

TELL ME
why
MY
CHILDREN
DIED

RABIES, INDIGENOUS KNOWLEDGE,
and COMMUNICATIVE JUSTICE

Charles L. Briggs & Clara Mantini-Briggs

T E L L M E

w h y

M Y

C H I L D R E N

D I E D



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COVER ART: Anita Rivas watches her husband's lament, Barranquitas, Venezuela, 2008.

Photograph by Charles L. Briggs.

FOR ELBIA AND MAMERTO
and the others who died in the mysterious epidemic

FOR LIBRADO

and

FOR FELICIANA, BILL, AND NANCY

and

FOR GUERINO, ESTRELLA, AND ALFREDO

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C O N T E N T S

Illustrations ix Prologue xiii Preface xvii Introduction 1

I

- 1 Reliving the Epidemic: Parents' Perspectives 29
- 2 When Caregivers Fail: Doctors, Nurses, and Healers Facing an Intractable Disease 76
- 3 Explaining the Inexplicable in Mukoboina: Epidemiologists, Documents, and the Dialogue That Failed 109
- 4 Heroes, Bureaucrats, and Ancient Wisdom: Journalists Cover an Epidemic Conflict 127

II

- 5 Narratives, Communicative Monopolies, and Acute Health Inequities 159
- 6 Knowledge Production and Circulation 179
- 7 Laments, Psychoanalysis, and the Work of Mourning 205
- 8 Biomediatization: Health/Communicative Inequities and Health News 225
- 9 Toward Health/Communicative Equities and Justice 245

Conclusion 260 Acknowledgments 275 Notes 279

References 287 Index 303

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ILLUSTRATIONS

maps

- P.1 Delta Amacuro State xviii
- I.1 Area where cases were concentrated 11

figures

- P.1 Inez Rivero with her baby daughter, 2008 xiv
- P.2 The team in Enrique Moraleda's *balajú*, *Misluoy I*, 2012 xx
- I.1 Houses in Mukoboina, 2010 12
- I.2 Clara, Enrique, Conrado, and Eumar planning the team's investigation, 2008 14
- I.1 The Baeza family garden in Mukoboina, 2010 30
- I.2 Wilmer Torres, 2008 33
- I.3 Graciano Florín, 2008 35
- I.4 The national identity card for Ángel Gabriel Florín 35
- I.5 Santa Morales with her youngest daughter, Yamileta, 2010 38
- I.6 Alfonso Torres, 2010 39
- I.7 Romer Torres, 2008 41
- I.8 Odilia Torres with her daughter, Yuneli, 2008 42
- I.9 Muaina, 2008 46
- I.10 Elders gathered for the meeting in Muaina, 2008 48
- I.11 Enrique speaks as the meeting begins, 2008 50
- I.12 Florencia Macotera and Indalesio Pizarro, 2010 51
- I.13 Florencia Macotera narrates Dalvi's death in the Muaina meeting, 2008 52

- 1.14 Mamerto Pizarro at the Indigenous University of Venezuela 55
- 1.15 Barranquita, 2010 61
- 1.16 Anita Rivas and her son, Romeliano, in her garden, 2010 61
- 1.17 Elbia Torres Rivas, 2008 62
- 1.18 Tito Rivas, Elbia's grandfather, 2008 66
- 1.19 Elbia, an hour before death, with her mother, Anita Rivas, 2008 67
- 1.20 Elbia's coffin at the entrance to the Barranquita cemetery, 2008 68
- 1.21 Placing coffin in the tomb, 2008 69
- 1.22 Passing large gobs of mud, 2008 70
- 1.23 Muddied and laughing, 2008 70
- 1.24 *Desmodus rotundus* 72
- 1.25 The new section of the Mukoboina cemetery, 2008 74
- 2.1 The Nabasanuka clinic, 2008 78
- 2.2 Home of Siawani's nurse, 2008 85
- 2.3 Nurse José Pérez with his son, 2008 86
- 2.4 Muaina nurse Mirna Pizarro, with son Roberto, 2010 88
- 2.5 Alonzo Moraleda, 2010 90
- 2.6 Jesús Moraleda, 2010 91
- 2.7 Inocencio Torres, 2010 97
- 2.8 Avelino Campero, 2009 101
- 2.9 Paulino Zapata and Ildebrando Zapata, 2009 103
- 2.10 Paulino Zapata and Clara Mantini-Briggs in Arawabisi clinic, 2006 104
- 2.11 Unfinished bridge in El Cocal, 2008 107
- 3.1 The maternal-pediatric wing of the Tucupita Hospital, 2010 113
- 3.2 One of the big blue water tanks, Mukoboina, 2010 122
- 4.1 Conrado Moraleda appears on the front page of *Notidiario*, 2008 132
- 4.2 Sinergia Torres, shortly after the death of her daughter, 2008 151
- 7.1 Singing laments for Elbia, Barranquita, 2008 213
- 7.2 Anita Rivas (right) sings alongside her sister, Rosaura, 2008 215
- 7.3 Arsenio Torres sings a lament, 2008 217

- 7.4 Anita watches her husband's lament, holding Romeliano,
2008 218
- 7.5 *El Nacional* photograph of team with pictures, 2008 223
- 8.1 Photograph of indigenous mother and child during the
cholera epidemic, 1991 230

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P R O L O G U E

Inez Rivero Borges's one-room home in El Cocal has a green plastic roof and open walls on three sides, and is perched on stilts above the mud bordering a broad river. This is where she sits with her infant daughter to recount, over the span of forty-five minutes, the details of the mysterious deaths of her two sons, Jesús, age three, and Lizandro, age five (figure P.1). She is thirty-seven years old and has been married for a quarter century to Darío Garay Mata. She has given birth to twelve children, but only five are still alive. The infant girl she is now nursing will soon fall ill. She is one of scores of parents who moved frenetically from one caregiver to another in a desperate search to save their children, only to end up traveling to the cemetery—sometimes, as with Inez Rivero, over and over. They passed along their observations to anyone who would listen; they offered to collaborate in figuring out what was causing the mysterious epidemic. But even after the dying ended, their search for answers went on. They continue to demand, thinking both of their own children and many others, “Tell me why my children died.”

First, Jesús “developed a fever out of the blue” in mid-March 2008. On the second day, when the fever grew intense, Inez said, “I went to my mother and told her, ‘I just don’t like it. Even though his fever is not high, I don’t like the look of his eyes.’ His eyes had changed color. His eyes weren’t the same.” When Jesús tried to swallow some acetaminophen in liquid form, “it didn’t work for him; he felt like he was drowning.” He swallowed a bit, “but then his eyes looked like they were crossed. His hands were stiff, like he was already going to die.” By the third day, at times “he became immobile, as if he were asleep. When he was asleep, his legs kept moving.” He was having trouble walking, and he fell a number of times. Soon, Jesús could no longer swallow food. Held tightly in his mother’s hammock all night, he tossed and turned; whenever he started to fall asleep, he had strange dreams. “We didn’t sleep at all that night.”

FIGURE P.1. Inez Rivero with her baby daughter, 2008. Photograph by Charles L. Briggs.



Strangely, “he would lose consciousness—but then seem just fine.” Jesús also had frequent seizures.

Inez went to seek help from a healer who lived nearby. “I jumped out of the boat and went right up to him and stood before him: ‘I came to you because my son is very, very sick and he couldn’t sleep.’” He treated the boy and requested a return visit that evening. Back home, Jesús played actively with the family’s dog and seemed fine, but later his legs were painful, and he seemed to be growing cold. His head hurt incredibly: “He wouldn’t let anyone touch his head; he kept moving it from side to side, from side to side. He was dying. He was dying.” Returning just as cooking fires marked the thatched-roofed homes in the waning light, the healer placed Jesús in a hammock and began to massage him, “but he died in the healer’s arms.” All that night and until noon the following day, Inez composed and sang *ona ribu*, laments for Jesús, while his father and other men fashioned a small coffin and built a small house-tomb for the child.

Two weeks after his death, five-year-old Lizandro “came down with a fever just like Jesús.” At first, he continued to run about like a normal child, but “he had trouble sleeping; he would play by himself in the middle of the night.” In the morning, he lingered in his hammock. On a visit to his grandmother, Lizandro ate taro and seemed fine, but, returning home, he got a bad case of hiccups and slumped into his hammock. Turning to the medicine that doctors

and nurses could provide, Inez told the local nurse, “I came to ask for your help because my son is ending up just like his brother. He has a fever—give him an injection to bring down the fever.” Lizandro got his injection and a hug from the nurse, which he returned. At home, Inez administered additional medication precisely as indicated, but it only seemed to make the child worse, and he began to have powerful seizures, falling down several times. The headache was so intense that he kept repeating, “‘My head, my head.’ He was getting worse; it was just the way his little brother died.”

Darío, Inez, and two of her sisters set out in a hired boat with Lizandro on an odyssey to find healers. Ready to go anywhere and stay as long as necessary, Inez said, “We took our hammocks with us.” When the first healer failed, they traveled to a more distant settlement to consult another. When he failed, they went to a larger settlement closer to home, Arawabisi, where several healers joined forces on Lizandro’s behalf. In España, farther down the Winikina River, they visited a healer who took out his sacred rattle and began to shake it, attempting to call *hebu* spirits/pathogens that might be lodged in Lizandro’s body. But as soon as the spirit stones moved within the rattle, creating powerful sounds and visible sparks, Lizandro cried out, “‘That’s terrible, no! That’s scary, that’s scary, Papa.’ . . . The boy said that he was frightened, and so [the healer] stopped singing and using the rattle. Since Lizandro was older, he could express himself.”

When the family returned to El Cocal, “He was near death—just like his brother.” Desperate but not giving up, they called a healer from across the river. After touching Lizandro’s body, feeling for the shape, hardness, and size of a pathogen and intoning a few words addressed to those areas of the spirit/medical world he commanded, he said, “No, that’s not the kind that I know; another kind of illness has seized him.” Healers had heard that a disease was afoot that neither they nor the nurses could stop. In all, Inez and Darío visited twelve healers, some more than once; the treatment sessions sometimes lasted most of the night. Still traumatized by Jesús’s death, they did not sleep for days and were exhausted from restraining Lizandro during his many seizures. “Since he was big, he was strong.”

But Lizandro’s death, when it came, “took place very fast. . . . Toward the end, the saliva came; at that point his saliva just gushed.” Inez, her sisters, and Lizandro’s siblings combined their efforts, but they “could not wipe away the saliva before more came.” Demonstrating, Inez’s right hand moves rapidly some twenty times from her mouth outward. Lizandro was *amoni diana*, close to dying. His fever was high; he overreacted to sounds; and he couldn’t perform simple bodily functions, such as swallowing or urinating. He lay in his hammock thrashing from side to side, thrusting his head and body backward

as if his back would break. "His lungs were making sounds," and "he was having trouble breathing." Lizandro "loved everyone. . . . He hugged his father strongly around the neck and held on tightly; and his father hugged him too." Lizandro then asked for his brothers, calling their names, starting with his older brother, Armando. In Lizandro's voice Inez calls, "'Come here, Armando, come here, Armando.' He wasn't around . . . but [Lizandro] called out to him." Then Lizandro named the names of "two *hotarao*," meaning nonindigenous persons, employees of a firm paid by the government to build cement bridges that would connect houses spread along the marshy ground, bridges that were never finished. "Now those drunken *hotarao* are gone. Back when there were many drunken *hotarao* here, they fell upon Lizandro, they hit him until he bled. . . .

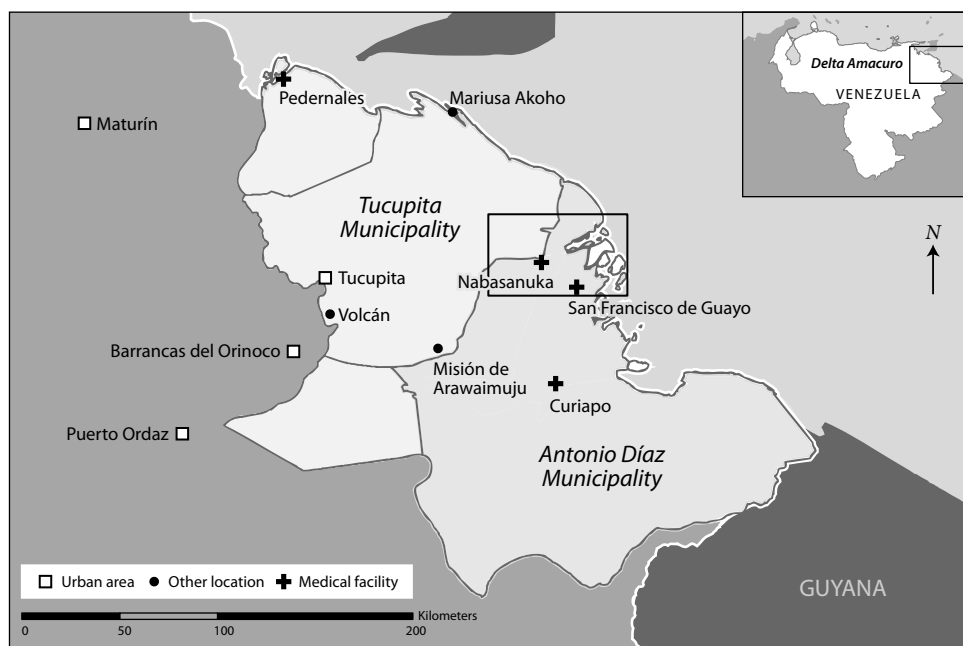
"Then my son died."

P R E F A C E

This is a book we did not want to write, about a project that we did not want to undertake, about experiences that were not framed as research and that continue to create deep ambivalence within us. Nevertheless, there are times when the world calls you and you must either respond or face the realization that you have turned your back on it. This is our response to a call to “tell me why my children died.”

The story we tell here looks into the depths of human misery, a nightmarish tale centered in a Venezuelan rain forest. It focuses on the death of children—sometimes one after another in the same family—from a disease that leaves no survivors, tortures bodies and minds, was never officially diagnosed, and, once symptoms appear, remains untreatable. Many of the words are not our own—they were spoken by parents who want the world to know about their children’s deaths, parents who refused to let their children’s deaths turn into memories deemed to be of significance only to them, only recalled as people lie in their hammocks in the darkness of rain forest nights. Other words are spoken by the nurses and doctors who tried to treat their young patients—only to watch them die in agony. Cuban and Venezuelan epidemiologists, in their turn, tried to solve the puzzle, which was as baffling and unprecedented as it was persistent. Healers were equally unsuccessful. Politicians and public health officials attempted to make the epidemic disappear—or turn it into more evidence of the supposed cultural inferiority of a population whose health they were charged with protecting. Journalists told readers and viewers around the world about the epidemic, only to drop the story after just two weeks, when the government claimed to have resolved the situation—without even providing the parents with a diagnosis or scientists with a scrap of evidence.

This book centers on a challenge that parents and local representatives continue to pose whenever doctors, officials, or journalists will listen: “Tell me



MAP P.1. Delta Amacuro State

why my children died.” The epidemic occurred in 2007 and 2008. Nevertheless, their demand still reverberates in the mist that hovers above the vast delta that the Orinoco River creates as it enters the Caribbean Sea in eastern Venezuela (see map P.1). They demanded that doctors use their seemingly magical powers to turn suffering into a word, a diagnosis, the name of the disease that numbed their children’s limbs and bedeviled their minds. Solving the medical mystery would, they hoped, enable doctors and nurses to tell them how to save the lives of their remaining children. The evidence we compiled as part of a team that included two local leaders, a healer, and a nurse suggested that the diagnosis was rabies, a disease that slowly and painfully takes control of the nervous system, and that vampire bats were the vector. Although rabies is almost 100 percent fatal, timely vaccination would have prevented infection and stopped the deaths; the vaccines, however, never reached the settlements where the children and young adults died. Bats still make their nocturnal visits, and the vaccines still have not arrived. Thus, the parents’ demand actually goes far beyond just revealing a diagnostic category that would end the mystery—they want to know why, half a decade later, no one seems to care that they have

grappled with some of the most acute health inequities in the world—and continue to do so.

The deaths led the parents, their neighbors, and leaders in the Delta Amacuro rain forest to identify lethal connections between disease and inequality. Activists noted bitterly that if the children who were dying were rich and white and lived in a nice part of the capital, Caracas, health officials would have mobilized armies of doctors and flown in international experts to solve the mystery. Why, the parents asked, did their children deserve only modest and fleeting attention? Why are their children's lives—and their own—deemed to be of so little value? Five years later, government officials still have not spoken the words that the parents demand to hear: "This is what killed your children, and we're sorry they died." So they refuse to be silent.

Our relationship to the delta and its residents has been long and intense. Charles began working there in 1986, learned the language (Warao), and studied healing, narratives, indigenous legal practices, gender relations, and interactions with government authorities. Given the precariousness of health conditions there, he witnessed numerous wakes and recorded the laments sung at several. Clara, a Venezuelan public health physician, began working for the Regional Health Service in April 1992, just months before a cholera epidemic killed some 500 delta residents. She served as the assistant regional epidemiologist and the state director of health education. After collaborating with residents in several areas to establish nursing stations and build cholera-prevention programs, we researched the underpinnings, bureaucratic as much as epidemiological, of such extensive death from a preventable and treatable bacterial infection. Afterward, we turned to other projects. One involved documenting how President Hugo Chávez Frías's socialist revolution had brought doctors, mainly Cubans, to live in most of the low-income urban neighborhoods in Venezuela.

After years of working elsewhere in Venezuela, it was our book documenting that epidemic, *Stories in the Time of Cholera*, that brought us back to the delta in 2008. Collaborating with healer Tirso Gómez and his daughter, nurse and paramedic Norbelys Gómez, and the residents of Siawani, we were using income derived from book royalties and prizes to explore new models for health programs. Upon our arrival in the delta, Conrado Moraleda, president of the local health committee, and his brother Enrique, a local political leader, approached us and asked us to join them and the Gómezes in trying to figure out what was causing yet another epidemic—this one ongoing and nameless. Chávez's frequent televised statements about constitutional guarantees to



FIGURE P.2. The team in Enrique Moraleda's *balajú*, *Misluoy I*, 2012. Photograph by José Moraleda.

health as “a fundamental social right, [an] obligation of the State,” in addition to his calls for an end to discrimination against indigenous peoples, struck a deep chord with Conrado and Enrique. They decided to unravel another mystery that the epidemic had revealed. If a revolution had brought doctors to and inspired residents in low-income neighborhoods elsewhere in Venezuela, why did health conditions remained abysmal in the lower delta? If the regional government lacked the will to bring the revolution in health to the delta, they resolved do so themselves, together with the parents who lost children in the epidemic.

This book is our response to the demands by parents and local leaders to make their words circulate, and it represents our participation in their efforts to solve the mystery and to help ensure that such a tragic scenario is not repeated. Centered on unknowns and mysteries, many of which have yet to be solved, it recounts how an unofficial epidemiological team of six people, traveling in a small wooden boat (figure P.2) and equipped with only a stethoscope, a sphygmomanometer for taking blood pressure, and a few medicines, and having no access to a diagnostic laboratory, tried to learn what was killing children

and young adults so they could figure out how to stop it. In doing so, the team faced questions such as: what is causing these deaths? Why did it stump parents, healers, physicians, nurses, and Cuban and Venezuelan epidemiologists alike? Why did this disease arrive in 2007? Did ecological change prompt it? Why didn't Chávez's pro-poor, pro-indigenous government—which devoted massive resources to addressing health issues in other parts of the country—respond more forcefully and effectively to the outbreak? If the team encountered people dying from the disease, what help could we provide? Could we combine indigenous healing, clinical medicine, epidemiology, anthropology, and the impressive sophistication of Warao storytelling to more effectively investigate the epidemic? How could indigenous leaders, whose only experience with the press had been on the receiving end of stereotypes and discrimination, get reporters to take them and their story seriously?

Tell Me Why My Children Died is not simply a tale of suffering, and—emphatically—it is not about passive people who waited for others to speak and act on their behalf. Even before the epidemic began, leaders like Conrado and Enrique Moraleta had already placed health inequities at the top of the agenda of the indigenous social movement. Moreover, the situation we document is not unique. Nearly every year, bat-transmitted rabies causes outbreaks in some part of the Amazon basin. (It also periodically claims a life in the United States.) Thinking more broadly about these events, although the mysterious epidemic's toll in the delta is appalling, respiratory infections, diarrheal diseases, and malnutrition—which also kill some 26 percent of children under five in the delta—also take too many lives in too many other parts of the world. These sorts of unconscionable health problems have been widely documented, and drawing attention to them is not our primary goal here. Instead, our focus is on recounting the ways that, in the midst of a worst-case scenario, people came up with novel insights into how acute health inequities are produced and are made to seem “normal,” and how they devised a creative vision of how we could all work together to end them.

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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, Mukoboina. 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

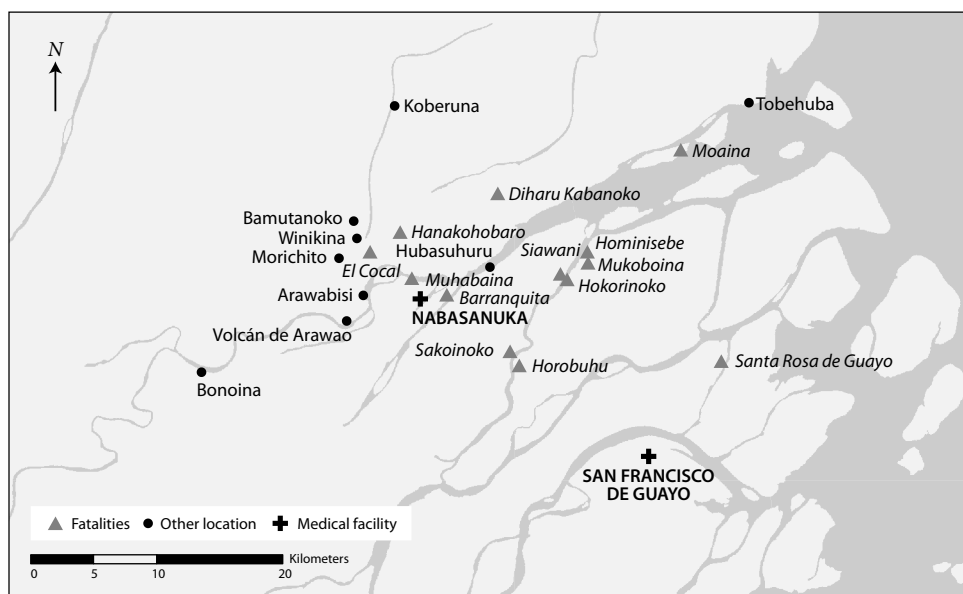
economies of the labor of care and health/communicative labor in different ways, this problem affects us all.

*“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 Nabasanuka 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 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 Mukoboina 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