an important idea far beyond health alone. It signals a deep history of fierce persistence against ongoing dispossessions and today includes a diasporic community of more than three hundred thousand strong around the world. "*Travelling* the ocean under British control" is the first theme that Joseph Palacio highlighted in his oral history work, when he italicized the word to signal its meaning as both a specific historical practice and a more abstract ideal of active navigation through a matrix of oppression.¹⁹ "I Have Traveled" (*Áfayahádina*) is a well-known Garifuna song that describes the composer's good fortune: "While she has traveled and seen the world, she chooses to remain in her home village."²⁰

Others wished for such luck. Reliance on medical technologies like dialysis often thwarted people's plans to eventually return home. Some in U.S. cities even considered themselves in medical "exile," stranded abroad with diabetes and its complications. Still others in Belize who were more tenuously connected to kin networks abroad nonetheless lived with full details of the medical specialists they could not reach.

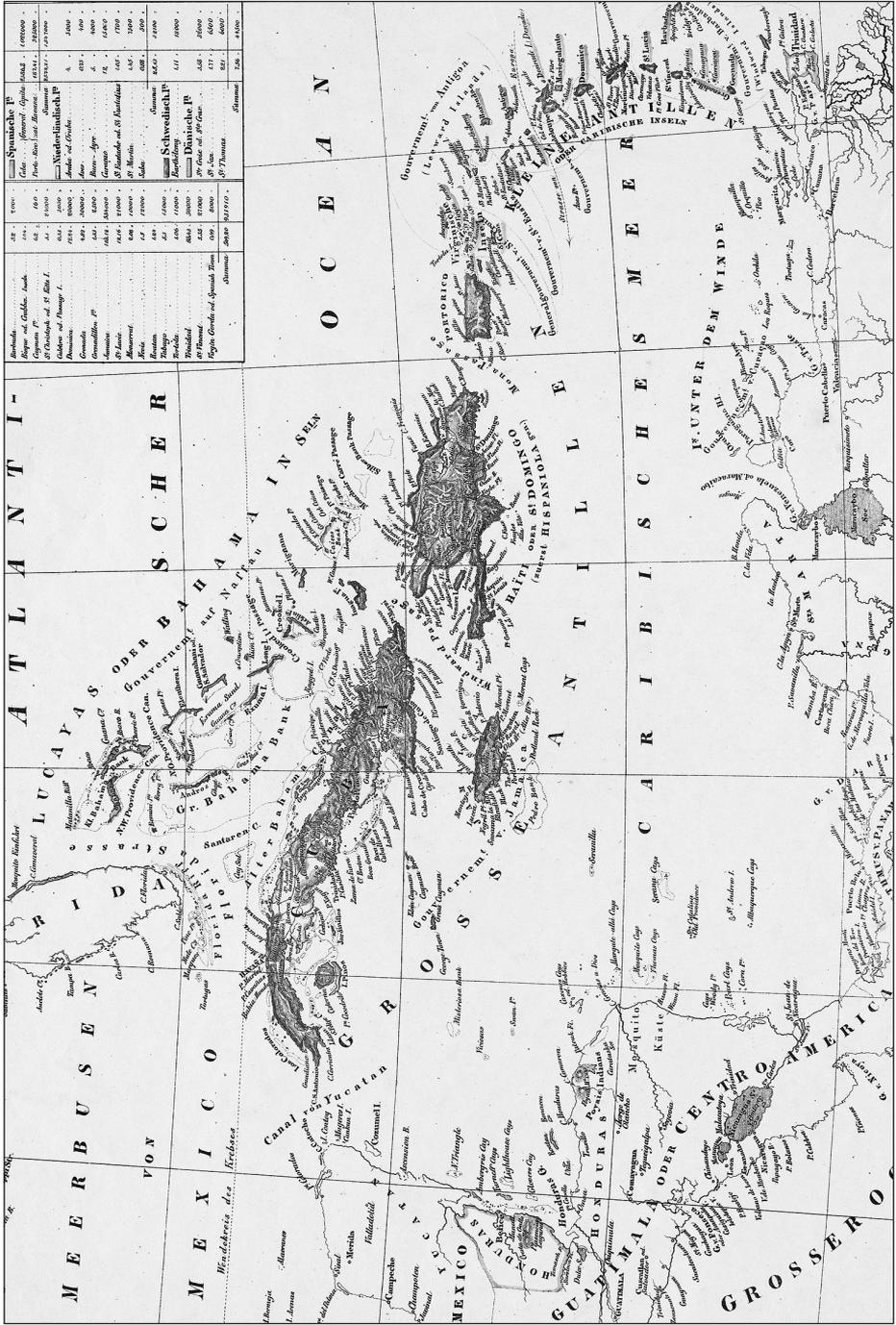
Even a modest job in a U.S. paper cup factory could open a world of retirement resources to be leveraged back home later, such as when one woman in Dangriga had her specialty diabetes prescription pills (unavailable in Belize for any price) delivered monthly via FedEx from a CVS Pharmacy in Chicago.

Traveling organizations like the Belize Diabetes Associations of New York and Miami coordinate with wider networks from across the Caribbean and Central America to bring care teams to Belize each year. Many individuals who contributed to this said they considered these kindred transnational communities as the publics—along with caregivers and families living with diabetes elsewhere in the world—that they hoped this project might reach. Accordingly, I have placed certain reflections meant for academics alone in footnotes and online, trying to find language that might also travel.²¹

Of course, the word *sugar* already contains many journeys and histories. One version of how sugar's pivotal episodes altered the course of Garifuna history might go like this: Columbus planted sugarcane on what became the Dominican Republic in 1492.²² By 1505, the first slave ships arrived.²³ The Caribbean archipelago at that time was one of the most heavily populated geographies on earth. By the late eighteenth century, some 90 percent of the Kalinago population and other Indigenous peoples of the Antilles had been exterminated by military campaigns and European epidemics, as island after island was converted into sugar plantations.

By the late eighteenth century, the last Indigenous-controlled sovereign territory in the Caribbean was Saint Vincent, an island strategically chosen as a fallback point because its mountainous geography allowed for fierce defense. It also became home to a growing community of mixed Indigenous and African ancestry (including men and women who escaped boat by boat from the sugar economies of surrounding islands), which colonial authorities soon labeled “Black Caribs.” This group that came to call themselves Garifuna²⁴ defended their land against European invasions for nearly two hundred years, winning a long series of wars against the British. In 1796, the British military finally managed to exile the majority of the Garifuna families from their land, which they had called not Saint Vincent but Yurumein, “Home-land.” This violent dispossession occurred because the English wanted their land for a sugar plantation.²⁵

There are at least *two* plants relevant to the topic of global diabetes that were growing on Saint Vincent on the day of Garifuna exile, both



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