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Crónica Four: Repair Work

* * * NOT FOR SALE * * *
*Maintenance Projects with Laura, Jose, and
Growing Collectives*

Review copy only

Everybody wants to build and nobody wants
to do maintenance.

—Kurt Vonnegut, *Hocus Pocus*

When Laura told me in 2010 that she hoped she wouldn't need dialysis, I thought back to the hospital garage. Being led through its padlocked door felt like stepping into an abandoned museum of medicine. The cavernous room, with a high tin roof set aloft by wooden rafters, was crowded with aging machines that were once used to restart American patients' hearts or wash their blood. Some of the devices were coated in sawdust and trailed electric cords and tubing, with piles of lumber and paintbrushes tucked around them. Others were wrapped in mummy-tight bundles, layers of cellophane revealing only the vague contours of an engineered anatomy underneath.

"People just keep bringing them down here. Mostly our American volunteers," a kindly hospital administrator named Ethan told me, explaining that most of the analog machines reached Belize in boxcar-sized containers carried by barge across the ocean. "I feel bad because they pay a lot for shipping," he added. "They really think we are going to be able to use them somehow, even the old dialysis machines with no cartridges and pieces missing." Ethan was quite sympathetic to the caring sentiments that motivated the volunteers' donations, if somewhat perplexed with his role of curating these fossils of good intentions. Yet he seemed unwilling to throw the broken machines away, searching fondly amid the hodgepodge to show me his favorite specimens with archaic buttons and retro dials.



We also encountered some recently opened cardboard boxes of building materials. Ethan explained that several years ago, an NGO had donated these tiles for a building project but had not included the specialized foreign laminate needed to actually install them. But a maintenance man at the hospital had figured out a method to soak the tiles in a bathtub to loosen the adhesive on their backs, which could then be scraped clean, one by one, and installed without the missing custom laminate. The workers subsequently began using these painstakingly modified tiles to help build what, as we spoke in the summer of 2010, everyone hoped would soon become the region's first public dialysis center.

The artifacts disintegrating in the garage seemed to demonstrate—or even caricature—the hidden sides of intervention practices focused on chronic conditions in Belize. It was hard not to be disconcerted by the gap between the volunteers' well-intended donations and the reality of what a hospital infrastructure needed. A colleague who once ran an NGO clinic in Sierra Leone pointed out to me that equipment donations mismatched with local needs were not always innocent—there could also be an unintended “dark side of bricolage.”¹ It was often cheaper for U.S. hospitals to dispose of old or unwanted equipment as a donation (and tax write-off) rather than pay for safe local disposal. Overstretched clinics abroad might then be left to manage accumulating unusable equipment—a particularly complex issue because such machinery often leaks toxicants as it ages, adding to accumulating chemical exposures that could well contribute to chronic diseases of the future.

On the other hand, the jumble that Ethan showed me was also something more than a dumping ground. The retooled floor tiles had arrived in unusable condition but were now being made into the foundation for one of the most innovative ongoing clinic projects in the country. Their team was taking up the work of receiving, and *activating*, the parts that came their way to remake this flotsam and jetsam into usable goods. “To create a life,” Kwame Anthony Appiah writes, “is to create a life out of the materials that history has given you.”²

HALFWAY TECHNOLOGIES

Diabetes treatments often rely on medical objects that have been called “halfway technologies”—devices that address “symptoms or manifestations of disease, rather than the underlying pathogenesis.” Such *halfway technology* “does not treat the underlying disease itself, but reflects the absolute failure of all efforts at medical and conservative therapy and is

a last ditch, gerry-rigged lifesaving solution.” And yet, the physician-author adds, “when a ‘halfway’ technology is also lifesaving, its value cannot be underestimated by the individual patient.”³

A common answer to *How are you doing?* in Belize was “trying to maintain.” When it comes to living with diabetes, organs, limbs, and senses will wear down without care. How does a body and its injuries interact with the infrastructures around it? According to the World Health Organization, around 80 percent of medical equipment in low- and middle-income countries is either donated or funded by foreign donors. Yet only a small fraction of this donated equipment—between 10–30 percent, depending on the country—ever gets working once it arrives. Another half of that breaks down in the first six months.⁴ Technologies might allow health to be extended, but require that bodies and infrastructures be maintained together.

The importance of infrastructures often only “becomes visible upon breakdown,” scholars of maintenance observe.⁵ Working to counter this, recent projects by Steven Jackson and other writers focused on repair have generated fields of academic enthusiasm around “processes of breakdown, maintenance, and repair as central but neglected moments in our individual and collective relationships with technology.”⁶ This Science and Technology Studies lens follows objects’ life cycles over horizons of time, linking up with insights that anthropologists of medicine offer about the “recursive cascades” of chronic conditions: tinkering is the kind of care work that will never be over, both for bodies and the technologies that might sustain them.⁷ As Annemarie Mol puts it: “Try, adjust, try again. In dealing with a disease that is chronic, the care process is chronic, too. It only ends the day you die.”⁸

Going further, Toni Morrison’s use of the term “repair work”⁹ several decades before Jackson’s contains all this but also destabilizes it. In her account, bodily reckoning with the violence of colonial histories implies longer horizons of time, memory, and responsibility. Read against unjust colonial histories, all maintenance today takes place in the wake of racial capitalism’s resource flows, legacies of five hundred years of material accumulations against which breaking even is not actually possible. In this context, risk and hurt are not evenly shared for venturing collaboration. Yet this fragility does not negate the force of people’s slow work in the face of debility—it only deepens the stakes of what is meant by aspirations toward “the right to repair.”¹⁰ Whenever bodies and infrastructures of food and medicine are maintained together—or not—questions about the irreparable are present in the



Hospital wheelchair in Belize City.

living histories in circulation. Yet these deeper contexts often get muted by the immediate minutia of surviving with chronic conditions in daily life. “Well, it is here,” one community leader said to me matter-of-factly of diabetes. “So we must deal with it, true?”

Before it happened to her, Laura recalled that she didn’t realize the acute danger because her leg had finally stopped hurting. It just felt like cement. She was the first to tell me another line that I would hear many times in Dangriga: “I was trying to heal [after the first amputation]. But then the infection was gone higher. The surgeon came back. He said, ‘*Let’s go to the theater.*’” Even the cells of her nerves struggled to fathom what happened next.

PHANTOM LIMBS

“The truth is, we all have phantom limbs superimposed on our real ones,” Princeton psychology and neuroscience professor Michael Graziano notes, since our brains construct a “phantom map” of our bodies: “It contains no information about bones, tendons, or the biochemical basis of muscle contraction. The brain doesn’t need to know those details in order to control movement. Instead, it generates a surreal description of magic segments connected by hinges. It’s a phantom body.” Scientists call such a map a *body schema*, and it helps explain

the mystery by which an unused phantom map can remain in consciousness long after the limb it modeled is gone. Severed nerves' "trunks" also remain alive, akin to how a tree's roots at times stay alive in the ground even after the rest is cut down, still bearing signals.

Nearly all amputees report phantom sensation for at least a few days. For some, the sensation keeps returning in erratic flashes. A few feel them forever, Graziano reflected in "How Phantom Limbs Explain Consciousness"—as in the famous 1797 British case of Lord Nelson's arm, lost in war off the coast of the Canary Islands (also home to the colonial world's first sugar plantations): "For the rest of his life he could sense it, as though the appendage were extending invisibly from the stump. He supposedly claimed that he now knew there had to be an afterlife because if his arm could have a ghost, then so could he."¹¹

Sometimes a phantom leg's locomotion is so distinct that someone still adjusting to an amputation can repeatedly collapse after standing without thinking about it. Strange ephemeral sensations also include tingling and itching, hot and cold, pressure or squeezing, wiggling toes, and the feeling of wearing shoes. Such perceptions offer clues about how our bodies perceive themselves in time and space more generally: *telescoping*, for example, refers to a phenomenon in which someone feels their ghost appendage getting closer to their stump as years pass—suggesting how phantom maps may be revised over time, but only partially.

Phantom limb pain is the more brutal aspect of this ghost sensorium, related to a nerve's memory of pain. Some amputees experience the feeling of being cut with knives or pulsing shocks in their missing limbs for the rest of their lives: "Severe post-amputation pains from phantom limbs have been recorded in survivors from World War II, some 50 years after loss of a limb."¹² Laura was among the people with diabetes I met in Belize who reported that blinding pains in her removed leg could be so overwhelming that on bad days she couldn't get out of bed during the day or sleep at night. But the lightning-flash pain that she described sounded less mysterious than many other aspects of phantom sensation—more like replaying a cut nerve's traumatic last memory of being electrically shocked and surgically severed.

Not long after we met in 2010 Laura had undergone the emergency procedure bluntly called a guillotine amputation. While the more common flap procedure gets closed with a seam of stitches, the harsher guillotine technique is occasionally necessary as an emergency measure to stop gangrene or sepsis from climbing further. This makes it harder to heal afterward since it leaves no healthy skin to suture. Laura had been



through two such cuts (segments of the same leg) in one week. But the second amputation was better than the first, she noted, because there was anesthesia.

When she invited me to visit her at home a few weeks afterward, Laura wore a bright turquoise rosary. It was the only time before or since that I saw her in a wheelchair. Laura had to laugh at herself, she said, because she liked to cover her face with a pillow each time her cousin changed the bandage. She was praying hard to heal, and to be eligible for a skin graft surgery later that might make it possible to wear a new leg.

Delicate “nerve repair” surgeries are being pioneered in wealthier countries to manage postamputation pain. (Decades ago, back when painful sensations were assumed to be localized in cut nerve ends, some surgeons attempted to excise the ends with an additional amputation—but this tended to compound the problem into a phantom leg and a separate phantom stump, both in pain.) Today, by approaching nerves more like living electrical circuits, some surgeons are finding techniques for pain alleviation by wrapping the roots of cut nerves together with the nerve cords nearby. This type of rewiring goes a step further than more common pain relief procedures also relying on neuroplasticity, such as burying the nerve in muscle after an amputation. Nerve healing matters not only for chronic pain—it also affects how a stump can later join with a replacement limb, since “painful cut nerve endings often prevent effective fitting and use of even the most rudimentary prosthesis.”¹³

From the outside, many amputations look more or less alike to a casual observer. But internally, very different neurological responses may be taking place. Pain can be caused by any number of typical things, including a bone spur (osteophyte) or a swollen ball of nerves (neuroma), especially painful if near the skin’s surface or a bone. “There is a close association between the presence and severity of stump neuroma pain and phantom limb pain,” as one pamphlet notes.¹⁴

At the level of nerve repair, pain’s neurological networks become contiguous with other infrastructures of limb restoration. I have never heard of a surgical procedure done to reduce postamputation pain in Belize. The specialists pioneering these delicate procedures in wealthier contexts are largely plastic surgeons (a specialty very rarely practiced in Belize, as is the case in many small countries). Since statistics documenting how many people in the world get amputations due to diabetes are already elusive, it is doubly daunting to estimate what subset also experiences phantom pain. Percentages must vary sharply across different contexts, depending in part on factors such as access to anesthesia (and

what kinds) during amputation and available remediation afterward. All of those I spoke with about losing limbs in Belize reported times of severe phantom pain, even those who otherwise felt only total numbness.

The article on “nerve repair” quoted above drew from research paid for (in part) by the U.S. Army. “You hate to think that war is what drives technology, but it does,” observed the vice president of prosthetics for Hanger, a major artificial-limb producer founded just after the U.S. Civil War.¹⁵ One of the key centers for prostheses production today, Hanger is based in Manassas, Virginia, not far from where Confederate soldier James Edward Hanger got hit with a cannonball and became the first amputee of the Civil War. The legendary Hanger Limb leg was first whittled from barrel staves in 1861. Hanger’s invention was legally patented under the Confederacy and, three decades later, also by the United States. This milestone in prosthesis innovation is indicative of a larger military legacy, including much of the literature on amputation as well as most funding for cutting-edge prosthetic design.

In Belize, I had encountered several elders who were veterans of World War II, Mr. P among them. England had enrolled soldiers from across its Caribbean colonies during the war, and each month Mr. P made a trip into town to pick up a small military stipend from the Crown. When Mr. P explained how he always went to pick up the money from England with another veteran who had lost a leg, I wondered if his companion had lost the limb in combat. “No. Sugar.” At the time, I was already struck by how this different cause changed the *social* meanings attached to the injury. But it took me years to learn that losing a leg to diabetes also holds major implications for a person’s *technical* options for prosthesis.

My previous imaginations of prosthetic limbs were informed by TV shows and movies: pro athletes running record-breaking sprints on carbon-fiber blades or advanced microcomputing robotics approaching the goal of what some designers call a “Luke arm” (so named for Luke Skywalker’s prosthesis in the *Star Wars* movies, hardwired together with nerves to respond directly to brain signals). Although military priorities drive much of this development, at times so-called civilian spillover offers something relevant for other traumatic accidents.¹⁶ Made to interface with lively nerves, however, these impressive advances in prosthetic limb technology are designed in a way that makes them hard or impossible to use following a diabetes-related amputation. The nerve and tissue damage that leads to diabetic amputation in the first place



would require an even more sophisticated interface than those being developed for postcombat and traumatic accidents. For nerves worn numb by diabetes, such electric interfaces might not be achievable.

At the same time, nobody really knows what potential innovations go unimagined when diabetes-tailored research receives such little specialized funding. Very little money goes into design for diabetic limb loss, though “only about 15% of amputees are trauma victims or cancer survivors—the types of patients who most often make good candidates for high-tech prosthesis. About 80% of amputations are due to vascular diseases like diabetes,” noted a piece titled “State-of-the-Art Prosthetics Are Incredible, but Not Always Useful.”¹⁷ This majority population tends to be much poorer and lower profile. Materializing what Lochlann Jain calls the “prosthetic imagination,” many people and conditions are rarely imagined in design worlds where “certain bodies—raced, aged, gendered, classed—are often already dubbed as not fully whole.”¹⁸

In some parts of the world, pamphlets that help prepare patients for amputation read something like this counsel from Johns Hopkins Medicine: “After surgery, you may have emotional concerns. You may have grief over the lost limb. . . . There are specialists who make and fit prosthetic devices. They will visit you soon after surgery and will instruct you how to use the prosthesis.”¹⁹

Laura remembered what it felt like to lie in a hospital room in Dangriga afterward, trying to get used to the sight of where her leg used to be, without any expectation of a prosthetic limb or therapist arriving at her door. So when she heard the news that her roommate from the hospital would also be getting her foot removed due to diabetic injuries, she called her right away, hoping to improvise a kind of talk therapy.

“I told her that if you dwell in this depression, you can lose your whole body in it,” Laura recalled. “We must survive. I want to see you again.” Those talks had meant so much to each of them that now Laura tried to contact any of her neighbors going through their first amputation. “My love has a lot of meaning. It is not just family, or care. It is something I am creating—*the carefulness*. It is a bond.”

Laura’s legs and feet used to bear a constellation of small scars that looked like cigarette burns. In her telling, they mapped out constellations from decades of recoveries—she remembered each diabetic ulcer, when it had appeared, what she had used to heal it, and which nurses or friends had helped. She always used to call the leg they’d had to remove her “depend upon,” because it was the side she always leaned her weight on.

The aftermath's mundane particulars made for a different kind of “uncanny ordinary,” to borrow a phrase that Zoë Wool recalls from Stanley Cavell.²⁰ In older theories of “the uncanny,” detached feet in motion symbolized Freud’s concept of how traumatic separation created strange doubles and involuntary repetitions. But if there were any uncanny doubles that haunted the stories that Laura shared, it seemed to me that their most unsettling fantasy space was the prosthetic limbs everyone saw on TV and online but had no way to personally acquire.

On Belize’s pirated cable, most any home could tune into shows like Smithsonian’s *Incredible Bionic Man*, which featured a team of scientists cobbling a bionic robot entirely of prosthetic parts.²¹ Globally, there have also been important advances around affordable limbs: some, like the famously versatile Jaipur Foot pioneered in India, date back to at least the 1960s.²² Others, like teams using 3-D printers that promise to revolutionize affordable customized limbs, aspire toward a wide reach in future markets. But none of these were actually available to Laura in the time and place that she lived.

Somewhere, these phantom limbs meet each other: The synthetic limbs that she knew existed somewhere in the world. Specialized prosthetics for diabetic limb recovery that no one has ever invested (or likely will ever invest) millions into developing. And what she kept imagining; what her nerves kept imagining. The leg that she could still feel there sometimes.

Laura had, however, heard of one group in Belize who might be able to help.

SUGAR SHOES

Fede vaulted from the high blue pickup truck and spun his skateboard around on the street, reaching up to slam the driver’s side door. Under his baseball cap, he had a quick smile and a salt-and-pepper mustache. He had offered to pick me up when a thunderstorm loomed on the afternoon of our planned meeting, arriving in a modified vehicle he drove with silver canes affixed to the gas and brake pedals.

As he jumped a curb from the rain-slick street up onto a walkway, I wondered whether Fede liked to show off his agility hard-won during the more than three decades since he was born without legs. Or maybe he just maneuvered so confidently that his routine methods of navigation appeared as acrobatic flourishes to a newcomer like me in Orange Walk Town—better known as “Sugar City” for its sprawling cane fields.



Propelling his skateboard toward the clinic's locked door, he fiddled with the key and waved me to follow inside. I jumped out of his truck's passenger seat and ran through the rain to catch up.

The workshop that Fede led me into looked the way I pictured a cobbler's workspace—only Fede did not make shoes. Their team made limbs. The room's shelves were stacked with feet in many styles, a selection of hinged legs and arms, and hundreds of appendages sorted in nooks labeled by features: heel height, shoe size, left or right. Some of the hands appeared to be holding each other. Other prosthetics around us sat in various stages of reconstruction, like one shoulder upside down near a toolbox laid close to a cabinet labeled "Extra Feet." One baby-sized foot rested on the floor next to a bag of cement and tubes of Epoxy.

I followed along as Fede gave me a tour of the adjoining rooms, wheeling alongside benches and explaining various workstations. One room had a wall of crutches and plastic orthotic braces. The smallest sizes were patterned with rainbows and Flintstones characters. Fede explained that the majority of their clients had diabetes, followed by people injured in traffic accidents. Still others suffered machete wounds or farm equipment injuries or were children born without legs. Saws, screwdrivers, and other tools hung from a pegged rack. Leaning on a low drill platform, Fede described the process of handcrafting each limb: casting, plastics and parts, shaping and reshaping. When they arrived, most of the prosthetic limbs were the color of beige Band-Aids designed for white skin. Fede described how he worked with new owners as part of their fitting to make the limb whatever color they chose, using a palette of custom-mixed colors. The adjacent laminating room held paintbrushes, bottles of pigment, and jars of resin in many shades of brown, yellow, red, and white.

Fede handed me the plaster cast of a knee as we spoke. Between waves of rain clattering on the tin roof above us, he described his first day of going to school as a child after his old prosthesis had broken, the day when the other children realized the extent of his disability for the first time. "It was devastating." He said that it had taken him many years of inner struggle to reach the place where he no longer felt concerned about wearing prosthetics for the sake of others' comfort around him. He now usually goes without them. But that childhood memory, Fede said, would always inform his work. "I will never operate something where only rich people can get legs. I think everybody deserves the right to walk."

The workshop we were standing in first began with a much more modest goal: a friend had fundraised to send Fede to Dallas back in

1995, in the hope that a professor of prosthetics she knew named Rob might be able to make Fede a new pair of legs. The three of them had formed a deep bond during the visit. Fede returned to Belize from Dallas able to walk with crutches and look people in the eye. Although he opted to return to his skateboard some years later, it was still greatly meaningful for him to have the choice to stand.

When their friend's NGO returned to Belize the next year, Rob asked to tag along, hoping to follow up with Fede and make sure his new prosthesis received maintenance. But he was "unaware that an announcement had been made on the TV and radio that the man who had made Fede's legs was coming to town and that if anyone needed a prosthesis, they should meet the team at The Diner." The resulting scene would be recounted later on their project's website: "Rob was astounded when the caravan pulled into the parking lot of The Diner and the patio was filled with amputees. . . . It was at this time that Rob learned that in the entire country of Belize, there were no prosthetic or orthotic services available to the citizens."²³

That became the origin story of Rob and Fede's collaboration. Their first improvised evaluations began in the diner's parking lot that summer day in 1996. They were committed to doing the prosthetic fabrications there in Belize. Fede began on the path to an informal apprenticeship with Rob over the next four years, which grew into a partnership: Rob bringing supplies and students from U.S. universities several times a year and Fede providing coordination and day-to-day maintenance support in Belize. He also gradually learned certain technical aspects of prosthetics crafting through collaborations with Rob and his colleagues.

The makeshift team did their first fittings in Belize in 1997, working in a local high school's auto garage while the students were on break for the summer. They custom crafted limbs and taught people to use them. American Airlines pitched in, giving Rob's team waivers to transport start-up supplies. "It was before 9/11 then, so we could send these big boxes of supplies on the plane from Texas," Fede explained. Later, U.S. team members brought the specialized resins and prosthetics to Belize in their suitcases. "I asked them to teach me. I got to see all their tricks," Fede said. "So I make my own now." (Much later, I learned this was a very different take than Rob's intention of imparting skills to help with maintenance). Over the years, these partners had made prosthetic limbs for over four hundred Belizeans, Fede estimated. They had come to call their collaboration Project Hope Belize.

When Project Hope Belize had outlined policy recommendations, shoe safety was one of their most creative suggestions: "Proper foot-



wear for diabetics is not available in Belize and importing shoes is likely to be cost prohibitive. The establishment of a diabetic shoe industry should be considered as a viable solution to poor foot wear options for diabetics in Belize in order to make low cost diabetic shoes, as well as create employment opportunities for diabetics.”²⁴ Funding for this creative proposal never materialized. In fact, I was surprised to hear of the existence of shoes that help prevent diabetic amputations, since nobody I knew owned them. But a quick Google search yielded images of pairs fastened by Velcro, commonly called “sugar shoes.” I thought uneasily of the growing need for artificial feet in relation to the lack of access to everyday measures like sugar shoes.

Constant fundraising went into keeping Fede and Rob’s collaboration afloat. “The poorest patients might arrive here without a dime,” Fede said. “They don’t have money for a hotel or food while they are here. . . . all of that, even the bus fare to go back home, we take that all out of our pocket. So how can you turn something like this into business?” Fede said that before their workshop opened, some well-heeled Belizeans had purchased prostheses from Mexico. But the last he had heard, a leg in Chetumal cost around four thousand U.S. dollars.

“They just give the leg to you in a box with a little paper of instructions,” he said. “How can you just hand someone the leg and say, go home and put this on? How will you know this person will not be in pain later? That is my job here. I listen to them, I teach them what I know. We adjust the thing together.” Sometimes their team even refitted prosthetics that came from Chetumal, Fede said, “to make it fit the person for real.” Their workshop in Orange Walk was located some forty-three miles south of the border town, along a highway surrounded by sugar plantations—some overgrown and abandoned, others active with trucks picking up bundled cane. In fact, Fede said, the cement building where we were talking that day had been built on land donated by a local sugar company. As a generous supporter of the country’s only prosthetics clinic, the sugar industry in Belize helps to provide diabetes education and various social and medical assistance to amputees, in the tradition of company towns. Fede said that he had learned how to make prosthetic limbs strong enough that some of their workers had returned to work in the cane fields after losing a leg to diabetic sugar.

Diabetes limbs were the hardest, Fede said, because of the delicacy of putting pressure on the stump. “If the pressure points are designed in the wrong place, that could cause a blister. And then the person might need another amputation, even higher.” Fede said he liked to meet the

person they were making a limb for before beginning the work. That way he could get a better feel for their needs and help them to prepare. “Shrinker” socks were a crucial step in this, he said. They were made especially for prosthetics, to minimize swelling of the stump and improve blood flow. He showed me one. It looked like a tiny elastic white stocking. Shrinker socks were especially important when it came to diabetes, due to the related circulation and nerve damage.

Fede said the organization’s waiting list was growing much faster than the pace at which they were able to make the prosthetics. Trying to imagine what it might mean to “scale up” such a personalized process, I asked Fede whether he envisioned becoming part of the national healthcare system in Belize one day. I was surprised when Fede said he worried that possibility could make their project vulnerable.

“Whoever is in power at the time, then the politicians will say you are supported by this party. Then the next party that comes in could squash you, especially how small we are. That would be the breaking point.” Fede worried about sustainability—but, counterintuitively, he said that was the reason he had not kept pushing for incorporation into national structures. “It’s hard, because then you don’t have anyone else to help. But I just want to keep this all politically neutral. I want to do a good thing for the people of Belize.”

Where, then, does one seek stability over time? That hovered as an open question. Fede said that he just focused on scheduling patients for the next of Rob’s visits. Rob had last been there just the week before my arrival, Fede added, and had brought three students. “We fitted six legs and one arm.” During these regular visits, amputees waiting across the country who had made arrangements with Fede would converge in Orange Walk for fittings. When he showed me the place where they set up handrails for people to try their first steps on a newly fitted limb, ready to make adjustments, I imagined Laura leaning on the metal bars. She was in touch with Fede by phone in 2010 and hoped to schedule a fitting sometime the following year. But it takes serious work to receive a prosthetic limb, even before an actual fitting. “Believe me, it is hard to wear a prosthesis. It takes a lot of strength. For someone who has been immobile, it is like learning to walk all over again,” Fede said. “It will take work to learn to use it. You have to start step by step, little by little.”

Some shelves were lined by more weathered limbs. On a wall by the door, I noticed one leg in particular that looked very heavy. Fede must have been following my eyes because he handed the artifact to me and noted the iron bar inside that the man had once used to walk, pointing



out the stratigraphy of additions and repairs that he and its wearer had made together during repeat visits over the years: heavy resin, a plastic encasement, a bright yellow thigh strap to hold it in place. There was a string looped around the knee just below its hinge and a beige foot bolted onto the scratched plastic shin in mixed skin colors. When components finally arrived from Atlanta to craft its wearer a new prosthesis, the man autographed his old calf in marker for their collection: “Clay Crawford lived in this leg for 27 years.”

“But it is better to keep on trying than not to try,” Fede had told me as he turned off the workshop’s last pull-string light bulb. I never imagined, back then in 2010, the tense situation that would unfold between Fede and his partners before the next time we talked. In fact, a painful falling-out would lead the organization to rebrand itself with a new name to signal a fresh start, Prosthetic Hope International, to which we will return later. But a snapshot of this place as it was then still captures a moment in time, and the complex social networks that both crafted limbs and people needing them in Belize have traveled through.

When her turn came to prepare for a prosthesis, Laura struggled with the shrinker sock. It squeezed her stump painfully, but she still wore it. “Darling,” she said, “we must live on.”

DIALYSIS: PRESSURE

I met one of Laura’s brothers in Belize City, but her other brother I had seen only in photo albums. We sat together on her blue couch as Laura told me about his death from kidney failure. I suddenly realized why her younger brother sounded intense when I asked him an interview question about kidney disease. “Needing dialysis has been a death sentence here,” he had said heavily. At the time when their older brother had needed dialysis, that was the harsh truth. As one Belizean news station described the situation back in 2003: “If you are acquainted with anyone who has suffered kidney failure, then you know that the unfortunate victim has two choices: go abroad for regular dialysis treatments or stay home and die.”²⁵

Diabetes is the most common cause of kidney failure, and kidney failure is one of diabetes’s most predictable complications. Its temporary treatment, dialysis, is a classic example of generative tinkering. The first working dialysis machine was cobbled out of sausage casings, orange juice cans, and a clothes-washing machine during the wartime shortages of Nazi occupation in the Netherlands.²⁶ Dutch physician

Willem Kolff's tinkering produced the world's first prosthetic organ in 1941 and transformed the history of medicine. Early models featured a rotating wood drum and a jug to hold drained blood. Kolff never patented the invention, in the hope that keeping the design open would make future machines widely accessible to others.

That physician-inventor's dream of affordable dialysis—like insulin's original one-dollar patent—did not last long into the twentieth century and its many privatizations. Today a new, high-quality dialysis machine the size of a small refrigerator costs around fifty or a hundred thousand U.S. dollars.²⁷ It took more than half a century for such dialysis devices to first reach Belize. In 2003, kidney specialist Dr. Miguel Rosado opened the first dialysis unit at a private hospital in Belize City. But Dr. Rosado died tragically three years later, after a car accident in Belize left him in a lethal coma at the age of thirty-nine. The hemodialysis unit he had founded remained open, but the country had lost its only kidney specialist and biggest advocate.²⁸

After Rosado's death, there was no nephrologist or endocrinologist practicing in Belize and no public dialysis unit in the country. By the time I visited the unit at the private hospital, dialysis sessions were available for a fee of around \$680 a week, costly far beyond the reach of all but the wealthiest. This is not an unusual situation in the world, according to the U.S. National Kidney Foundation: "Of the 2 million people who receive treatment for kidney failure, the majority are treated in only five countries"—the United States, Germany, Italy, Japan, and Brazil—"yet this number may only represent 10% of people who actually need treatment to live."²⁹

For those trying to enter this slim margin, that 10 percent implies other numbers that are harder to turn into statistics. One of them is miles. As I write this from my childhood home in the United States, for example, there is a DaVita dialysis center about a three minutes' drive away. In contrast, the first person I met receiving dialysis in Dangriga, a man in his fifties named Max, traveled by bus for eleven hours (each way) to Mexico three times a week. To make the trip to Mexico was his choice to try to maintain, he said. Max suddenly peeled back a patch of medical tape and showed me the bright blue valve and clear plastic tube sprouting out of his wrist. Max's wife, Elena, then showed me the balled-up plastic bags in her purse. (One of dialysis's common side effects is nausea.) She made the long bus trip with him every Monday, Wednesday, and Friday to Mexico.

In 2009, I started hearing about something unusual happening in Belize City. There were national news headlines about dialysis access



and photographs of patients protesting in the streets. It was the first group protest of any kind I had heard about in relation to affordable health care in Belize (much in contrast to surrounding countries like Mexico and Guatemala, which have robust populist traditions of health protests). Late in 2010, I traveled to Belize City to learn more.

Before the Chateau Caribbean Hotel later burned down in 2016, the old colonial wooden building had long, narrow rooms and strange keyhole-shaped doorways—partitions left from when the hotel was still a private hospital and each room a ward built for eight or so beds. After checking in, I headed to the newer private hospital across town where, at the time, Belize's only dialysis unit was located. Unlike my hotel's aesthetic of a hospital ward, the private hospital's colorful furniture made its rooms look like welcoming hotel suites.

"We have a list of people waiting," Nurse A told me when I arrived at the dialysis unit. "Here, you will only meet the lucky ones."

Most of the people close to death I had met up until that point were spread out, but in the dialysis center they filled chair after chair. I recognized some of their faces and names from news stories about the recent protests, including a Kriol woman who waved me over. She introduced herself as Carmela and asked me to use her real name, as the national papers had; she was strategically trying to turn herself into a public figure. With changes on the horizon in partial response to their media work, the room's group of patients were learning to leverage the stories of their plights in new ways. "Share the story when you go home. Diabetes," Carmela said. If it wasn't for the dialysis, she added, "I would have died already." I had the sense of stepping straight into the news cycle stories that had brought me to that room in the first place:

Carmela . . . told our newspaper that February 2009 will mark one year since she has been taking dialysis treatments. She, too, is concerned about the lack of a doctor at the dialysis unit.

"I know that it's hard, because we don't have a doctor. When our pressure goes up, God is the doctor. When my pressure goes up high I pray God please help me and I beg him because I don't have any money for any doctor," [she] shared.³⁰

"I didn't know how I was going to get here today," Carmela told me, repeating the worry she often emphasized when being interviewed by the national news stations. She wanted people to know about the dialysis situation in general, but also had a specific goal in telling her story:

Carmela was always trying to raise bus fare. The bus from Belmopan to Belize City cost three U.S. dollars for a ride of one hour and required a taxi (five U.S. dollars roundtrip) to reach the clinic from the bus station. She needed to make this trip three times a week. Every Saturday, Tuesday, and Thursday, Carmela spent most of her day telling her story to other Belizeans in the hope of raising sixteen dollars for the round trip so that every Monday, Wednesday, and Friday she could reach the dialysis sessions the government had begun unevenly subsidizing that year. Having media confirmation of the reality she was describing became a useful tool in this endless work. Carmela felt she had been very lucky to get on the list, reciting the others with diabetes in her family: a sister and brother both already “dead off of sugar,” but also another sister trained in nursing who had managed to get a kidney transplant in Cuba. As we spoke, a loud Spanish love ballad floated over the clinic din from the next room. “That’s my cousin.” Carmela shook her head, smiling. “He likes to sing on the machine.”

It felt intense to enter such an instrumental space of stories being performatively told and lived. Patients shifted restlessly in their chairs during the hours-long treatment, calling me over with things they wanted to say into someone’s tape recorder: whether or not they were on dialysis “scholarships”; the ways they obtained money to take the bus here; whatever they knew about the person whose death opened a spot for them in this room.

On a Monday morning, after visiting the week before, I heard the news alongside the room of patients that one of the country’s twenty-one dialysis patients had died over the weekend. Someone waiting would be bumped up the list kept on a paper taped to the desk near the phone. A new regular would be sitting in his chair by Wednesday. “I was just talking with him on Friday,” reflected one man getting dialysis. “You can be walking today and by tomorrow morning you are . . . *not here.*” The unit’s patients on once-weekly treatment were dying so quickly that it created a palpable sense that everyone was sitting in someone else’s former place, and that someone new would occupy their blue chair once they were gone.

I felt myself being immediately enrolled into some much more fortunate transient rotation, one in a long line of past and future storyteller-witnesses visiting that room. At times I stopped writing in my notebook because I was listening so intently that I knew each word would be imprinted on my mind later that night anyway. Other times I would stop writing for the opposite reason, because bodily I just could not



take in anymore. Both limits left me feeling dizzy and spilling over. It was at times a physical relief to have a tape recorder rolling on those days, and to think it would be possible to one day process whatever could not be absorbed in real time. But later I found the tapes almost unbearable to listen to—piercing machines, background televisions, and bits of hardship coming from all sides that I found no way to process and share on a relevant interval. Many of the patients who were sitting in one of those chairs that day died many years before this book was finished.

But others have lived on and on. One young woman just a few years older than me, Katherine, covered 250 miles each week for the sessions. She wore her long dark hair straight down her shoulders. In her late twenties, Katherine said the diabetes and kidney troubles had developed during pregnancy. Her son, who was five by the time we met, lived far south with her parents in Toledo; Katherine didn't want him to move to Belize City because so many children had been caught in the violence. He loved Spider-Man, she smiled. I thought how his superpowers are also made possible by moving between infrastructures. Katherine's strategy was to arrive with her suitcase packed at every Friday session, ready to undergo the trip to her parents' village to see him for the day on Saturday before making the return trip on Sunday to be back in Belize City for Monday dialysis.

As Katherine told me this, intricate feats of fluid mechanics were occurring in tubes inside the machines around us. Blood flowed in one direction and clear dialysate fluid (technically, "a buffered electrolyte solution") in the other. The liquids were being brought together inside an encased plastic cylinder about a foot long, which is the dialyzer cartridge that actually serves as the "artificial kidney," dwarfed and fed by the larger mechanical apparatus. The cartridge simulates the work of a glomerulus (Latin meaning "little ball of yarn")—the knotted balls of vessels and fibers that make up the kidney's semipermeable membrane for filtering toxins. Today most semipermeable membrane simulations use a new mechanism, a far cry from the original sausage casings model. Blood is channeled inside tiny hollow fibers, each only about the width of three human hairs, capillaries submerged in a bath of dialysis solution inside the cartridge's inner chamber. Very small pores in the fibers' walls keep larger blood cells and proteins, which need to be returned to the body for survival, inside the filtering membrane. But smaller molecules of accumulating toxins, including excess potassium, sodium, and bicarbonate that can rise to dangerous levels in the blood without a

kidney, diffuse through the membrane's tiny pores and dissolve into the chamber's fluid. Invisibly laden with waste, salt, and extra water from the blood, the used dialysis solution, going half a liter a minute, drains discretely behind the machine.

Meanwhile the filtered blood flows back into the patient's veins, preferably through a fistula in their arm. Natural looking once healed, a fistula is made by surgically joining a vein and an artery, which makes a bigger blood vessel but needs careful upkeep. Needlestick options alone include the ladder technique to allow for healing between climbs up the vein, or the buttonhole approach akin to a pierced ear. Either requires vigilant monitoring for infection along the length of the limb. Just that single entry point can reorient senses of bodily motion in many domains of life—for instance, patients need to avoid sleeping on their arm with the fistula. One dialysis center website cautions patients to listen to their fistula access for the sound of flowing blood—called the bruit—usually loud enough to hear even without a stethoscope. “If the sound gains in pitch and sounds like a whistle, your blood vessels could be tightening (called stenosis),” caution these instructions. The “vibration of blood going through your arm is called the ‘thrill.’ You should check this several times a day. If the ‘thrill’ changes or stops a blood clot may have formed.”³¹

If a fistula surgery cannot be performed for a dialysis patient, then more obtrusive hardware might need to be installed, like a catheter or graft (plastic tubes used to surgically connect veins and arteries, which bulge under the skin). In Belize, the dialysis unit's walls had also been fitted with plastic tubing as part of specialized filtration hardware to supply ultrapurified water as the base for the dialysate fluid. I imagined these infrastructures of plastic tubing reaching between the building and its patients.

Yet not just dialyzing technology itself but also the very idea of a right to it was a front for tinkering. The expectations I heard in Belize were very different from, for example, what Sherine Hamdy has described in her work with dialysis and transplant patients in Egypt. In that case, patients asserted an idea that both their state and their kidneys had failed—charges and protests that also animated future demands in Egypt, and spoke of a responsibility (if a largely unfulfilled and highly contested one) that the state was widely understood to have toward its citizens in the first place.³²

In Belize, I struggled to understand why I never heard anything like this. With so many people who had diabetes dying preventable deaths and



sustaining other losses all around me, patients still seemed to implicate themselves and take the limits of the state system in stride. Some people called the opportunity to get one subsidized dialysis session a week a “scholarship” (although they needed three to survive). People in crisis largely focused on getting anywhere they *could* receive the sessions—trying to find some route to Mexico, Guatemala, or the United States, for instance—rather than agitating for change within their state. Economist Albert O. Hirschman famously described the channels through which people respond to social injustices: voice, loyalty, and exit.³³ It would be fair to say that most Belizeans facing trouble (health or otherwise) were in the habit of trying to exit their tiny country when survival became strained. Belizeans have never had a constitutional right to health, nor a patient activist group that had come together to leverage a particular demand from the state.

This was the backdrop against which I met Jose Cruz in Belize City in 2010. Cruz and the group of patients coalescing around his spokespersonship had reached a certain level of celebrity in the country, after initiating what was apparently the first rights-based patient activism movement in the history of Belizean medicine. Together with other dying patients and their families from the Kidney Association of Belize, they organized civic protests and generated collective momentum that eventually pushed the government into greater action.

“I didn’t even know what the word *dialysis* meant when I heard he needed it,” Jose Cruz’s wife, Mileni, later told me. The costly sessions drained their life savings in a matter of weeks. After that, the generosity of a cousin carried Cruz through a few more months of sessions. But the others around them dying without dialysis were a constant reminder of this dumb luck.

“One day, a man from Dangriga came into the unit,” Mileni would recall later. The man, Mr. Z, pleaded with the nurse to hook him up to the machine. He had managed the seven-hour journey through the Maya Mountains to get there, but just didn’t have any more money. “I’m so sorry,” the nurse told him, her hands tied by strict hospital policy. Cruz and five other patients hooked up to machines in the room that day looked on. They recognized how badly Mr. Z needed dialysis from the signs they’d each experienced when things got rough. And they knew how much those signs not only signaled danger but hurt—face so puffy the crescents under the eyes bubbled out, feet bloated to the point they no longer fit in shoes and looked about to burst the skin—the outward signs of kidneys no longer able to regulate fluid levels in the body.

Mileni remembered getting the phone call that morning. “Babe, how much money do we have?” Jose asked her, describing the scene in front of him while Mileni counted what she could get that day. It was a Monday morning. Mileni had the money already waiting for her husband’s Wednesday dialysis session, two days later. Jose and Mileni agreed it was the right thing to do. She returned to the hospital and made a beeline for the cashier.

Mileni showed Nurse A the receipt. Surprised and relieved, Nurse A hooked Mr. Z up to the machine right away. As the three hours passed, Mr. Z’s swollen face and feet melted back to their true size. He looked ten years younger, like a different person, by the time he shook Jose’s hand.

Several weeks later, the same scene played out again: Mr. Z arrived in acute need of dialysis, his body looking so swollen after the long journey from Dangriga. Only in the repeat version, it was Friday. Jose called Mileni and asked the same question again. But that time, the couple had already used their cousin’s weekly deposit to pay for Jose’s three sessions that week and didn’t have any cash that day to share with Mr. Z.

Absorbing the news, Mr. Z died right there in a wheelchair in front of them.

Jose couldn’t sleep all week. “We need to find a way,” Mileni remembers him saying.

“WE DON’T WANT TO DIE”

Ready to try anything, Cruz began a makeshift media campaign. He called in to Love FM, Belize’s popular radio station, and described the situation. “People are dying, all the time.” He was invited for an interview on air and told the story of his own experience and of the many people he was watching die around him. “The people of Belize need to know about this.”

Not long after, a group of dialysis patients—including Cruz, his cousin Carmela, and Mileni—protested in front of the hospital, surrounded by news cameras they had invited to the event from the full range of Belize’s media outlets. Their small movement had gained a powerful immediate goal when the group learned about a letter from a U.S.-based organization that had offered to supply dialysis machines and train personnel if the Belizean government agreed to refurbish two unit locations and commit to certain care criteria over time. Cruz called



the U.S. organization himself when he learned that the letter had gone unanswered. The first time, the NGO office hung up, because they were not familiar with the sound of a Belizean accent.

Cruz called back. “Listen, don’t hang up. I am a patient,” he said, recalling the memory to me later. “Tell me what we need to do.”

Together with the leaders of the Belize Kidney Association and a close-knit team, Cruz began assembling documentation that he hoped would be a step toward the government signing on to the agreement with the U.S. organization. He also continued going to the media and appearing on TV and radio, asking people in Belize to talk with each other about dialysis and the conditions that were making so many patients need it. His words hit home for many people dealing with kidney failure in their own families. Belizeans began calling in to the Ministry of Health from across the country, asking what they were going to do.

“When one media started, then all the media were interested,” Mileni recalled. After Cruz caught the media spotlight, he worked to leverage the attention. Once the government began providing dialysis three times a week for him, he started agitating for the others who received just one session instead of three—and for those like Mr. Z still dying without any sessions at all. For a time, Cruz even boycotted his own dialysis until the government took steps to offer the same to others on the waiting list. As he told one news station:

I need to see something happen. I am willing to stop doing my dialysis. I am willing to die for it.

This is nonsense. People are dying for God’s sake. . . . We have people dying, literally dying and nobody’s paying attention. So I am making a stand today.³⁴

His makeshift tactics kept changing as his body did. At one point, when Cruz was told he needed to go to Guatemala City to avoid losing his leg, he took that story to the media too. “It’s going to be a toeless Christmas” ran a caption over a picture of his decaying foot.³⁵ Generosity poured in from across Belize, helping to fund the trip to a specialist in Guatemala. Later, Mileni would fondly recall the way the kidney specialist there spent a whole hour with her and her husband. “He said, ‘Don’t be afraid. People can live with this. This is what you need to do.’” The specialist patiently explained to them what each test meant, what Jose could eat with kidney failure, and what groceries to buy at the supermarket. The experience of repeatedly traveling to Guatemala City on the



Jose Cruz convening a press release about his pending amputations.

verge of death and returning feeling revived was heartening but eye-opening. Seeing what was possible in Guatemala, Mileni remembered the first time Jose said out loud: “Why doesn’t Belize have this?”

Trying to bring attention to a system unable to support patients like him, Cruz started convening amputation “press releases” for national media outlets each time a part of his body was about to be cut off.

João Biehl describes two ways that patient-citizens in Brazil are learning, in their words, “to enter justice” around their state’s constitutional right to health: one can “enter through the court” (by filing a lawsuit for access to medications) or “enter through the press” (by getting media coverage about missing rights that puts public pressure on the state for upholding them).³⁶ But in a country like Belize without a right to health written into its constitution or law, what do such tactics become when they rely on the press alone? What bodies are stories like this meant to put pressure on?³⁷

“It is open for us to affect human history,” Cruz had told me on the morning we first met. By that time, in September 2010, he had already gone blind and was missing one leg and several fingers. “I’m a young man trapped in an old man’s body,” Cruz said with a laugh. A self-declared “difficult patient,” he preferred to arrive shirtless for his sessions and then be covered with a sheet. He was also known for his overdone singing during the awkward first part of treatment getting connected to the machine—mostly romantic Spanish ballads learned



from his grandfathers, one born in Guatemala and the other in Mexico. “It kills the time a little faster.”

Cruz was diagnosed with diabetes when he was twenty-eight years old. “The problem with diabetes it that it has different effects,” he said slowly. “For example, because they did not diagnose the problem in time, I suffer retinopathy in both eyes. . . . my vision went in a span of about two years.” It turned out that Cruz had lived for many years with the diagnosis of diabetes before finally learning that his high blood sugar was actually rooted in a deeper pathology: polycystic kidney disease. This genetic disorder causes little cysts on the kidneys to grow and burst, triggering infection as well as Cruz’s blood sugar spikes. “Over 500,” he said of his glucose during times of infection. “When that happens, it makes dialysis . . . complicated.”

For about four hours a day, three times a week, a dialysis machine removed and spun the entire volume of Cruz’s blood outside his body every fifteen minutes, filtered it clean, and returned it to his veins. Unsurprisingly, this can cause blood levels of all kinds to tick up or down in ways that sometimes have an impact on the chemistry of treatment. Although rising blood pressure and blood sugar are concerning while “on the machine,” the most immediate danger is crashing. Nowadays, glucose also gets added to dialysis fluid to prevent it from lowering the blood’s sugar level while the fluids mingled during osmosis. But even with precautions, the unit was seeing more than its fair share of patients who suddenly stopped breathing.

In a country with no nephrologist, Nurse A—as the only nephrology-certified nurse in Belize at the time—fell under tremendous pressure. Participating patients each had to sign a waiver before getting hooked up to the machine, acknowledging that they accepted the risks of getting dialysis even though there was usually no doctor present. Whenever a patient went into crisis, Nurse A immediately phoned for the doctor on call to come. But there were many times when no doctor was available at that exact moment.

“She brought me back to life,” Cruz told me. “Most of us in the room.” A Maya woman whom Dr. Rosado had sponsored for a nephrology course before his accident, Nurse A had for decades been managing her own diabetes. She resuscitated many of the unit’s patients over time, tense moments with the whole room watching. Several patients spoke of this as a profoundly personal connection, to know and trust the person who kept them alive through heart failure. Her role in their advocacy grew out of this intense context.

“She stood up for her patients,” Mileni would recall later. At one point, Nurse A even resigned for a short time, leveraging her position as the only nephrology-certified nurse in the country at the time as her contribution to advocacy. She and the patients asked that a physician—any kind—be available on-site in case one of the patients went into heart failure or other crisis. Her patients protested in front of the hospital to demand she be hired back. In news photos of the protest, Jose Cruz held a message printed on yellow poster board that read WE DON’T WANT TO DIE.

In this context of normalized deaths, what gets branded as fatalism? Realism about the actual proximity of death could easily blur into what could be read as a certain resignation to it. It therefore became a major feat of advocacy just to counter the assumptions about diabetes and dialysis patients that were so often repeated.

On one hand, it was true that the extreme time and travel commitment required of patients needing dialysis meant some people did not consider the benefits worth the costs in their particular case, a deeply personal choice that each patient uneasily faced. On the other hand, the difficult decision made by some to forgo spottily accessible dialysis (given these numerous obstacles of various kinds) certainly did not apply to everybody in Belize—an inaccurate assumption I sometimes heard repeated to normalize gaps in dialysis availability for those people who *did* want and urgently need it to survive. Against this backdrop, Cruz and the other patients in their group made signs illustrated with skulls and crossbones, calling attention to the thin line between realism and fatalism. Many of them were indeed doing inner work to prepare for death—but that was the reality they were there to protest.

“I was told it couldn’t be done,” Cruz told me, flashing a mischievous grin. “But you can see the doctors are circling up already. That is what I’m doing. Despite the fact that I’m always fighting with them. That is part of it, fighting all the time, or it is never going to happen.” At some point, fellow patients and their families began calling him “Dr. Cruz,” a striking nickname to emerge from a context where patients were getting dialysis without a physician. Cruz became both patient in and doctor of the system.

Cruz’s use of press coverage enabled a way to talk about the need for end-of-the-line treatments like dialysis—but he hoped that this might only be the first step in expanding chronic care more broadly. He worried aloud that many have come to accept the fragility of their systems—“they are used to it,” in his words—and often ask for nothing more. “Because they determine . . . we’re in a third-world country. That’s the



reason I am so much an advocate of critical dialysis,” Cruz told me. “We deserve to have good healthcare in this country. For the individual . . . in the population, no? As part of the population.”

On the day I left the dialysis center in 2010, Cruz was belting out “I’m Singing in the Rain” in a comedic opera voice, the patients around him laughing with a shake of their heads. He waved goodbye with a three-fingered hand, trailing tubes and singing like a showboat. I did not know at the time that he and his inner circle had begun receiving death threats for their advocacy work. But even then, the sense that his routine performances were a serious joke remained larger than life in my memory. And so did the first image I had seen of him on the news back in 2009. Cruz had both legs then, marching in the midst of a protest in Belize City. One of his hands still had all its fingers. But he held the sign in the other, the missing few fingers read as part of his poster’s message: A PROMISE IS CONSOLATION TO A FOOL.

“This is the first time in [Belizean] history we have a group of actual patients suffering from an ailment come together and demanding what they want,” Cruz told one Belizean news station. “I hope that the Belizean people are taking notice.”³⁸

FOOD INFRASTRUCTURES

As Laura fought to recover in 2010, she hoped to grow a few vegetables around the ramp that her husband built for her on the back of the house. A local hardware store kept a rack of seed packets near the cash register for aspiring gardeners in Dangriga, packaged by a U.S. seed company based in Philadelphia. For lack of alternatives, this was where the local Belize Diabetes Association pointed people with diabetes if they wanted to buy vegetable seeds. Garden projects like this were markers of how infrastructures of food and of medicine are connected—reminders that dialysis machines and prosthetic devices were intimately related to another set of missing tools and apparatuses, namely, around land and agriculture.

In another vegetable initiative, members of the Dangriga BDA discussed the possibility of a “field trip,” traveling together by local bus to a nearby Mennonite village to buy vegetables. It was heartening to hear neighbors come together in trying to figure out ways to reach the healthy foods they could not affordably purchase in their own town’s market. But their proposed weekend plan also struck me for the problem being underlined yet again: even for people living in a district capital, actualizing the option of a large supply of affordable vegetables would require

a trip that took hours. And not only that—getting outside food desert conditions meant a trip to its whitest villages. How was it that agriculture had been so incentivized for Belize’s recently arrived Mennonites, when farming was systemically discouraged for so many others attempting similar projects in the country’s history?

Mennonites came up in other conversations about diabetes care as well. I once met a woman named Lucy who had worked for decades with Honduran laborers in the southern banana villages of Stann Creek. She and her daughter both had diabetes and helped each other with insulin shots. They sat side by side on a threadbare red couch adjoining their kitchen, surrounded by posters emphasizing the family’s East Indian heritage. Lucy removed a sandal to fully display her foot, missing two toes. She credited a Mennonite hospital with the fact that she was able to keep the rest. “They saved it,” she said, even after being told in the hospital that the entire foot would need to be amputated. Lucy described the treatments that the Mennonites had used to restore the imperiled tissue: homemade herbal poultices applied to the wound, periodic massage, a strict diet of raw vegetables fresh from their gardens, and a cryptic process that she described as “removing stones.” It was one of several Mennonite medical rescues I had heard about from people living with diabetes around the country, several of whom reported “miracle” cures, such as salvaging dying limbs that hospital experts said would certainly need amputation and restoring eyesight that no one had expected to return.

One day in August 2010, I set out to find the place that Lucy had described to me as a “vegetable hospital.” The road stretching north was unpaved but freshly graded, grayish and chalky in comparison to the orange-red soil of Stann Creek. It passed through a village where the aboveground cemetery looked at first glance like a city of miniature cathedrals. A little later, the sugarcane plantations turned into cornfields, and the tractors rolled on metal claw wheels instead of tires. We were in Mennonite country.

“Their vehicles can have an engine or rubber tires, but not both,” one traveler named Saul explained, since the compressed air to fill tires is considered a restricted technology. He said of one Mennonite town: “We call these ones Mechanites, because they like these machines. But some of the stricter kinds won’t use any machines at all. Some of them won’t even use paint. And the ones who do cocaine crossings and drug stuff we call Moneyites, because of how much money they have now.” We passed a small lake. The farmhouses were spread far apart, set back



from the road on a hill. Besides the bearded driver of a horse and buggy, the only people we saw outside were three young children with white-blond hair in front of a farm. They ran away barefoot into the house, dressed in the suspenders and modest dresses of tiny adults. “They are so pretty, but they always hide,” Saul laughed of the shy Mennonite children before returning to a story about his own life passion, caring for wounded alligators.

It took me a while to find the clinic, a sturdy cement building reinforced inside with rebar. Disappointed that the clinic appeared closed for the weekend, I copied the handwritten text of the sign on its door:

*Open Monday
Tuesday + Wednesday
Offen fuer Deutche
Freitag u Sonnabend*

I don’t speak any German, but a colleague in Belize once described this Plattdeutsch language to me as “like coarse Prussian from the 1830s.”³⁹ The Mennonites have been political exiles for centuries. Originating from an Anabaptist group in which many of the founding leaders were killed for their subversive teachings, this violent history is recounted in the 1660s book *Martyr’s Mirror*.⁴⁰ Survivors scattered across Europe and later the world, developing distinct sects. Today, Mennonites live in at least fifty-one countries across the globe, a range of diasporic histories cataloged in the *Mennonite Historical Atlas*.⁴¹ During the 2010 census, there were over ten thousand Mennonites in Belize.⁴² Mennonites are known for large-scale agriculture of their land and itinerant autonomy. By last national count, 6 percent of Mennonites in Belize had diabetes, the second-lowest rate for any ethnic group besides “White.”⁴³ (For context, it is worth noting that Mennonite in Belize would code as appearing of distinctly European descent—in contrast to other sects in countries like Guatemala, where converting local residents has been more central to Mennonite presence.)

A Mennonite woman approached me as I was copying the sign into my notebook. She said that she and her husband together owned the clinic and asked why I had come. Her bright blue eyes matched her plain dress, though her gaze cast to the grass as we spoke. Her head was wrapped in a black scarf held in place by a single bobby pin, and her black apron partially covered the subtle pattern of tiny purple flowers on her dress. When I explained my project, she visibly relaxed and

introduced herself as Elizabeth. Opening the clinic door, Elizabeth quietly explained that she was descended from apple farmers in Canada. I would later read that the Mennonite population there originated from a group sent to the gulags of Siberia and Kazakhstan after becoming embroiled in World War II, when Germans invaded the area of the Russian steppes they had been farming. Many of the Mennonites who made their way to Canada had escaped from Western Siberia by dogsled.⁴⁴

Inside, the clinic opened into a small wooden room. It strongly resembled my imagination of a nineteenth-century apothecary shop. Behind its narrow counter, there were shelves crowded with herbal medicine bottles: bee pollen granules, evening primrose oil, horsetail and black cherry concentrate, capsules of manganese and chelated zinc. Intermixed with the Puritan's Pride-brand selenium and dolomite bottles, there were also a few more decorated boxes, like one of Korean ginseng tea and Nin Jiom Pei Pa Koa from Hong Kong. Next to a grandfather clock with a gold pendulum, a 1988 *Physician's Desk Reference* leaned against an antique brown book with a battered leather cover embossed with a gold filigree O. Elizabeth's husband, Isaac, shyly explained to me that the book was over 140 years old and showed me the second crumbling page that was signed "Cincinnati 27 November 1863." Those were the only words I could understand, save a handwritten recipe tucked between the pages; the rest was written in German. Isaac told me that the book was about herbs, and he returned it to its prominent place next to bags of psyllium husks and licorice root.

Elizabeth brought me into a back room to explain her collection of essential oils for massage therapy, which she kept in a row inside a handmade cabinet. She opened one vial at a time and had me guess the smells: lavender and lemon, peppermint and thieves. "These oils can get so deep," she told me, explaining they are a key treatment for the limbs of patients who are facing possible amputation. In the room, she had a massage table alongside a regular bed. As we walked down the hallway, I saw other tiled rooms as well, where patients could stay overnight if they wished. There were two beds with simple frames and pristine white sheets, the rooms' only decoration a clock and one seashell.

We sat in handmade mahogany chairs as I told her more about my research. "Diabetes is the most complex disease," Elizabeth said. "It is difficult to be released." She did have several patients who no longer needed their hospital medicines though, she said, and even some who no longer needed herbs. "But when the symptoms come, blindness or wounds and nerve issues and so, these are the last signs," she explained.



“We try to get to the root, to understand why the body is suffering with these signs.” She showed me acupuncture charts of the bottoms of two feet and a diagram of the organs associated with various nerves along the spinal column. There were also diagrams of two eyes sectioned into slivers, which they studied when people came to the clinic with symptoms of diabetic retinopathy. When I mentioned how the woman I met spoke of “stones” removed from her, Elizabeth went to a stack of pictures and pulled out two, explaining their scale: “These are a little larger than life. Here, this one is of the real size.” The pictures showed brown egg-shaped lumps, glistening an iridescent greenish color with purple around the edges. “These are gallbladder stones,” she explained. “It usually takes one day and one night to pass these.” Kidney stones, on the other hand, had to be treated for a longer period prior to passing, to wear down their razor-sharp edges. “With that, it comes out more like a dust. Sometimes I tell people to let a glass of their urine sit for half a day, and then you can see it on the bottom.”

Elizabeth next produced a series of photos documenting patients’ excrement, highlighting specimens with distinct patterns: bulging and swirled, narrow and ribbed. These forms each meant something different, she explained. Not all patients chose to share this, but it helped with diagnosis. Elizabeth handed me another of her favorite herb books, describing wild carrots and chokecherries, dandelion, cattails, and acorns. “These books have taught me a lot,” she said. “But something of experience teaches you too.”

Elizabeth’s husband was a soft-spoken farmer who kept his thumbs tucked in his suspenders. The six languages he spoke (including fluent Spanish and several registers of German) encoded his family’s layered histories and the Mennonites’ seemingly paradoxical entwined values of nomadic staidness: after his family left Mexico, Isaac said, he had lived in Spanish Honduras for a number of years before finally settling down in British Honduras in 1961.

“Probably about 60 percent of our patients have diabetes,” Isaac estimated. He described one woman who came on the bus all the way from Nicaragua, her knees swollen because of excess uric acid. “She felt good when she left here,” he said. Then he picked up a photo they had on the shelf of a woman with gangrene. In the picture, her foot was black and its toes white. She had spilled boiling water on her foot, Isaac said, but because of her diabetes she had not been able to feel the injury. By the time she reached their clinic, the woman had already been told the foot would have to be amputated. Isaac and Elizabeth had worked with her

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closely during her stay, supplying fresh vegetables to eat in addition to her other treatments. In another photo, a Kriol woman wearing an orange American flag T-shirt looked amused, staring down at the dead foot as Elizabeth tended it. “Her flesh came back, and it could feel again,” Isaac said. “The feeling came back. Her sugar was 500 when she came, and it was below 200 when she left. It was working.” He looked sad as he described the hope the woman had left with, but she had trouble affording vegetables every day at home. They heard that not long after, her foot suffered a relapse and had to be cut off a few months later.

While we spoke, Elizabeth was bustling around blending the powders from foil bags. She knew how to mix custom-made powdered ingredients for each patient. Once the various green, brown, and earth-colored dusts were ready, Isaac’s role in their partnership was to mix the powders together in a bag and hand make each pill by pinching the mixture into clear gelatin capsules that twisted close. “I can do about two hundred in an hour,” he explained. In the room where Elizabeth made her mixtures, she had over three hundred ingredients tucked in tiny wooden drawers. There was a scale for measuring powder on a silver plate. It rested next to a hemoglobin meter and an unlit oil lamp, its glass lantern patterned with Spanish dancers. Elizabeth showed me olive leaf powder and spikenard root dust. “It’s what Mary used to wash the feet of Jesus, in his Holy Scripture,” she added. Whenever she handed me a bottle or fresh sprig, she always said the same thing of each herb: “It is so precious.”

Before I left, Elizabeth took me to her garden, where we stepped between seedling orange and lime trees. She pointed out a new tree she was trying to grow under a wooden crate. Its leaves were yellow next to a cracked eggshell. Back past the water tank, wild spinach grew among the sorosi. Next she showed me the leaves of yucca and sweet potato, which can be eaten like lettuce. We picked some for lunch, and she gathered sprigs of spinach and greens for me to take back to Dangriga, their stems wrapped in wet napkins so they could be replanted.

I put the spinach in a water bottle until my next visit to Laura’s house, for her new garden. For a while, the greens grew near the ramp to her kitchen, eventually producing a single salad. Trying to understand the space between Laura’s dream of a garden and the actual difficulty of starting one up is the reason analysts talk not only about garden projects but also about *food infrastructures*.⁴⁵ That term emphasizes that even for those who want to grow some vegetables or try a kitchen garden, there are many bigger issues at play that make the dream easy or difficult. What growth gets capacitated by institutions?

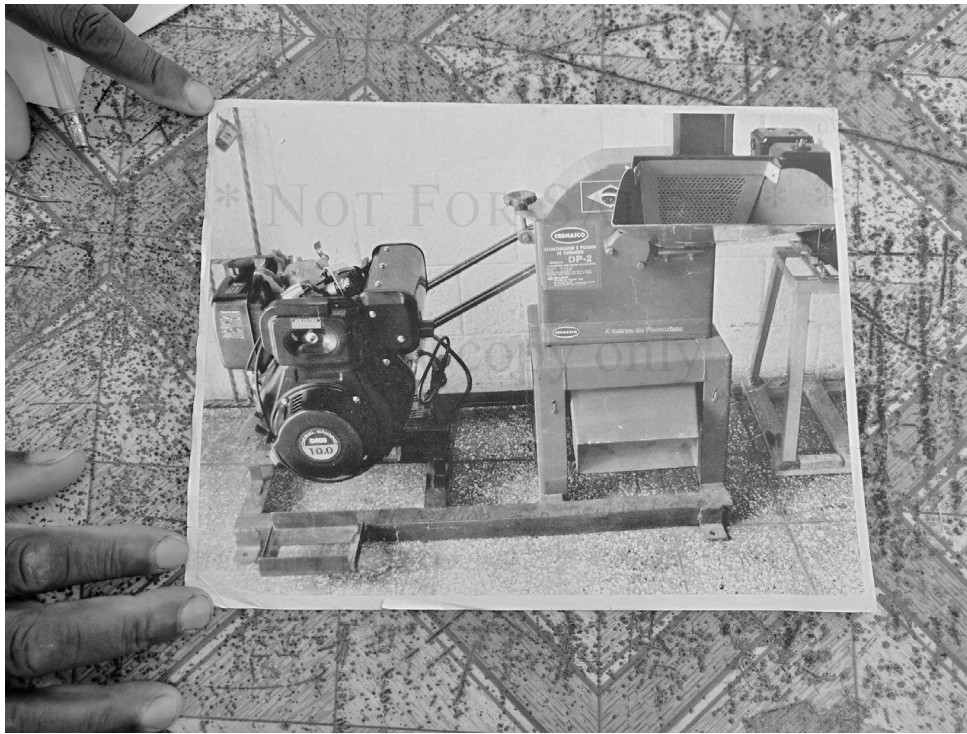


What gets discouraged? Land titles, start-up capital for machinery, state-guaranteed markets or support, tax incentives, trade deals, legal protections for small collectives, and easy access to meaningful seed supplies all come together in how Elizabeth and Laura were part of different food infrastructures.

The historical idiosyncrasies of the Mennonites' situation are illuminating to think with but impossible to replicate. No other ethnic group sits outside national tax structures (the Mennonites pay no agricultural taxes due to religious exemption). This is a major part of what allows their community to be actually self-governing and independent from global food trade policies. I heard that certain Mennonite sects elsewhere focus on social justice outreach such as access to repairable technologies, like machines to grind peanuts. But the only people I met in Belize who had acquired farm machinery from the Mennonites purchased it at their John Deere store, in an agro-industrial community where (many other Belizeans were quick to note) the well-paved road ended immediately at the town's edge.

Actually, a machine for processing peanuts had been the dream of one local Garifuna farmers' cooperative. The group had been looking to market a nutritious protein cereal—Cerebuitu, they named it, Good Cereal—as a grassroots business, hoping to supply nearby school breakfast programs. The cereal they envisioned could be made not only from organic rice but also from banana, yam, and breadfruit. To start out, they had perfected a recipe with a base of organic peanuts and rice, flavored with ground ginger and nutmeg. When I sampled the bag they shared with me, it tasted nourishing and subtle, reminding me of something from a high-end health-food store. But the collective needed a particular machine from Guatemala City in order to process a market volume of peanuts. The group's leaders had met with government officials and NGOs, typed up an itemized budget, and even visited Guatemala City to price and photograph the necessary machine. It cost six thousand dollars. By the time they showed me its picture, they had been looking for a funder for many years.

Three farmers from the collective brought me to a building full of drying sesame. By that time, their collective was contemplating turning the space into a tilapia farm to finance equipment for the cereal initiative. As we walked through waist-high grasses, a farmer with loose silver dreadlocks told me how their collective had grown a huge quantity of peanuts that first year, hoping to launch the cereal project. They had



The machine from Guatemala that a Garifuna farming cooperative in Belize hopes to buy for their healthy cereal project.

a hand-crank grinder meant for family supply and had printed some labels for packaging. But the group had not been able to track down any governmental or other support to scale up equipment or distribution. I was surprised to hear about the difficulty because foreign peanut supplements like Plumpy-Nut have become well funded among donors concerned with childhood nutrition. But after sharing, selling, shelling, and grinding all the peanuts humanly possible without an industrial machine, the farmers eventually had to agree there remained a large quantity of peanuts beginning to rot. Maybe the next year, they hoped, things would work out with the machinery. Before the remaining crop became a nightmare to haul, they returned it to the village ecosystem—micronutrients for crabs and fish, fertilizing the land and water system they would grow from again next season.

Or at least, that was the most optimistic way to think of seventy-two thousand pounds of organic peanuts, grown with dreams of starting a healthy Garifuna food program for children, that had to be dumped into a swamp.

Another major Garifuna food sovereignty project underway in Honduras is spearheaded by Miriam Miranda, president of the Black



Fraternal Organization of Honduras, whose work has helped capacitate a generation of thriving Garifuna farmers along the Honduran coast. Recently, a Canadian investor announced plans to build a series of “charter cities” as part of a tourist megaproject on their land. The collective is now also battling this planned foreign construction across the land of twenty-four Garifuna communities.⁴⁶

This especially tense case in Garifuna Honduras amplifies certain contradictions of food infrastructures. But in more subtle forms, they are actually quite common. People with diabetes are frequently made to feel like it is their responsibility alone if they develop chronic health conditions. But it takes rather extraordinary and personally risky measures to try reforming the agricultural *systems* that make such conditions likely for many. When Miriam Miranda won a food sovereignty prize in 2015, her traveling companion to the United States, Lenca Indigenous activist Berta Cáceres, was assassinated at home shortly after the two returned. Miranda has continued her work even after multiple death threats and a kidnapping.

Collaborating between the Garifuna communities of Belize and Honduras, collectives at work on food justice issues have continued despite rising violence toward environmental activists in Honduras. In November 2015, two Garifuna activists there were run off the road. The next month, the president of the Garifuna Land Defense Committee was shot in his driveway in Honduras, after speaking out against a land grab by Canadian tourism developers; he survived the three bullets, one in his lungs.⁴⁷ Several other Garinagu were killed by police in Honduras amid strange circumstances in 2016, 2017, and 2018 (events linked with a growing U.S. military presence, according to activism and solidarity statements by the Belize National Garifuna Council). But you won’t find any of that on the clinic educational pamphlets suggesting that patients with diabetes reduce their stress and eat more vegetables.

BETWEEN HURRICANES

Chronic weather was what Laura used to help explain her diabetes: she said it felt like watching a hurricane approach. Good cooking had always been very important to her because it was a way she could live with “open hands,” sharing with her family and giving to neighbors even though there wasn’t extra money. “You can’t eat the money!” she would laugh. It was an upsetting dilemma for her to realize that the food she had always cooked with love—with ingredients that could be

stretched widely enough to have extra to freely share—was part of how she ended up losing a leg. Speaking with tenderness of both past and future generations, Laura merged collective memories of hurricanes like Hattie with her views on how foodways have changed to explain to me how it felt to watch an emergency approaching so slowly.

Her metaphor began with a memory of storms. “We used to have a big house, but not cement. A wooden house on the beach,” she described. “And right there, you could stand up inside and see when the water was coming [when the sea levels rise during a hurricane]. We were just little kids, but we weren’t scared. . . . family members and neighbors would come. This house was full of people. But how many people would die in that house because we didn’t move from out the sea?”

That was what diabetes felt like to her, Laura said—a hurricane coming. It was part of a system much bigger than any individual, but there were certain measures that people knew to take nowadays to protect themselves and their families, she explained. But back then, it was different: “We didn’t know,” she recalled of the way her family used to stay in their wooden house during hurricanes. With what they know now, “even if I have a big house, if a certain category of hurricane comes, I wouldn’t stay there. Because it’s coming! It’s going to come at me.” Laura evoked a sense of food climates and weather systems together reaching their tipping points. Her sense of chronic risks and the long-term patterns that precede a crisis made me recall how diabetes is biologically characterized by overheating on the cellular level, both kinds of warming gradual in accumulations and then suddenly erupting into crisis.⁴⁸ Laura stayed with these overlaid images, returning to Hattie: “God saved our lives again. . . . My mother was just fighting her way through. My mother didn’t even know to move from there.” In contrast, Laura said, “What I wouldn’t do now! I wouldn’t stay here, with my grandbaby. So it’s funny, the eating . . .”

As Laura spoke, we both kept looking out at the sea in front of her sister’s house. During my time in Belize in 2010, already Hurricanes Alex *and* Karl had hit, and Hurricane Richard struck weeks afterward. In that moment, her analogy about food climates and hurricanes felt like more than a metaphor. What happens when not only houses and bodies but shorelines and atmospheres are in need of repair?

There is something in diabetic foot care known as *demarcation*—slating a body part to amputate itself at a particular line and choosing not to intervene with an active procedure. It seemed to me that demarcation was increasingly being applied to the changing landscape: Certain sections of the Mesoamerican reef closest to tourist markets in



“London Bridges” in Belize.

Cancun had received health insurance policies for emergency care in cases of a hurricane. (“If you cut any place of your body, and you get attention very quickly, you have more possibility for getting healthy. It’s the same with the reef,” explained the backing insurance company.)⁴⁹ Some Belizean groups like Fragments of Hope work to replant nursery corals on metal rods, like little prostheses for dying sections of the reef, trying to shore up against the warming ocean. But other places were not considered salvageable. “The problem of the twenty-first century is the problem of the water line,” Stefan Helmreich observes, as global warming interfaces with the long-standing color lines that W.E.B. DuBois famously described.⁵⁰ “The entire Belize City will be submerged by an encroaching sea in under 7 decades,” the Belize Ministry of Health replied when asked about one eroding coast.⁵¹

In Belize, this problem feels both old and new: about 1 percent of the population already lives in “London Bridge” communities over water. As one official in Belize explained to anthropologist Herbert Gayle, “That is the only place where I see such unity among the poor. They come together and extend the bridge to each other’s shack.”⁵² Cobbled from improvised scraps, London Bridge homes often emerge in flood zones, where the state has little presence with infrastructure or roads. Their architecture is named for the nursery rhyme: *London Bridge is*

falling down. . . . Build it up with wood and clay. . . . Wood and clay will wash away. . . . Build it up with bricks and mortar. . . . Bricks and mortar will not stay. . . . Build it up with iron and steel. . . .

Even in some of the bleakest areas, an unlikely infrastructure of collaborative maintenance sometimes emerges. “What people call [a] nice place now was morass and people dump it [in the] same way. We put the plan in place afterwards. . . . Belize City sits on a delta. The people of old have been doing this, so we’re learning the technique and we’re creating another space,” explained one resident.⁵³ Such chance bits sometimes come together in rearrangements more meaningful than any of their single pieces—structures that contain shards of painful history but sustain new possibilities, with the force of jagged affinities and unauthorized tinkering.⁵⁴ Yet there are places where it is nearly impossible to travel with crutches or a wheelchair.

PROSTHETIC HOPE INTERNATIONAL

When Laura received a prosthetic leg from Fede, her granddaughter called it their household “robot foot.” But the leg hurt, Laura said. On the day I visited to see it, she was stretched out in a hammock and the leg was in a corner, a folded napkin in the socket.

Diabetic stumps in particular often swell and contract, even in the course of a day. It is not uncommon for a prosthetic socket that fit when made to later need modification, because stumps’ shapes often change over time. So Laura’s concerns did not strike me then as out of the ordinary. In my mind back in 2010, Laura’s work getting a leg from Fede was one of few stories that seemed to have a sort of resolution: cobbling across the odds, Belizeans in partnership working hard to help other Belizeans recover. But looking back, I realize that I had trouble hearing her that day. She tried to tell me that the limb was not free of charge, after all. (I had figured this must be a misunderstanding.) And more than that, she told me that the socket was not fitting right. She said that she’d had trouble sorting out an adjustment with its cobbler and could barely even use it just to wear in church.

Setbacks are integral to the realities of maintenance stories, so it wouldn’t feel right to leave this next part out: Laura wasn’t the only one who ended up in this kind of situation. I was surprised to learn years later that Fede had been let go from the organization, in tensely fraught circumstances. Several people told me that Fede had started charging patients “under the table” for limbs made by the organization—in some



cases exorbitant prices, even for patients with few means or for poor-quality legs. By the time I followed up on our earlier interviews, Fede was no longer working for what was once called Project Hope Belize. In the aftershocks of their schism, the organization had shut down for several years to rebrand and rebuild. Fede and Rob both offered to share a retrospective comment about what happened.

Fede and I met up at a Chinese restaurant, his flashy pickup truck long gone by then. He arrived on a hand-pedaled bicycle. Charismatic as ever, he focused his narrative on the more philosophical aspects, which were easier to talk about: What was a good enough foot and for whom? Fede said he worried that prosthetic students passing through from other countries made limbs for Belizeans *as if* they were going to get maintenance. He said that his constructions were considered rough and overly heavy by those working in other contexts; but that he'd seen people's legs snap, even top-of-the-line models, because their parts weren't engineered for tropical environs like Belize. Some clients worked in heavy labor in agricultural fields, or lived on the beach and needed a leg to walk on sand, or otherwise asked him to make something that would last five or ten years. By the time we spoke, Fede explained he was down to the dregs of his supplies. But he said there were people who came to him because they didn't want to wait many years in hopes of a better leg. That was his side of the story.

Yet something is not always better than nothing, Rob said with worry when I caught up with him later in Atlanta. A poor-quality prosthesis can be dangerous. "She had a right amputation, he offered her a left leg," one of these stories began. I told Rob how I was struggling to write about what had happened, and felt uneasy now writing about the way things had appeared back in 2010. He felt uneasy too, and told me that I wasn't alone in wishing there was a way to rewrite the past few years. Rob spoke passionately about the work ahead but honestly about the pressure. "You want to go down to Belize and make legs for people, there's all this other stuff you gotta do to keep the machinery running." He realized that many Belizeans were waiting for his team in order to get a limb and wished he could be in two places at once. Rob said it was a strange feeling to keep going without Fede, some twenty years into their collaboration. He sounded just as sad about the lost relationship as Fede had. "You know, we were in our twenties when we met. He was one of my best friends."

After lunch, Rob waved me into the shade of an enormous warehouse. Recycled objects were stuffed in a maze of cardboard boxes on

red shelves stacked four high, with lumber piled on the highest tier near the tin roof. Many boxes held retired Delta Airlines uniforms, but Rob's section had very specific labels, like "left foot shells" or "6 ply socks." Rob pulled down a crate of right feet to show me some of the supplies for their next trip to Belize, coming up in a few months. Rob and his partners renamed the organization to signal a fresh start: Prosthetic Hope International. The group has started working more closely with the Belize Assembly for Persons with Diverse Abilities (BAPDA). They estimated that around two hundred people are currently on the waiting list for either new prosthetic limbs or old ones needing repair. One of them was Laura.

Last I heard, Fede was contemplating moving to Guatemala, which would leave no one I know currently living in Belize who makes or repairs prosthetics. Rob remained committed to going to Belize several times a year, and is working to collaborate more closely with the Belizean government now that the issue is more central on their radar. He hoped to secure a grant to team up with a Belizean craftsperson for on-the-ground daily repairs and expand care.

If the whole situation was a parable, it might be about how each collaborator could use a figure like the other: balancing global resource flows with consistent presence and local knowledge, bringing distinct kinds of expertise together.

This is not a parable though, just another tough reality faced by many countries. One thing is sure: the demand for prosthetics is not going anywhere. The last thing Fede told me was that he feels worried about his kids since the whole family now lives on his wife's grocery clerk salary of one dollar a day, which means that most days they can only afford meals of plain noodles. While Fede was born without legs, he said his mother recently lost both of her legs as well, to diabetes.

HOLDING MEASURES

Mileni told me she dreamed of one day continuing the dialysis and advocacy work that she and her husband, Jose, began. Most people who pass Mileni in her unassuming cleaning uniform don't realize the kind of life she has lived since childhood, which warrants a book of its own. But that is a story for another time, Mileni added with a laugh. For now, she wanted to tell me how her fight at Jose's side had ended.

All the couple's possessions had been stolen from their home shortly before his death. Mileni recalled how someone broke in and took their



mattress, couch, and furniture. They even took the little plastic egg that Jose had bought as a surprise for her birthday one year, a funny gift that she missed more than the wedding ring it used to hold. But they didn't take the box of her husband's papers about the advocacy movement, so Mileni had been saving them for many years. The box held the bureaucratic traces of their fight: Jose's back-and-forth with the U.S. dialysis organization and Belizean officials. Shuffled in with the rest were also news clippings, love poetry, medical records, and eleven cassette tapes on which Cruz recorded his own narration of his advocacy projects and life chapters, bearing sticky labels in his handwriting with titles like "Fudge: His Life."

In retrospect, Mileni thought Jose somehow knew clearly when it was coming. She remembered her husband's urgency on the day before he went into heart failure, when he suddenly wanted a burrito from his favorite restaurant, owned by a close friend. Later, she said, the proprietor had told her that Jose said goodbye that day. It gave her peace to be able to give thanks for how it happened: "My husband died of natural causes." Her favorite way to remember him was singing karaoke—like at her friend's wedding, when he had surprised her by getting up in front of everyone. Already blind and missing a leg by then, he sang the Bryan Adams classic "Heaven," a Belizean favorite, dedicating the song to Mileni. Jose had a pitch-perfect voice after singing in so many dialysis sessions. Whenever the song came on the radio, Mileni said, she felt him near.

Later, I wasn't sure how to read that year's protest events: Was the dialysis patient activism I had seen in 2009–10 a citizen consciousness that might continue growing around other aspects of healthcare or an evanescent moment that coalesced around a few charismatic individuals? I don't know if it might be a story still unfolding. But since Cruz's work to create an idea of rights took place largely through the news stories written about him, I am trying to take seriously the different work of narrating these stories myself. As always, the center of gravity shifts depending on where you stop or start the story.⁵⁵ Being in dialysis units made me think of people I'd met who couldn't access them—how there was nothing to say when twenty-year-old Jordan showed me his bloated feet and said that he was not even on the waiting list. Apparently his kidneys were so bad that he was considered a poor candidate for the costly treatment. I remembered, too, how when Cresencia's legs filled with fluid, she could find relief only in ancestral interventions.

But I could also tell a more heartening story about what I saw when I returned to Belize years later, to the same location where, almost five

years earlier, Ethan had shown me the space being prepared for the newly arriving dialyzers they hoped to install. Ethan was gone by then, having moved on to work elsewhere. Jose Cruz died on a December morning, three months after I interviewed him in 2010. But there it was on the hill, landscaped with dirt from recently dug oil wells in a Mennonite town nearby: a low building and a small sign directing patients into the Jose Cruz Memorial Dialysis Unit.

It took me a minute to compose myself enough to take a picture of the open clinic, thinking of the past lives its sign marked and the ongoing ones it might now extend. But I suppose you can't freeze-frame a happy ending any more than a tragic one. Inside the unit, two visiting dialysis nurses bustled around. Later, a government official worried aloud to me that the U.S. donor who had originally funded the center had now drawn back after three years of training and support, as had been planned, leaving the machines to the state for maintenance. A large percentage of the Ministry of Health's entire operating budget was being spent to keep dialysis centers running, although there were still shortages around more basic technologies—such as glucometers and strips for home testing (too expensive to be provided by the state) and insulin (provided by the government in three of the country's six districts)—which will mean more Belizeans needing dialysis in the years ahead. After hard work by the policy planning office, some 25 percent of patients who needed dialysis in the country were now receiving it, up from what was initially 10 percent. But the other 75 percent were still waiting. Government officials were looking for investors to help them maintain the units, hoping to find a potential partner abroad.

But also there in the clinic, getting dialysis in the room that morning, was my old friend Guillerma. It was striking to see her in that room after our earlier conversations in such a very different context all those years ago, when her mother, Arreini, had hosted an ancestral meal for protection, at a time when Guillerma was understood to be dying from diabetes complications and could not get dialysis at all. The last time I had seen Guillerma was in a Belize City hospital at the end of 2010, when she had just started getting one of the three dialysis sessions she needed each week, due in large part to Jose Cruz's advocacy. It was a fraction of the care she needed but had still opened some precarious margin of survival.

Sitting there in the Jose Cruz dialysis unit, where Guillerma was now getting all three weekly sessions, these histories meant something different to both of us already. But they were also part of the "repair work" that had sustained her until now. I showed Guillerma the picture I had taken



during my last visit, when she had been sitting in the same chair in Belize City where Jose Cruz once received treatment—though the two had never met, she told me. “Let them know, I am still right here fighting it,” Guillerma said, four years later then. Three mornings every week, she woke up at 4:00 A.M. and took a taxi and then a public school bus three hours in each direction to receive her hard-won 8:00 A.M. session. “I look *good*. People don’t believe I am on dialysis until I show them my fistula.”

We watched from the window as people walked down the big hill. It was so hot that with the steep climb, many patients who had just gotten off the machine had fainted at least once while walking down it. (“They boxed me up,” Guillerma once laughed while we waited for the bus, recalling the last time she was slapped back to consciousness by her favorite nurse.) I thought of the evening when Arreini had first told me about her daughter’s “dialys” and the place in her village she had planned to bury her. Instead, all these years later, Guillerma wanted to share pictures of the beautiful deep-red dress she had bought to walk her own daughter down the aisle.

The dialysis machine whirred and beeped next to us the entire time we spoke, like a shrill but persistent third voice in our conversation, as it removed accreted toxins from Guillerma’s blood. In many parts of the world, dialysis is considered a “holding measure”⁵⁶ until renal transplant becomes possible. But in Belize, where no renal transplant has yet been performed in the country’s history, dialysis was instead a “holding measure” against death.

I remember how mechanical those exact machines had looked back in 2010, still stiffly wrapped in factory plastic, when I had photographed them in their storage room with the air-conditioning blasting to preserve their delicate parts. It was somehow comforting that the medical tubes now carrying her blood into one of those very machines looked more pliable than I expected: less the electrical circuitry of a cyborg, more like an umbilical cord. Guillerma followed my eyes. “Still alive,” she smiled. The electrodes and wires threaded the air between us, awkward and alive, into its tenuous machinery. Together we watched the centrifuge wheel her blood backward like a broken clock, trying to turn back enough time for the week ahead.

THE GRADUAL INSTANT

Public health and medical sciences read very differently when juxtaposed against the lived histories of people actually navigating care for

chronic conditions. Their arts of survival and repair often ricochet against any assumptions that take for granted what diabetes looks like and where it comes from—bringing attention to what James Baldwin once called “the questions hidden by the answers.”⁵⁷ At the same time, this account has tried to do something more than note diabetic sugar’s many complicated questions, by also following along with those trying to put pieces slowly together into habitable stories. Guided by people “still fighting it” (as they say in Belize) and trying to work up to their insights and craft, this book has attempted to assemble pieces together in ways that more closely reflect how they were lived: as material fragments searchingly rearranged into whole worlds that often astonished me with the force of their improvisation and pain, but also with their persistence and love.

“How’s our miracle?” Laura’s surgeon liked to ask, which always made her laugh.

“I’m doing good, doctor.”

Whenever Laura recalled again her story of getting those amputations of the same leg only days apart, the awfulness of the procedure was not the part that made her emotional. “It was funny,” she said. “It was quite funny.” Laura kept replaying that scene in her mind. She could never talk about it now without crying, she explained when her voice started to break a little, because that day in the hospital, she had seen her whole family unexpectedly gathered together.

Laura saw her brother pacing in the hallway, scratching his head (an anxious habit of his that she remembered from childhood). She saw the expression on each of her children’s faces as they realized they might lose her, and she heard the way her husband called out to her, “*Tone, gial,*” like back in the days when they had first fallen in love, after the hospital staff told them it might be the last time they saw her. Laura wanted to tell them all, “I will be okay, either way,” but she could not talk. Laura said that she would never forget the image she had seen in that moment when the nurse wheeled her through the door of the operating theater: her entire family watching, each one of their faces. “How much they love me.”

That, for her, was the day’s gradual instant. Listening, I realized that my first impulse had been to describe the events with an emphasis on what led to hardship, the accumulations that necessitated the cut. But in Laura’s telling, she focused on the slow care that got her through it. “I wish everyone with this sickness would know, please try to take care.



Laura cooking for her family.

Because it's not just you," she said. "It is your whole family that goes through it with you."

By the end of 2010, Laura had invented a way to turn her walker into a makeshift seat, affixing a blue strap borrowed from another appliance and weaving it through the handlebars. Using this makeshift chair of suitable height to sit by her stove, Laura could begin cooking again, which had once been her profession. Her favorite dish to make had always been *darasa*, a Garifuna word meaning "slow." Laura laughed about this and the slow work she was trying to do for her family—to keep herself healthy enough to avoid the dialysis her doctor said she might need otherwise; to make her mother's and grandmother's family recipes while tinkering with their ingredients; to take the time to shred carrots and prepare vegetables in special ways to bridge tastes. "Look

at my grandbabies,” she smiled to herself, and called out to a four-year-old playing near us. “K, come here love. Do you like broccoli?”

“It’s delicious!” said K, running behind the couch and peeking warily at me over a pillow.

“It’s delicious,” Laura repeated with an amused grin. Her granddaughter was learning to like vegetables for the taste, with no idea yet of the cost of broccoli; or that generations before her had not eaten this recipe; or what her grandmother was trying to protect her from, in the daily labor of making special recipes and shredding carrots into a more tender dish of peels.

“Nothing is sudden,” Anne Michaels writes. “Not an explosion—planned, timed, wired carefully—not the burst door. Just as the earth invisibly prepares its cataclysms, so history is the gradual instant.”⁵⁸ If slow violence is characterized as difficult to discern, slow care might be even harder to see: meal by meal, gesture by gesture. Its culmination is not the moment when something dramatic happens. Its culmination is every day that it doesn’t.

“I will never ask God why,” Laura had said and nodded toward her remaining leg, which she used to consider her worst side because of its two amputated toes. She laughed when she told me of her daily prayer: “Just please leave this one for me. So I can still hop around the house.”

It was such a profoundly humble petition that, eight years later, my stomach knotted when Laura told me over the phone that she had lost the second leg too. It brought to mind the pains she often described and what difficulty she’d already gone through adjusting to the first prosthetic leg that Fede had made her. I wondered what she was going to do, now that the country’s only prosthetic workshop was in transition and unstaffed by a repair person on a day-to-day basis.

Yet when I arrived the next day, trying to hide my dread that I might find Laura disheartened after also losing her “hop around the house” leg she had prayed to keep, the scene was the exact opposite of the tragic immobilization I had imagined. Actually, it was the most nimble and confident I had ever seen Laura. Even when she had both legs, their pain and numbness had meant she walked slowly. Rather than dreaming of a second prosthetic leg this time, Laura said, now she suspected that she no longer needed any prosthesis at all. She was wearing a tight green tank top that showed off her arm muscles. “My son said it looks like I’m going to do yoga,” she laughed of the athletically styled shirt.



The prosthetic leg that Fede made for Laura, now no longer needed.

Her husband made us popcorn, which he had begun selling in plastic bags from his cart some days instead of ice cream.

Laura and I sat on the porch floorboards and listened back to our interview from 2010, as she helped me pick the best parts to highlight here. “You know, it’s amazing for me to hear my own voice,” Laura said when the recording ended. She joked about the old tape recorder we had been listening to play back her words: “I never knew this gadget would be here for me!” I asked if she had anything she wanted to add, these years later.

“This is for any friends or public,” Laura started a bit formally, as she tried to imagine you who might read her words one day and what your reasons were for picking up this book. “It is good to learn from each other, from inside the life of one living it. What is reality? What you can’t change. I’m not hiding away from that. You just have to take care, as much as you can. Right? We must set our minds to what we can do.”

In Laura’s case, what she could do included a combination of strength and balance exercises that began slowly rebuilding her muscles and dexterity, until the day when she was sure she would be able to visit her relative’s house again—even though it had high, steep stairs. But Laura



wanted to surprise her family with the ability she had been honing. She turned down her son's invitation to carry her up into the house. Step by step, Laura did not look down at them watching on the road below, moving up each rise of the wooden stairs by balancing the weight on her palms—steps as slow as the years it takes most anything to change; as difficult, local, and specific as the stairs at home for someone walking on their hands.

When Laura got to the top, she didn't want her daughters to make a fuss if she looked back, so she just called out a little joke to them over her shoulder. Whenever I try to imagine the scene now, her words feel like an open question for all of us:

“Well, are you people coming?”



140. It would take further research to know which species were imported later into British plantations created on Garifuna territory, and which descended from plants growing on that land before the 1796 dispossession.

141. Llewellyn (2013).

142. Grove (1995, 297–308).

143. Anderson ([ca. 1798] 1983, 98).

144. Palacio (2005c, 159).

CRÓNICA FOUR: REPAIR WORK

1. Mika (2015).

2. Appiah (2005, 231).

3. Brown (1996).

4. Jones (2013); see Strebel, Bovet, and Sormani (2019).

5. Star (1999, 382).

6. Jackson (2014); Russell and Vinsel (2018).

7. Manderson and Warren (2016); see Manderson and Smith-Morris (2010); Kleinman and Hall-Clifford (2010).

8. Mol (2008, 20; 2009).

9. Morrison (1987).

10. The movement for “The Right to Repair” (<https://repair.org/stand-up>) holds implications for technologies treating health conditions linked to historical repair (CARICOM Reparations Commission 2013; Coates 2014).

11. Graziano (2016); Rugnetta (2018).

12. Neil (2015, 107).

13. Anderson (2014).

14. Neil (2015, 108).

15. Hanger (2015).

16. Geil (2017).

17. Eveleth (2014).

18. Jain (1999).

19. Johns Hopkins Medicine (2018).

20. Wool (2015); Cavell (1986).

21. The show’s subtitle, “Million Dollar Man,” played on both the military-restoration sci-fi movie *Six Million Dollar Man* and the approximate cost of the prosthetic parts used in the show.

22. Jaipur Foot, Rajasthan, India, jaipurfoot.org.

23. Prosthetic Hope International (2011).

24. Kistenberg (2005, 50–51).

25. Woods (2003).

26. Blakeslee (2009, 1).

27. This estimate is for U.S. hospital-quality models (but lower-quality used machines can be found for much less).

28. All the dialysis described here is hemodialysis.

29. U.S. National Kidney Foundation (2018).

30. 7 News Belize (2009); Ramos (2009).

31. Davita Kidney Care (2018).

32. Hamdy (2008, 2012); see Sharp (2013).
33. Hirschman (1970).
34. This quote by Cruz comes from a television interview with channel 7 News Belize on December 30, 2009.
35. Ramos (2009).
36. Biehl (2016).
37. Nikhil Anand (2017) explores situations where infrastructures reveal the ways different kinds of “pressure” are made by people. People in Belize spoke constantly of rising pressure, which commonly went hand-in-hand with high sugar. In the common phrasing “I have *pressure*,” it was often literally impossible to tell if someone meant blood pressure or social pressure.
38. Channel 5 News Belize (2010); Ramos (2010); 7 News Belize (2010a; 2010b; 2011).
39. I realized later that this sign doesn’t seem to be a bilingual translation after all; the English gives one set of hours, while the Plattdeutsch adds “Open for Mennonites on Friday and Saturday.”
40. Published in Dutch by Thieleman J. van Braght around 1660, this book is a catalog of Christian martyrs that begins from the first century and prominently includes Anabaptist persecutions in the sixteenth century. Along with the Bible, it became a major document for many Mennonite sects.
41. Schroeder and Huebert (1996).
42. Statistical Institute of Belize (2011).
43. Gough et al. (2008, 51).
44. Schroeder and Huebert (1996).
45. Frohlich et al. (2014).
46. Bartlett (2015); Nobel Women’s Initiative (2015).
47. Cuffe (2015).
48. Hayden et al. (2005).
49. Flavelle (2017).
50. Helmreich (2016, xxi).
51. Ramos (2017).
52. Gayle et al. (2010, 134).
53. Ibid.
54. Although Claude Lévi-Strauss (1966) famously envisioned the bricoleur (a figure of constant tinkering) and the engineer (a scientist who lays out design plans ahead of time) in contrast to each other, London Bridges serve as a reminder that such practices and ecologies are not always in easy opposition after all. Sometimes the bricoleur defines the contours of where the engineer will one day work; their practices can be intertwined and cumulative.
55. See Han (2012); McKay (2018).
56. Mitaishvili (2010).
57. I first encountered this quote in Claudia Rankine’s *Citizen* (2014). She noted in a recent interview (Schwartz 2016): “I thought I was writing a book about why things like diabetes and high blood pressure disproportionately affect black communities. I was thinking: What are the stresses that bring these things on? For me, these stresses were connected to the negotiation of racism.”
58. Michaels (1998, 77).