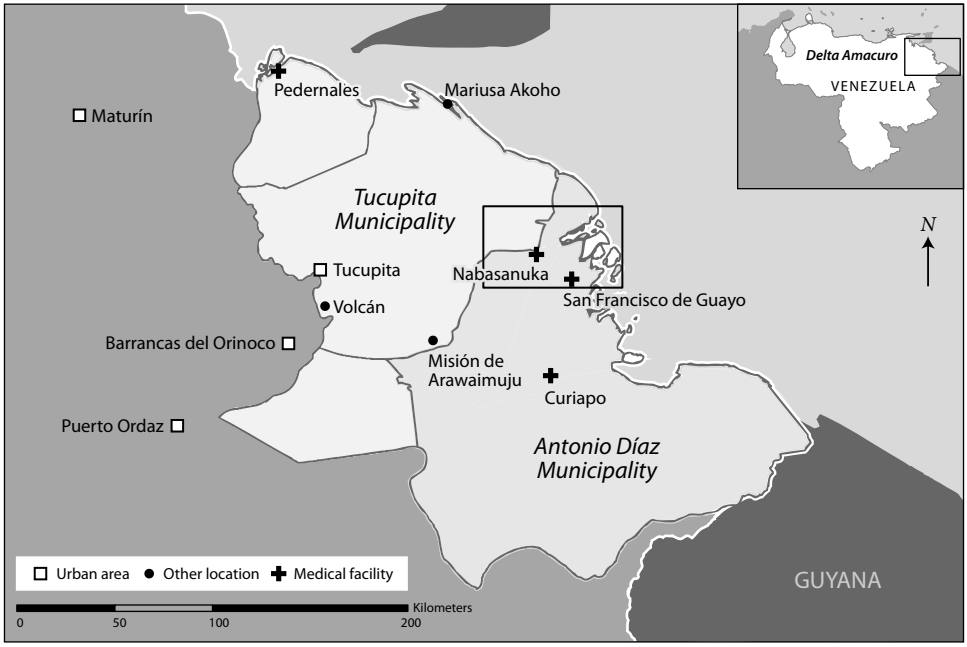
PREFACE

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 Moraleda 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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