

INTRODUCTION

This book proposes a new way of thinking about health, from daily interactions with biomedical professionals and alternative practitioners to addressing some of the most pressing problems of global health. But the fundamental insights on which it draws did not emerge sitting at a desk or staring calmly at a computer screen, nor are we their originators. They were born in the middle of a terrifying and confusing epidemic in the Delta Amacuro rain forest of eastern Venezuela, forming part of parents' and caregivers' efforts to save the lives of their children. They also emerge from reflections on why the epidemic occurred and why it has never been officially diagnosed and on the unconscionable everyday health conditions that preceded and followed it. And, finally, they were born of a conviction on the part of people who face some of the worst health conditions on the planet that their ideas could play a crucial role in making a healthier and more just world. We accordingly need to introduce the book's contribution by placing it in the context in which it was forged.

The issue is global in scope. As we were finishing the manuscript, Ebola hemorrhagic fever was wrenching apart areas of West Africa. As of 6 May 2015, 26,593 cases and 11,005 deaths were reported in the region.¹ Some observers appealed to cultural logics—projecting West Africans as believing in “witchcraft” and “witch doctors” and impeding the efforts of physicians—in explaining the disease's wide dissemination and substantial case fatality rate.² Others rejected these sorts of cultural logics in favor of structural explanations, reading the epidemic as a symptom of the inadequacy of health infrastructures in the region,³ exacerbated by rising global income inequalities and policies fostered by multilateral lending organizations and First World governments. When experimental drugs and multimillion-dollar treatment modes were used to save the lives of white health professionals from the Global North but not West Africans, perceptions that some lives were judged more valuable than others

abounded. Ebola thus sharpened questions of access to health care, gaps within as well as between countries, as some people have access to organ transplants or drugs costing hundreds of thousands of dollars a year while the lack of cheap vaccines and treatments leaves others vulnerable to preventable and treatable infectious diseases.

Issues of access are indeed an important concern for global health. They were certainly key to incredibly high mortality from cholera in the 1992–1993 epidemic in Delta Amacuro. Caused by the bacteria *Vibrio cholerae*, the disease can be prevented by providing potable water and treated effectively with rehydration therapy, often supplemented with antibiotics. Nevertheless, if untreated, cholera can kill an adult through dehydration in as little as eight hours after the onset of symptoms. Given that reaching a clinic with a resident physician in an unmotorized canoe could take over a day, access to health care was crucial.⁴ As commonly happens in epidemics (Rosenberg 1992), cholera X-rayed everyday inequalities in the region: nearly all deaths occurred in the population that is racialized as indigenous, specifically as the Warao ethnic group. These deaths came on top of what epidemiologists in the region refer to as the normal deaths from diarrheal and other diseases, including the staggering current figure of 26 percent child mortality (0–5 years).⁵

But when another epidemic began in July 2007, the deaths could not be as easily explained by questions of access to health care. This epidemic came in the midst of a socialist revolution. Starting in 2003, President Hugo Chávez Frías's Bolivarian revolution championed the health of low-income Venezuelans—the majority of the population—as a major priority. Ending decades in which access to public health eroded, most low-income neighborhoods in the country soon boasted a small health care facility, often staffed by a Cuban doctor. In the 2007–2008 epidemic in the delta, most of the patients were treated by a local nurse and taken to a clinic staffed by a resident physician. When he couldn't figure out what was killing his patients, the doctor sent them to the hospital in the state capital, Tucupita. Most were then transported to tertiary care facilities, where they were treated by specialists in the intensive care unit. Epidemiologists came to investigate, but they never determined the cause. No one was denied care, and no one was charged a dime. Nevertheless, the mysterious disease killed 10 percent of the population in one small settlement, Muko-boina. Some families lost two or three children. No one in the region had ever seen cases of the disease that caused this epidemic. Cholera was comparatively easy to diagnose, but the 2007 epidemic stumped doctors, nurses, epidemiologists, and healers. The underlying question thus shifts: despite significant

improvements in access to care for Venezuelans, why did so many die in 2007–2008, and why did the disease elude diagnosis?

A crucial clue to unlocking the mystery—and to addressing key problems of global health more broadly—was provided by the parents’ incessant demand, “Tell me why my children died.” They still pose this challenge to doctors, nurses, health officials, healers, epidemiologists—just about anybody who will listen. It has, as they stressed, two components: First, they demand to tell their stories, to relate their efforts to save their children’s lives. They were constantly observing symptoms and how patients responded to healers’, nurses’, and doctors’ treatments. They thought insistently about what was going on and anything strange that might have preceded the illnesses. Their demand entails having their contributions taken seriously, sharing in solving the puzzle. Their insistence that people listen to what they have to say also involves recognition that their children’s lives had value and that their deaths matter to more than just their relatives.

The second dimension of their challenge requires sharing: they asked doctors, epidemiologists, healers, and health officials to tell them what they had learned about the disease. The parents answered clinicians’ questions and provided details requested by epidemiologists, but few health professionals deemed them worthy of a response, even to say, “We don’t know, but this is what we are thinking.” Or simply to say, “We’re sorry your children died.” “Tell me why my children died” thus constitutes a demand for dialogue, for a laterally organized and collaborative exchange of knowledge. What is at issue here is not a liberal, even paternal, gesture, an extension of empathy in the face of suffering. Given that the disease had never appeared before, pooling knowledge would seem to be a rather good idea. And, more generally, even when diagnoses are easy to come by but successful strategies for stopping preventable diseases and deaths are hard to find, breaking the monopoly held by “experts” who produce what they believe to be the only valid forms of evidence might open up exciting new possibilities for addressing global health problems.

When the children kept dying and health professionals did not respond to their overtures, the parents recruited two local leaders, brothers Conrado and Enrique Moraleda. Their deceased brother, Librado, had been one of the most respected indigenous leaders in Venezuela. Serving as the president of the health committee for the local clinic, Conrado listened to the parents’ stories every time they brought their children for treatment. He realized how much knowledge they had to share and how their offers to share it had been rebuffed. They pressed him to approach the director of the Regional Health Service (RHS) in town, tell him about the epidemic, and request a more ambitious

response. Conrado made the trip several times. After a second wave of deaths began in January 2008, the parents grew more anxious and angry; Conrado then bypassed health authorities, demanding a hearing with politicians and journalists. Health officials responded angrily; they discredited Conrado and the parents through rumors circulated in town, radio broadcasts, and articles in the local newspaper.

Try a thought experiment for a moment. You devote all of your resources—and place yourself deeply in debt—trying to save the life of your child. You go to every type of caregiver you can find, trying to figure out what he or she has to offer, and supply the requested information, in the language of the practitioner. Nevertheless, none have more than passing interest in what you have to say, and some denigrate what you have said and done. When one fails, you look for another. You end up in a strange city, your dying child surrounded by machines; you lack anywhere to sleep or resources to buy food. And then your child dies. Just as you return home to bury her, your parents tell you that another of your children has come down “with the same disease.” Then you learn that doctors in the city are blaming you on the radio and in the newspaper for negligently killing your own children, by feeding them garbage or poisonous fruit or fish or intoxicating them with lead or mercury.

Reading these articles and listening to the parents’ angry responses convinced Conrado and Enrique that the root of the problem, in the epidemic as much as in everyday death in the delta, did not lie with pathogens alone or the availability of health care but also fundamentally involved the production and circulation of knowledge about health. In 1992, health officials adopted a two-pronged strategy for dealing with the cholera epidemic. At the same time that they contained the spread of the bacteria, they countered political fallout generated by extensive national press coverage by claiming that the problem was not unhealthy health policies—the failure to provide potable water, sewage facilities, or adequate health care—but “the culture of the indigenous Warao ethnic group.” As a result, the stereotype of “the Warao” that persisted right into 2007 was of a homogeneous population incapable of understanding what doctors say or participating adequately in caring for their own lives or those of family members, let alone contributing useful knowledge.

When a third wave of cases beginning in June 2008 was met with silence on the part of public health officials, the Moraledas decided that it was time to take action themselves against both the disease and the persistent lack of a response to the parents’ demands. They began to connect the dots, perceiving how deeply the failure to value the voices of delta residents in clinical consul-

tations, epidemiological investigations, and demeaning news stories lay at the center of both the failure to come up with a diagnosis and how the RHS was structured. If this pattern shaped the epidemic, the failure to diagnose it and the lack of concerted action on the part of public health officials required a bold effort to overturn public health business as usual. Deciding to form their own investigation, Enrique and Conrado recruited the two of us, healer Tirso Gómez, and nurse/EMT Norbelys Gómez. A novel type of collaborative work emerged, one that placed indigenous knowledge production at its core. Soon the parents' testimonies clearly revealed that the symptoms, not to mention the 100 percent case-fatality rate, lined up squarely with rabies and correlated with the incidence of nocturnal bites by vampire bats.

This book is not just an epidemiological thriller, a Sherlock Holmes–style narrative that reveals a viral killer. It rather explores other dimensions, ones that have implications that extend beyond the temporal contours of this particular epidemic and the delta's riverine geography. We are rather interested in how a socialist revolution, persistent ethnoracial inequities, relations between humans, viruses, bats, cats, chickens, trees, and other nonhumans, and interactions between parents, children, healers, physicians, nurses, epidemiologists, and journalists came together in producing an epidemic and impeding the collaborative knowledge exchange needed to diagnose it and stop it. Building on critical insights that emerged in the epidemic, our broader goals include diagnosing health and communicative inequities, analyzing their central role in creating health inequities, and reflecting on the call for justice pioneered by delta residents.

From Lay Labor in Health to Health/Communicative Labor

Two central features of the medicalization of health are the equation of clinical institutional sites with the labor of care and the identification of biomedicine as the locus of knowledge production in health. Even Annemarie Mol (2008), who envisions care as emerging collaboratively between patients and providers, identifies the clinic as the site where “the logic of care” unfolds. Argentine Mexican medical anthropologist Eduardo Menéndez (2009) rather explores ethnographically how clinical medicine depends on the labor of care performed by laypersons outside clinical settings. What scholars have missed is that the labor of care is coproduced with the labor of communicating about health, much of which is also performed by laypersons outside of clinical settings. Connections between care and communication have most commonly

become visible to scholars and practitioners in the realms of “doctor-patient interaction” and health communication, but the epidemic and the way that the parents and the Moraledas responded to it revealed how other sites—such as epidemiological research, news coverage of health, and policy discussions—are involved and how deeply they are connected, if in precarious and shifting ways.

Who gets the credit for and who becomes invisible or gets blamed for the labor of care and communication follows the lines of professional hierarchy, but its distribution also parallels ethnoracial and class-based health inequities in complex and consequential ways. A landmark study by the esteemed Institute of Medicine hit upon this connection in seeking to explain why African American and Latino/a patients receive inferior treatment compared to Caucasians in the United States. It pointed to clinicians’ perceptions that patients classified as members of these populations will be less capable of understanding diagnoses and treatment recommendations and less able or willing to turn this knowledge into behavioral changes as one factor that prompted clinicians to recommend less favorable treatments (Smedley, Stith, and Nelson 2002). By scrutinizing assumptions about the quality of the patient’s labor of care and communication, this finding points to how health and communicative inequities are tied at the hip. Clinical medicine, once again, is not the only place where these inequities are coproduced: health/communicative inequities are inscribed deeply within health education and communication, epidemiology, public health policy, and news coverage. These health/communicative inequities reconfigure structural factors as the projected inadequacies of ethnoracial minorities in health communication.

Health infrastructures do not rely on cables, computers, CAT scans, record systems, software, and the Internet alone but also on the forms of communicative labor that situate people in relation to them. Health-related roles, including those of parent and child, physician and patient, are relationally defined, that is, constructed in relationship to one another on the basis of their difference. These positions are certainly constituted through care—who gets to touch whose body and use technologies like thermometers and stethoscopes in particular ways and administer or prescribe medications—but they are also defined through communicative labor. Learning to play the “sick role,” in Talcott Parsons’s (1951) terms, or that of the patient (Harvey 2008) involves learning when to call 911 and when to ask a receptionist for an appointment, how to talk about symptoms, how to answer receptionists’, nurses’, and physicians’ questions, how to listen to diagnoses and treatment recommendations, and much more. The Institute of Medicine study suggests that medical outcomes depend not only on access to care or even how well individuals learn to play the

patient role but whether clinicians give them credit for mastering these complex ways of performing biomedical literacies. A major focus of health journalism is providing advice regarding how to be an active patient who brings information to the doctor, asks questions, and helps shape decisions about treatment. Pharmaceutical ads teach television viewers to “ask your doctor if [a particular medication] is right for you.” Parents are instructed in how to speak with their children about drugs, drinking, and sexually transmitted infections. Medical schools teach physicians not just how to talk with their patients but how to circulate medical information through notes, records, tests, and consultations with other health professionals (Cicourel 1992; Good and DelVecchio Good 2000). The complex forms of communication related to obtaining authorization and reimbursement from government agencies and insurance companies not only constitutes a great deal of the labor that professionals and patients alike devote to health in some countries but also fundamentally structures care—to the chagrin of many physicians and patients. Research suggests that ignorance and confusion are sometimes hardwired into such health services as Medicaid to cut costs by limiting how much people can overcome forms of “bureaucratic disenfranchisement” generated by “withholding information, providing misinformation, . . . and requiring extraordinary amounts of documentation” (Danz 2000: 1006; see also Horton 2014; López 2005). Looking closely at how the roles of caregiver and patient are relationally defined suggests to us that forms of health and communicative labor are deeply entangled and fundamentally out of sync, simultaneously crucial for enabling the work of care and constituting one of its fundamental obstacles.

A major reason that the importance of this nexus has been so seldom perceived is the commonsense opposition—largely reproduced by scholars—between media and communication versus the domains of science and medicine. Challenging this perspective, we follow Jesús Martín Barbero (1987) in suggesting that constructing “the media” or communication as a separate arena that exists apart from the spheres they seemingly represent should not be a presupposition that shapes our analytical framework; we should rather document ethnographically how, when, and why this category emerges and in opposition to what. This binary is particularly evident in news coverage of health issues, to which we return below. Scholars generally invoke health news only in extracting what seem to be transparent windows on popular perceptions; health professionals complain about how journalists sensationalize or distort medical issues, thereby relegating them to a sphere of “the media” that seems to exist apart from how these objects come into being and get imbued with value. Such treatments fail to take into account the pervasiveness of health news:

consuming health-related media forms, including direct-to-consumer advertisements, and ingesting pharmaceuticals and dietary supplements compete for being the most pervasive ways that health is woven into daily routines. Science-technology-society (STS) studies researchers almost never include journalists in the actor networks of scientists, politicians, microbes, technologies, and infrastructures they study. The epidemic revealed what scholars miss: that narratives circulate between news stories, clinical encounters, complementary and alternative medical practices, epidemiological investigations and reports, and health policy debates in complex and consequential ways. Again, sensing that health news can both reflect and extend health inequities, thereby buttressing unhealthy health policies, Conrado and Enrique turned their investigation of the epidemic into an alternative media strategy, one designed to produce medical and communicative justice.

The communication versus medicine binary also enters in other sites in which communicative and health inequities come together. Elliott Mishler (1984) and Howard Waitzkin (1991) argue that communicative inequities structure doctor-patient interaction in ways that thwart diagnosis and treatment; Brad Davidson (2001) details how medical translation can widen these gaps. Deborah Lupton (1994) and Mohan Dutta (2008) point to how fundamental inequities are built into dominant perspectives and practices of health communication, thereby turning efforts to overcome health inequities into key sites for extending social hierarchies. Clive Seale (2002) argues that health news similarly projects health communication as a hypodermic injection of knowledge into the minds of ignorant lay audiences. Herein lies the reason that we do not use the term “health communication” to frame our work here. What Dutta and others refer to as hegemonic perspectives in health communication imagine a linear, hierarchically structured process by which information produced by biomedical specialists—including scientists, clinicians, and epidemiologists—is transformed by health communication specialists into lay language and then transmitted to laypersons. Reproducing the media/medicine opposition thus excludes journalists, health promoters, and doctors and nurses—in their work of talking to patients—as well as laypersons as producers of knowledge. We accordingly introduce a new term, *health/communicative inequities*, to suggest how knowledge about health is coproduced by health and communication professionals and laypersons in a broad range of sites. We go beyond simply looking at both communicative inequities and health inequities to analyze how they emerge simultaneously, one powerfully shaping the other and often exacerbating its effects.

Even as researchers have explored how “neoliberal” or market-oriented restructurings of health and other institutions increase inequities by projecting normative models of rational, self-knowing, and self-interested subjects (Adams 2013b; Clarke et al. 2003; Rose 2006), João Biehl (2005) carefully documents how even progressive efforts to extend access to health care—mainly in the form of providing pharmaceuticals—can create “zones of abandonment.” Critical epidemiologists (Breilh 2003) and social epidemiologists (Krieger 2011) scrutinize the way that epidemiology can turn assumptions and forms of social classification that reflect the position of dominant sectors into what seem to be objective, statistical measures of the distribution and causation of disease.

One of the central contributions of this book is to bring concerns that have largely been viewed in isolation into dialogue by ethnographically documenting how health/communicative inequities are coproduced in clinical encounters, epidemiological investigations, media coverage, and the development of health policies. By challenging the boundary-work (Gieryn 1983) that patrols borders between “health” and “communication,” we demonstrate how health/communicative inequities structure care, epidemiology, journalism, and public health. We detail the different forms that these inequities take in each context, demonstrating how they form the social glue that connects sites as bodies, narratives, and reports accumulate, juxtaposing more and more extensive and complex assemblages. The parents’ narratives that we highlight here focus as much on the health/communicative labor they performed as the work of care they undertook in trying to keep their children from dying. Breilh (2003) argues that documenting health inequities is not enough: we should go on, he suggests, to analyze how they are produced. We argue here that health/communicative dimensions play a central role in producing health inequities, as much in rich, industrialized countries as in those in which incomes and health services are more limited.

Failing to analyze health/communicative inequities limits research on the production of health inequities and bolsters the many ways that they come to feel like natural, inevitable features of contemporary life. In asserting demands for health/communicative justice, the parents and our fellow team members demonstrated that justice in health can only be achieved when efforts to challenge health inequities go hand in hand with more democratic health/communicative practices. Moreover, the labor of care and health/communicative labor are also often entangled and out of sync in situations that are not directly structured by marked inequalities. Thus, even as we are positioned in

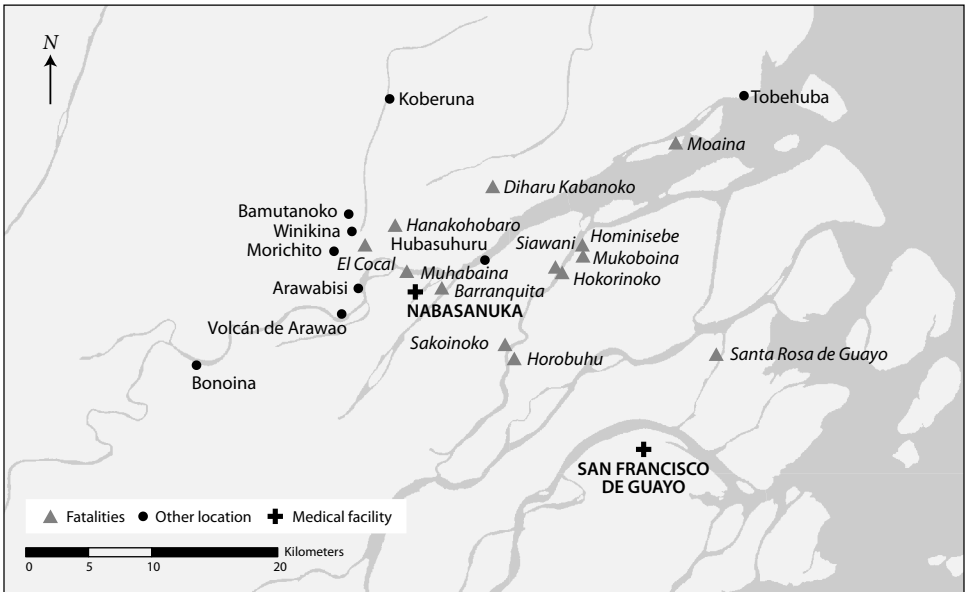
economies of the labor of care and health/communicative labor in different ways, this problem affects us all.

*“Mystery Disease Kills Dozens in Venezuela”:
An Overview of the Epidemic*

A mystery disease has killed dozens of Warao Indians in recent months in a remote area of northeastern Venezuela, according to indigenous leaders and researchers from the University of California at Berkeley, who informed health officials of the outbreak on Wednesday.—*New York Times*, 6 August 2008

Given the complexity of the events that unfolded, a brief, chronological summary might help. The following overview encapsulates what happened, how people tried to diagnose the disease, and the work of the team that Conrado and Enrique organized. In July 2007, a strange disease appeared in Mukoboina, a settlement of some eighty persons located in the delta of the Orinoco River, the third largest in South America, near where the river enters the Caribbean next to Trinidad (see map I.1).⁶ In Mukoboina, houses are open-air structures with thatched roofs built on stilts above the river and swampy land (see figure I.1). People call themselves Warao, claiming membership in a population that has lived in what is now Delta Amacuro State since before Columbus first stumbled onto the South American mainland in 1498. Residents speak an indigenous language, similarly called Warao; some also speak Spanish. There is no clinic, school, or other services. One by one, children developed fever, headache, and body aches. Parents took them to see Mukoboina’s leader, Inocencio Torres, who is a healer. When he could not figure out what was wrong or stop the symptoms, they turned to a nurse practicing in a nearby settlement and other healers, but all failed. Strange symptoms appeared—a tingling sensation in the legs, followed by numbness and paralysis. The children stopped eating; then they couldn’t drink. They sometimes had strange hallucinations and bouts of anxiety.

During this period, a team of nurses made a routine visit while vaccinating for childhood diseases. Ronaldo Domínguez, coordinator of the nursing program for the local Antonio Díaz Municipality, examined one of the Mukoboina patients shortly before he died. Seeing that something strange was going on, he returned several times in the following days while vaccinating nearby. When another child became ill, he, like the local healer and nurse, urged the parents to take the boy to the Nabsanuka clinic some forty minutes away by motorized canoe or several hours by paddle; it was staffed by bilingual nurses and a newly graduated doctor.⁷ Hooking up IVs, the staff tried analgesics to stop the child’s intense pain, antipyretics to lower the fever, antibiotics to treat



MAP I.1.1. Area where cases were concentrated

a possible infection, and more. But nothing worked, and another child died. When the next patient appeared, an eleven-year-old boy, the doctor sent him to the maternal-pediatric wing of the hospital in Tucupita. Physicians there could not figure out what was wrong, and soon the symptoms worsened. They transported the boy by ambulance to Maturín, a larger city several hours away, which boasted more advanced care, where he was placed in the intensive care unit. The results, however, were the same—death without diagnosis.

All in all, seven Mukoboína children between three and eleven years of age died in July–September 2007 and one more the following January—some 10 percent of the population. Four children died in nearby settlements in September and October and four more in January and February 2008, all with similar symptoms. Taking their children to town imposed new forms of anguish on parents—once there, they had no place to stay and little or no food or money, and generally felt ignored and mistreated by the hospital staff. Back in the delta, many parents stopped taking their children to the clinic, even for easily treated diseases.

As president of the local health committee in Nabasanuka, Conrado Moraleda visited the clinic each time a new patient arrived and kept an eye on his or her progress. Like the nurses, he first heard about the initial deaths through



FIGURE 1.1. Houses in Mukoboina, 2010. Photograph by Charles L. Briggs.

what is jokingly called Warao Radio, the passing of news from mouth to mouth, settlement to settlement. Conrado then saw what happened when patients reached the clinic; he listened to the doctor and nurses tell how the disease baffled and worried them. Starting just after the first cases reached the Nabasanuka clinic, Conrado repeatedly visited the director of the RHs and the regional epidemiologist in Tucupita; he expressed concern about the situation, related that residents were terrified, and asked for action. The regional epidemiologist and a Cuban epidemiologist affiliated with the Mission Barrio Adentro program visited Mukoboina in September 2007. They obtained detailed data on the children who had died and the households in which they lived. They filed reports that presented several hypotheses but reached no conclusion as to the cause of the disease. After one more child died in October 2007, the strange disease seemed to go away, and nothing further was done.

Then five more children died in January and February 2008. Parents, nurses, and local leaders believed that the regional government in Tucupita was indifferent. Conrado joined parents of the dead children and nurses

in trying to press the regional government to act. Traveling to Tucupita, they asked sympathetic members of the Legislative Council to hold a public hearing, resulting in embarrassment and anger on the part of RHS, which then conducted a large epidemiological investigation. Jesús and Lizandro died in El Cocal in March and April, but then the disease seemed to disappear again.

June 2008 ushered in a new wave of deaths over an even wider area, including eight in Santa Rosa de Guayo to the southeast, three in Muaina, a settlement near the coast, and one around the corner from Nabasanuka in Barranquita—seventeen deaths in three months (see map I.1). Local leaders were frightened and furious, and their anger focused on Conrado and other activists, blaming them for failing to force the government to act. Conrado and Enrique hatched a bold plan—they would compile their own data and then bypass the state government and go straight to Caracas. But without documentation or a diagnosis, it would be hard to get a hearing. That's why Conrado and Enrique almost literally pounced on us when we arrived in Nabasanuka on 24 July. They weren't looking for outsiders to tell them what to do—they had had enough of that. Rather, they thought that a physician and an anthropologist with whom they had worked for decades might be of some value. They also recruited an indigenous nurse, Norbelys Gómez, and a healer, Tirso Gómez.

Our six-person team traveled in a small wooden boat throughout the entire region, visiting thirty settlements (figure P.2). We located fourteen places in which someone had died from the disease. In each, we set up meetings in which parents who had lost children, local representatives, nurses, and other people could tell us their versions of what had happened. Many located the deaths within the broader context of hunger, social conflict, exploitation by businesses operating in the area, ecological change—whatever they felt was important. Our goals were twofold: first, because we had no idea what disease was afoot or exactly when it had started, we wanted to cast a wide epidemiological net—to collect any potentially relevant detail. Learning, as we did, that all of the chickens had died a year earlier or that many people had adopted cats might be irrelevant—or might be crucial to solving the mystery.

We sought, second, to provide a more substantive response to the parents' demand, "Tell me why my children died." Anger, pain, and fear were rampant. Even when epidemiologists and public health officials had visited, as in Mukoboina, people did not feel heard, never gaining the sense that their questions and observations had been taken seriously or their grief acknowledged. They wanted answers, but they also wanted public recognition of their loss and their struggles to keep their children alive. Listening to their stories, recording their



FIGURE 1.2. Clara, Enrique, Conrado, and Eumar (from left to right) view map of Manuel Renault Parish while planning the team's investigation, 2008. Photograph by Charles L. Briggs.

perceptions, thinking with them about what could be happening, and just plain saying that we were sorry that their children had died was important. Enrique asked Charles to photograph each parent, resulting in the images that emerge in these pages, and to videotape as much of the work as possible.

When relatives asked Clara and Norbelys to examine Elbia Torres, whose husband had just died, we came face to face with the disease. Now there was clinical information to complement the “verbal autopsies,” the parents’ accounts of their children’s illnesses. This enabled Clara to reach a presumptive diagnosis, which would have to be confirmed by laboratory tests: clinically, the disease seemed to be rabies. And if rabies was the disease, there was no cure, so all Clara and Norbelys could provide was palliative care; visiting Elbia twice a day, they eased her pain as we supported her relatives.

By the time Elbia died on 2 August, the team had compiled detailed information on thirty-eight cases. Using a laptop computer in a house deep within the rain forest, we pulled data from handwritten notebooks and fashioned them into a spreadsheet and a report. Conrado, Enrique, Norbelys, and Tirso wanted to stop the epidemic, but they also wanted to fundamentally change the way Delta Amacuro State's government treated the people they classified as indigenous. The report and photographs would demonstrate that delta parents care deeply about their children, that indigenous people had important knowledge about health to share, and that residents had the right to participate fully in the design, implementation, and evaluation of health programs. Our work was interrupted several times as we returned to participate in Elbia's wake and funeral; the sounds of her parents' laments and the hammer nailing her coffin shut rang in our ears each time we returned to the task of writing.

The team showed up on 6 August in the lobby of the national headquarters of the Ministry of Popular Power for Health in downtown Caracas. We made it clear that we were not trying to embarrass the government but were all supporters of President Chávez who were looking to present high ministry officials with a report that would assist them in addressing a health crisis. It was a fiasco. We were greeted by security guards, not the minister. They told us to go back to the delta—that we should never have left. Officials refused to meet with us or even accept a copy of our report. Reporters for the *New York Times* and *El Nacional*, a national newspaper aligned with the anti-Chávez opposition, witnessed the standoff. Finally, Conrado, Enrique, Norbelys, and Tirso were allowed to meet with the national epidemiologist. The six of us became a cause célèbre, appearing in newspapers around the world and on the government's two television stations, applauded as heroes by many Chávez supporters and members of the opposition alike. At the same time, however, national and regional government officials were pulling out all the stops in attempting to discredit us. They declared variously that there was no epidemic, that it was smaller than we stated, that we had confused the disease with "normal" diarrheal infections, that the real problem was "Warao culture," and even that it was all dreamed up "by an agent of the Empire" (referring to Charles's status as a U.S. citizen). We were harassed and threatened with incarceration. Commissions were sent to the delta, but their major goal was to prove us wrong; they never publicly presented an alternative diagnosis or took significant steps to address the underlying health issues.

In the end, officials simply erased the entire affair: Chávez's socialist government defended a regional administration affiliated with the United Socialist Party of Venezuela (PSUV) rather than standing by its commitment to provide

health care to low-income Venezuelans and countering discrimination against indigenous people. The parents were forgotten. Officials forbade nurses to talk about health conditions or strange diseases with anyone other than RHS supervisors—and particularly not with reporters or researchers. Conrado, Enrique, Norbelys, and Tirso were threatened, warned to keep quiet and stay out of sight. They expressed deep discouragement and some bitterness that their leadership and aspirations for a better world had sparked only official contempt and denial. Meanwhile, to this day the parents continue to demand, “Tell me why my children died,” and to press the six team members to keep the memory of their children’s lives and deaths circulating—“We want lots of people to know!” Conrado, Enrique, Norbelys, and Tirso keep insisting that what we did involved more than the epidemic itself, that our efforts demonstrated that people who face acute health inequities can lead the way to a healthier and more just world. We collaboratively produced a memoir in Spanish, *Una enfermedad monstruo: Indígenas derribando el cerco de la discriminación racial en salud* (A monster disease: Indigenous peoples breaking down barriers of health-based racial discrimination), aimed at readers who face similar health problems and policymakers. The present book rethinks the epidemic from a variety of participants’ perspectives and focuses on the relationship between health and health/communicative inequities, bringing a range of analytical tools to the task of sorting out what happened and reflecting on its broader implication.

*Narratives, Knowledge, Mourning, and Biomediatization:
Forging New Points of Departure*

Such a simple, linear, straightforward narrative of the epidemic was never told in the delta from start to finish, with all participants and places woven together and without the narrative being interrupted by fear, anger, and uncertainty or by accusations and recriminations. If this book simply retold the story in this manner, it would place us in the position of omniscient narrators and clairvoyant analysts, turning patients, parents, local leaders, doctors, nurses, healers, and epidemiologists into characters in need of our assistance in order to render their thoughts and actions transparent. Such a book would simply reproduce the health/communicative inequities that helped give rise to the epidemic and amplified its destructive effects. Our approach is rather to unsettle established ways that scholars, practitioners, activists, and others think about health inequities and open up new possibilities.

Our efforts to slow down conventional approaches takes several forms, two of which are primary.⁸ In part I—which focuses on the participants’

lenses—we complicate and fragment this story, bringing out the uncertainties and contradictions, the links and gaps between ways that different participants tell the story. We start with the perspectives of parents who lost children in the epidemic, following their efforts to save them, their observations, and their views of the healers, nurses, and doctors with whom they collaborated. Their stories reveal how intimately their labor of care was woven together with that of health/communicative labor, as well as the obstacles they faced in attempting to foster exchanges of knowledge that could have yielded a diagnosis and a way to save their children. As the stories build on one another, they can feel relentless, unnerving. Our writing here is deliberate. During each of the three waves of cases, the epidemic produced a feverish, chaotic, frightening avalanche of stories, bodies, and encounters with healers, nurses, doctors, hospitals, and coffins. For parents who lost more than one child, their own stories seem to haunt them at each step as they started to be repeated even as the principal character shifted to a second—or third—child.

We then consider the perspectives of doctors, nurses, and healers. Some physicians and nurses may initially be taken aback at having their stories placed in dialogue with those of vernacular healers. We mean no disrespect; indeed, Clara herself is a physician, even as Charles was trained as a healer in the delta. In juxtaposing healers, nurses, and physicians, our point is not to suggest that they share a common lens. Rather, we explore the differences and similarities in how they faced the enormous challenge of diagnosing the mysterious disease and trying to save patients. One common thread between them is that none succeeded in diagnosing the disease or saving patients, and we explore the diverse affective trajectories that shaped their responses.

We then join the individuals—mostly physicians but also nurses and other professionals—who looked at the disease epidemiologically, trying to find forms of evidence and patterns that would help them figure out what the heck was going on. Listening to their stories also entails reading the reports that they drafted. We listen to them as they try to balance their drive to find a diagnosis with public health officials' efforts to limit potential political fallout from the epidemic. Eventually, the disease rose to prominence in the regional, national, and international news media, and the last lens we follow is that of journalists. We focus in particular on the two individuals who were most involved in reporting on the epidemic, one who worked for the local newspaper and the other a leading health reporter for a national, opposition newspaper and a national radio network. Rather than singling out the work of journalists, we look closely at how their professional ideology and practices were woven into the fabric of public health, electoral battles, and social movements.

In part I, our writing takes on an experimental edge. Beyond disrupting a single, linear, definitive account of the epidemic, we place readers in the middle of the work of care (and epidemiology and journalism) and of health/communicative labor as they unfolded during the epidemic. We have tried to avoid presenting any perspective as being more exotic, rational, commonsensical, or authoritative than any other. We do not project the members of any class of practitioners as sharing a homogeneous perspective: no two parents, physicians, nurses, healers, or epidemiologists reacted identically. Nor were individuals themselves always consistent. In the case of the resident physician in the local clinic, for example, there seemed to be two Dr. Cáceres, two voices in one body, and we tried to let both of them emerge.

Entering someone else's head and revealing what transpired there is tricky, particularly when we must rely on memories and interpretations that themselves change over time as controversies emerge, stories circulate, and conversations unfold. Indeed, we could not claim to be able to reveal transparently the contents of even our own hearts and minds during the epidemic; these events were challenging and confusing for us too, as much emotionally as conceptually. We cannot offer clairvoyance, only honesty and a certain depth of familiarity that follows from having worked in Delta Amacuro and having known many of these individuals for decades and from tracing the resonances and the discrepancies between their accounts.

After engaging the frenetic pace of the epidemic in part I, we focus on slowing it down, analytically, in part II, on disrupting and reconfiguring the frameworks that scholars, practitioners, and laypersons bring to thinking about these issues. Unraveling the many mysteries that unfolded and exploring what they can teach us requires a complex work of unwriting the story even as we write it, of challenging the commonsense categories— notions that are widely accepted, without reflection, as being just the way things are—that shape these issues. Each chapter in part II unravels a particular set of prevailing frameworks in order to open up new possibilities.

Chapter 5 breaks new ground by rethinking the relationship between care and narration. Scholars often position narratives in their accounts as providing a window on how the narrator—such as a patient, relative, or practitioner—thinks about a disease or treatment. The rich social scientific and medical literature on doctor-patient interaction views patients' efforts to tell a story about their illness as aiding the diagnostic process and establishing a supportive clinical relationship. Arthur Kleinman (1988) argues that a physician's willingness to grasp patients' lifeworlds and understandings of illness through the narratives they tell lies at the center of patient-centered medicine. Good and DelVecchio

Good (2000) note that becoming “competent” as a physician is intimately caught up with learning to tell particular types of stories about patients, oneself, and other doctors; medical students are thus taught to overlook details that are not deemed medically relevant and to position the particulars they do use within medical narrative structures.

Even approaches that celebrate such stories generally place narration outside the realm of care; like Linda Garro and Cheryl Mattingly (2000a), we rather focus on how the two are intimately entangled. Drawing on Menéndez’s attention to forms of care that are provided outside the clinic, we examine how care was entangled with the work of narration in complex and consequential ways in each site where it unfolded, including the anticipation of how that particular moment would be carried forward narratively. For the parents, narrating and the work of care emerged simultaneously with each touch, observation, treatment, and trip. Except for the parents of the first child to be infected, their stories—and their perceptions of symptoms—started with other stories of children taken by the strange disease; narratives thus tied their children’s bodies to other diseased bodies and the forms of care they received. The parents’ labor of storytelling thus did not simply report on their labor of care but formed a crucial part of it. In clinics, hospitals, and encounters with epidemiologists, however, health professionals reduced their narratives to answers posed to their own questions; they excluded this rich archive of observations and the forms of care provided by the parents and other caregivers they had recruited from entering clinical spaces.

In this book, we point out how placing narration at the center of care requires a rather different work of documentation. These stories did not emerge exclusively in clinical spaces; epidemiologists, journalists, and local leaders told stories about the epidemic. Moreover, stories were not confined to particular contexts but rather circulated broadly through Delta Amacuro State. Public health officials spent at least as much time trying to stem, channel, and transform the circulation of other people’s stories about the epidemic in clinical settings, epidemiological investigations, and newspapers as in telling their own or undertaking other types of interventions. By deciding when the story began and when it ended, the places in which it unfolded, who constituted characters, and what types of actions and perspectives were included, narrators tried to shape what would count as evidence and what types of explanatory logics could be used.

Our goal is not to add to the body of research that celebrates the place of narratives in medicine and healing. Having professionals interrupt and discredit their stories and hearing stories told by health authorities that turned them into inadvertent murderers of their own children greatly deepened the parents’

pain and anger and augmented its persistence, right through the present. The problem was not a shortage of stories any more than it was a shortage of access to health care. The challenge here is to broaden the analytic lens beyond the usual attention to how narratives circulate in one site, generally a clinical one, to think about why this hypercirculation of narratives impeded diagnosis and more productive modes of collaboration. When the team created a context in which everyone could speak, different types of stories and other genres could be brought into dialogue, thereby expanding evidentiary frames and juxtaposing perspectives in ways that facilitated collaboration in producing a diagnosis. This experience thus opens up possibilities for thinking about new types of relations between narration and care.

We did not find this project—it found us after we returned to the delta to collaborate on a health project. After we acceded to Conrado’s and Enrique’s insistence that we join their project, the team’s work did not begin with interviews or clinical examinations. Invited to participate in a meeting, Tirso, Norbelys, and the two of us showed up shortly after dawn one morning in a small coastal settlement to find a group of mourners gathered around the body of a young man, Mamerto Pizarro. They were singing laments, acoustically and affectively charged songs in which mourners collaboratively remember the dead and decry the loss. Our work thus began not with epidemiological reports, clinical narratives, and the stories about the epidemic that circulated through the lower delta but with a very different genre. As Enrique put it later, “We wanted each word spoken about the epidemic to connect with the sounds of [Mamerto’s] relatives’ wailing.” The lamenters framed the investigation that was beginning that morning as part of their work of mourning.

This phrase comes from Sigmund Freud’s classic essay “Mourning and Melancholia.” In chapter 7, we build a dialogue between ways that psychoanalysts and the lamenters have thought through the complexities of mourning. Collectively composed and performed songs asked tough questions about not only the physical death of a young man but also the social deaths of the people who died in the epidemic: the apparent lack of acknowledgment by government officials that their lives were of sufficient value to require public recognition and more concerned action particularly troubled lamenters. Even as we use psychoanalysis, anthropology, and public health to think about how relatives mourned the individuals who died in the epidemic, we ask how these fields might be transformed by reconfiguring them as part of the work of mourning, meaning not just responses to physical death but to demands for collaborative knowledge production and epistemological openness. In a number of fields, researchers have stretched beyond the borders of academic research to think about how

their work can respond to critical situations that emerge in contemporary life; these include Latin American social medicine and critical epidemiology, popular epidemiology, community-based participatory research in public health, and public or engaged anthropology, to name just a few. We ask how this call to join the work of mourning—not just in response to physical death but to demands for acknowledgment that all lives and deaths matter—might enable scholars and practitioners to sharpen analytical frameworks, broaden modes of investigation, and increase the impact of their work.

All parties wanted to stop the deaths, and everyone agreed that knowledge was needed to identify the disease and figure out how to end the epidemic. Parents, their neighbors, local leaders, nurses, doctors, healers, epidemiologists, and others all actively sought to produce knowledge while the children were dying; some persisted when new cases were not appearing and even after Elbia Torres Rivas—the epidemic’s last fatality—died on 2 August 2008. But why did so much knowledge fail to produce a diagnosis? Why is the epidemic still officially undiagnosed? This problem raises issues faced by researchers in a number of disciplines. The STS scholar Bruno Latour analyzed how scientific practices, technologies, and forms of writing enable knowledge to circulate (Latour 1999), as quintessentially embodied in “immutable mobiles,” objects of knowledge ideally capable of traveling anywhere without shifting reference or losing significance (Latour 1988). Nevertheless, a great deal of health officials’ efforts went into trying to produce *immobility*, to prevent scientific knowledge regarding the epidemic from spreading. They invested substantial energy in ensuring that even the most scientifically authoritative accounts—as compiled by their own epidemiologists—would circulate only in very particular ways and end up in administrative dead files. We also need to account for ways that producing knowledge was intimately entangled in producing nonknowledge, in relegating other perspectives on the disease to the categories of ignorance, superstition, error, or political interference.⁹

In chapter 6 we draw on STS and linguistic anthropology to think in new ways about the nitty-gritty, the mechanics of the production of knowledge and nonknowledge and of circulation and immobility. All parties based their claims to produce knowledge on their relationship to the same dying and dead bodies, providing a powerful common focus. The types of relationships that people claimed to those bodies, those of kinship, care, statistics, laboratory analysis, clinical examination, and journalism, turned them, however, into what STS scholars refer to as boundary objects, held in common by actors occupying distinct social spheres but defined and used in different ways by each (Star and Griesemer 1989). We reflect on how participants sought to position the bodies

in relationship to space, time, medical technologies, and forms of care in such a way as to define the points at which they might yield the knowledge needed to produce a diagnosis. We look at the role of genres in invisibly shaping dividing lines between knowledge and nonknowledge: epidemiologists elevated laboratory results and epidemiological statistics as most accurately and transparently representing knowledge; clinicians favored clinical histories; and healers privileged myths and dreams. Nevertheless, people who are not versed in these specialized genres were cast outside the sphere of knowledge production and circulation. The stakes here for understanding health inequities are huge, given that these mechanisms ensure noncollaboration and miscommunication between people who want to figure out what leads to negative health outcomes and to address skewed distributions of health and illness. The sort of zero-sum game in which I have to cast your observations as ignorance or error in order to elevate my own as knowledge turns out to rest less on self-interest or ill will than on complex interactions between these sorts of generally unstated ways of configuring knowledge production and circulation.

Trying to figure out why the epidemic occurred, why it went on so long, and what thwarted diagnosis also entailed considering nonhuman actors as integral to knowledge production. The epidemic brought together not only patients, parents, physicians, healers, and other human participants but also viruses, bats, chickens, cats, and tigers, as we detail below. Clinical and epidemiological accounts of the epidemic cast humans exclusively as knowledge producers, while nonhumans became natural phenomena that had to be known and controlled by humans. Tirso Gómez, a healer as well as team member, disrupted this projection of a gulf between nature and culture, human and nonhuman actors by challenging the relegation of the vampire bat—who played a crucial role in the epidemic—to the status of a natural phenomenon lacking in knowledge-making capacity or any relationship to the social world until it became a disease vector. Other healers invoked the power of water spirits and magical candles, as unleashed by people classified as nonindigenous who were bent on adding supernatural violence to the forms of political and economic power they wield.

Here our story leaps to the heart of issues connected with what has been called “the ontological turn” in anthropology and other disciplines. Eduardo Viveiros de Castro (1998, 2004) argues that Amerindians view persons, animals, and objects relationally through the way they “apprehend reality from distinct points of view.” Isabelle Stengers (2005) suggests that recognizing multiple ontologies engenders a “cosmopolitics,” that is, political recognition of the coexistence of different ontological worlds and their divergent and often competing epistemological and ethical claims. Marisol de la Cadena (2010) points to the inclusion

in the Bolivian and Ecuadorian constitutions of the Quechua phrase *sumak kawsay* (translated as “good living”) at the center of relationships to other humans, animals, the environment, and material objects. Eduardo Kohn (2013) developed a semiotic analysis, based on fieldwork with an Amazonian people, to think about particular ways that humans and animals communicate, thereby shaping ongoing definitions of the human in response to nonhuman perspectives and actions. Mel Chen (2012) examined how representations of nonhumans, including animals and seemingly inanimate things like lead and mercury, are used in casting some humans as fully sentient, alive, and agentive and, at the same time, relegating other humans—racialized, queer, or disabled—along with nonhumans to a lower status, one that lacks full animacy.

Bringing nonhuman actors and forms of knowledge to the fore helps us think through a continuing puzzle: if the epidemic was caused by bat-transmitted rabies, why did the vampire bats suddenly increase their nocturnal attacks? A partial answer lies in a preceding sudden die-off of chickens, which form a major part of their blood supply. Why did the chickens die? Why did the rabies virus proliferate in the bats’ saliva? Why did one to three individuals die in some households, leaving as many as a dozen family members untouched? Why did dying patients speak in sometimes horrifying, sometimes endearing ways that seemed to lie beyond “normal” human powers of articulation? When a nine-year-old’s last words generate a new understanding of the meaning of life and death, even as he attempts to provide his mother with words that will soften her mourning, who is speaking? We dare to ask if viruses speak through human bodies and if animals—including chickens and bats—might have been providing the clues to discover not just the name of the disease but shifting ecologies of human, nonhuman, and environmental interactions. At the same time that these sources provide us with ideas for thinking beyond biomedical and other frameworks that reserve knowledge-making capacity to humans, how our delta interlocutors juxtaposed myths, laments, healing, political critique, and science points to ways that proponents of multiple ontologies and natureculture (non-binary) perspectives might underestimate how contemporary afflictions (Das 2015) require complex and sometimes fatal ontological balancing acts.

Another focus of these conceptual reworkings centers on the issues of health and media that we raised earlier. One of the largest and most pervasive dimensions of communicative infrastructures of health now lies in media, the constant circulation of health information through television, radio, newspapers, the Internet, and social media. For example, epidemiologists track disease outbreaks by monitoring Internet traffic, social media, and health news. Scholars generally cast such “media representations” as immaterial, secondary features

that come after the primary facts of research, diagnosis, and treatment have already emerged. Research on the pharmaceutical industry suggests, however, that media and public relations professionals collaborate with scientists all the way through the process of producing a new drug, from the creation of a new disease or risk factor to laboratory research, the design of clinical trials, publications in medical journals, approval by federal regulators, advertising, media coverage, and efforts to convince clinicians to accord it a central place in their pharmacopoeia.¹⁰ In short, biological and media components are coproduced, but we know relatively little about how they are made and circulated in widely dispersed sites by media and health professionals, marketers, and laypersons.

Understandings of health news reflect commonsense cultural models of the production, circulation, and reception of health knowledge. The most prevalent construction envisions this process as reflecting the production of knowledge about diseases and treatments as enacted by health professionals in such specialized sites as hospitals, laboratories, and epidemiologists' offices. This knowledge is projected as then being translated into popular representations by "the media" and health communicators for reception by lay audiences. Health news stories thus both teach audiences a given body of biomedical content and impart ideas about what counts as health knowledge, who makes it, and how laypersons are required to assimilate it. The types of health subjects who are projected in this process are hierarchically ordered in terms of knowledge, authority, and agency; ethnoracial differences often project minority populations as simply being out of the loop, too ignorant, inattentive, or irrational to learn how to save their own lives and those of their children.

Looking ethnographically at how news about the epidemic was produced and received—rather than relying on content analysis alone—enabled us to see that it resulted from complex collaborations between health officials and journalists. Rather than coming after the medical facts had been determined, the news coverage sometimes structured subsequent epidemiological investigations and shaped their policy implications. Indeed, as we document in chapters 3 and 8, news coverage sparked the two largest epidemiological investigations carried out in the delta during this period, both of which were geared toward producing particular sorts of stories and precluding others, toward casting some actors as producing knowledge and others as reproducing superstition and ignorance.

Looking closely at the epidemic thus pushed us to document what we call *biomediatization*,¹¹ the coproduction of medical objects and subjects through collaborations between health and media professionals, laypersons, and others, as unfolding in a wide range of sites. We trace how news coverage informed

what took place in homes, clinics, hospitals, and public health offices as well as the complex and shifting alignments of health officials, journalists, politicians, and activists that shaped what figured in coverage, how it was framed, what did not get covered, the roles assigned participants in stories, and the complex, heterogeneous political effects of coverage. News stories about the epidemic were consequential even for people who violently challenged their veracity. Conrado and Enrique grasped the powerful role of biomediatization in shaping public health policies and practices in the 1992–1993 cholera epidemic. They accordingly insisted on mediatizing knowledge about the epidemic even as we were producing it; recording stories, producing statistics, and asking Clara to come up with a diagnosis and Charles to take photographs were all designed to infuse delta residents' accounts of the epidemic with mobility, to enable them to reach Caracas. By telling the story themselves to national and international journalists, Conrado, Enrique, Norbelys, and Tirso were determined to disrupt biomediatization-as-usual and how it reproduces fatal stereotypes. At the same time that this discussion opens up a new line of inquiry, it suggests that no attempt to locate health/communicative inequities and no effort to achieve health/communicative justice will be adequate if they fail to address biomediatization.

A Note on Names and Images

A few final words about names and photographs. Our narrative practices follow the guidance we received from the parents and our fellow team members. The demand, “Tell me why my children died” goes hand in hand with a challenge to circulate the parents' stories about their children and how they died. In their continuing efforts to counter the social deaths that followed their children's physical demise, the parents want their children's names spoken and demand recognition for their labor of care and communication. The nurses and healers also asked to be recognized for their efforts to save their patients. On the other hand, many were concerned that naming doctors, epidemiologists, health officials, and journalists would engender retaliation; some of these professionals requested anonymity, expressing similar concerns. We have honored these requests.

The parents expressed particular interest in photographs. They asked that “people everywhere” learn about their children, how they lived, how they died, and what the parents did in trying to keep them alive. Given the uneven distribution of money and photographic technologies, few of them had pictures of the children who died. Enrique asked Charles to photograph and film the

parents' testimonies; the photographs became a crucial part of the act of witnessing, of hearing these stories. They were also designed to help increase the mobility of the parents' accounts, to equip them to engage national health officials and journalists and, simultaneously, to keep our work from turning into disembodied numbers and clinical descriptions. In Caracas, Enrique took these photographs out in each meeting with officials and journalists. Having been asked to participate in the work of mourning, these photographs signal our recognition of this role. When we return to the delta, the parents proudly treasure the copies of the photographs we bring them, despite the pain.

We have thus included a great number of photographs of the parents and, in several cases, of their children. They are presented as images, not ethnographic supplements, standing beside the text, not subsumed under it (Stevenson 2014). We present them for three reasons. First, they are of and for the parents. We want them to see themselves, literally, in the pages of this book. The images signal that the parents, nurses, healers, and others are crucial members of the audience for this book. Second, the photographs invite readers to construct their own relationships with these individuals and use their own experience and imaginations to enter into these stories. Finally, they are for us, interpellating the book's authors as part of its audience. As we suggest in chapter 7, the parents charged the six members of the team with participating in their work of mourning. Every time we look at them, these images keep us focused on this responsibility at the same time that they enable us to imagine new ways of undertaking it, new types of relationships with the parents, their lost children, and the world around us. They remind us that this book is just part of a larger project, one that is not linear, not finished, and not of our own making.