MAT Medicine Anthropology Theory

THINK PIECES

Ecologies of evidence in a mysterious epidemic

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Abstract

An epidemic in a Venezuelan rainforest in 2007–2008 killed thirty-eight children and young adults, puzzling clinicians, epidemiologists, and healers alike for over a year. This essay traces the way each contribution to knowledge production formed part of a larger 'ecology of evidence'. Focusing on how the parents' knowledge was exploited and denigrated by clinicians, epidemiologists, and healers alike points to the 'health/communicative inequities' – grossly unequal distributions of access to the production and circulation of evidence – that structured ecologies of evidence in ways that thwarted diagnosis. Recruiting a nurse, a healer, a physician, and an anthropologist, two indigenous leaders launched an investigation that juxtaposed parents' narratives, vernacular healing, epidemiology, and clinical medicine, resulting in a clinical diagnosis of bat-transmitted rabies. This case suggests that perspectives in global health will fail to become fully critical unless they attend to health/communicative inequities, how they structure ecologies of evidence, and strategies for transforming them.

Resumen

En una zona selvática de Venezuela en 2007–2008, treinta y ocho niños, niñas, y jóvenes fallecieron en una epidemia. Utilizando el concepto de 'ecologías de evidencia', este ensayo analiza como médicos, epidemiólogos y curadores todos, explotaron y al mismo tiempo menospreciaron el conocimiento de los padres y las madres de los fallecidos, creando 'inequidades comunicativas en salud' que dificultaron el proceso diagnóstico por más de un año. Conjuntamente con una enfermera, un sanador, una médica y un antropólogo, dos

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líderes indígenas iniciaron una investigación que daba importancia a las narrativas de los padres y las madres, la medicina indígena, la epidemiología y la medicina clínica, resultando en un diagnóstico presuntivo de rabia transmitida por murciélagos. Este caso indica que las perspectivas en salud global no pueden llegar a ser realmente críticas sin analizar como las inequidades comunicativas en salud estructuran las ecologías de evidencia, y sin explorar posibilidades para transformarlas.

Keywords

Global health, health/communicative inequalities, ecologies of evidence, rabies, indigenous health

Figure 1. Holding her son Romeliano, Anita Rivas watches her husband, Arsenio Torres, sing a lament over the body of their daughter, Elbia Torres Rivas; Barranquita, Venezuela, 2008. Photograph by Charles L. Briggs.

Medical anthropologists have studied the production of evidence in clinical trials, public health programs, genetics, brain scans, and much more. Particular attention has been directed to the fetishization of statistical measures, images, and means of converting genetic samples into information as privileged sources of evidence. An ethnographic perspective might push us to investigate what I call 'ecologies of evidence', broader assemblages of interlocking ways of producing specific types of evidence and rendering them mobile, demoting other forms to the status of ignorance, superstition, or pathology, and simply rendering others unthinkable. I suggest here that attention to how authoritative forms of evidence both depend on and distance themselves from these broader ecologies points to the fundamental role of what I call 'health/communicative inequities': grossly unequal distributions of access to the production and circulation of evidence.[1]

Epidemics are particularly useful sites to explore in tracing ecologies of evidence. Public health officials, politicians, journalists, and others jointly transform theories of disease causation into linear narrative and dramaturgical forms that condense epidemiological, social, and political complexities into moral frameworks, bringing together 'ideology, social structure, and the construction of particular selves' (Rosenberg 1992, 279). Epidemics in which the production of evidence resists transformation into a diagnosis are particularly interesting for exploring ecologies of evidence ethnographically, given battles over what constitutes evidence and who possesses it in the face of pervasive uncertainty (see Anderson 2008; Lindenbaum 2001). Rather than reading mysterious epidemics as germ thrillers, we can use them to think conceptually about everyday ecologies of evidence. This essay explores an ecology of evidence that emerged during an epidemic in the Delta Amacuro rainforest of eastern Venezuela, detailing how health/communicative inequities thwarted diagnosis for more than a year. It argues for the importance of critical perspectives on health/communicative inequities in achieving critical public health.

> *They didn't tell us. I have no idea. . . .*
> *They just gave us the boy and we came back here.*
> – Graciano Florín

Mukoboina could have won an award for being the most nondescript among hundreds of small settlements in the Delta Amacuro rainforest of eastern Venezuela. Mukoboina boasted

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[1] I use the term 'inequities' rather than 'inequalities', following Breilh (2003), in order to target not simply observed patterns but the factors that produce them.

some eighty residents and a dozen thatch-roofed houses perched on stilts above the mud and water of a midsized tributary of the Orinoco River. It was literally sliced out of the surrounding jungle.

Figure 2. Wilmer Torres tells the story of losing two of his children to the strange disease; Mukoboina, Venezuela, 2008. Photograph by Charles L. Briggs.

And then Mukoboina's children started to die, mysteriously. 'Gabriel suddenly developed a fever in July 2007', father Wilmer Torres recalled.[2] When the fever persisted and the eight-year-old child grew weaker, Wilmer and wife Zoila Torres took their son to the local *wisidatu* healer, Inocencio Torres. But 'it was impossible, impossible. He treated and treated him, but . . . nothing happened. Then heavy saliva appeared'. Strangely intense and persistent symptoms followed, disconcerting bodily states that challenged familiar diagnostic

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[2] Parents asked us to use their names and those of their children: 'We want lots of people to know!' Names of government officials and physicians are pseudonyms.

categories. Gabriel died before reaching the clinic, some twenty minutes away by motorboat or hours paddling a canoe. Then on 8 August, 'just the same way, his little sister developed an identical fever. It was the same sickness'. They took two-year-old Yuri to see Uncle Inocencio, who again worked much of the night, but the results were no different. The next day, the parents visited nurse José Pérez, telling him, 'We took her last night to the *wisidatu*, but she was just the same in the morning'. The nurse placed her in a hammock to treat her, but his medicines failed too. Next they headed for the clinic at Nabasanuka. During the trip, 'Yuri just kept getting sicker'. She cried out continually and she couldn't even walk by the time they arrived. Yuri was the first case of the strange disease to reach the clinic, where experienced bilingual nurses worked alongside a newly graduated physician.

By September five more Mukoboinan children had died, followed by one in January 2008, part of a second wave of cases. Odilia Torres and Romer Torres lost all three children, leaving only an infant born during the epidemic. Each illness sparked a frantic search to find someone who could provide a diagnosis and point the way to treatment; hiring a boat and buying gasoline and oil placed families deeply in debt. They visited scores of healers of different specialties, nurses, the local physician, the hospital in the state capital, and the intensive care units of metropolitan hospitals, only to bring their children home in coffins, terrified that they would find that even as they sang ritual laments and began funeral preparations, another child would suddenly display 'the same fever'. June 2008 ushered in a third wave over a wider area – sixteen deaths in two months, including six young adults. In total, thirty-eight died.

> *The parents were very nervous because they could see*
> *that this child was going to die just like their daughter. . . .*
> *I had never seen any disease like that.*
> – Dr. Ricardo Cáceres

The local physician, Dr. Ricardo Cáceres, recalled that the first patient with the strange symptoms 'had a temperature of 41 degrees [Celsius], an intense headache, and great difficulty breathing. I administered rehydration solution and an antipyretic to control the fever'. A stethoscope revealed 'severe hoarseness and a crackling sound, so I also nebulized him', that is, administered an inhaler. Cáceres paused, took a deep breath, and then related that three more Mukoboina children, between six and eight years of age, soon arrived with the same symptoms; he referred them immediately to the hospital in the state capital, Tucupita. The Regional Health Service (RHS) had never repaired the fluvial ambulance used to take patients upriver, so Cáceres had to work with the local health committee and Claretin missionaries to find boats, drivers, gasoline, and oil.

When Cáceres could not diagnose the disease, his treatments did not help, and children were returning from urban hospitals in coffins, the parents and their neighbors wanted answers; the tone in which they questioned Cáceres grew increasingly worried, then insistent, then angry. But neither health officials nor urban specialists provided Cáceres with answers. Romer Torres ended his narrative describing the death of their third child from the disease with a chilling description: ‘And when we arrived here and opened the casket, it looked as if they had split [their daughter Yomelis’s] head open from front to back, and she was cut from her neck down’. He slid his finger down to his navel. Autopsies were performed on children without consent, explanation, or warning.

When parents opened the coffins provided by government officials after their children died in urban hospitals, they found that their children had been turned into evidence. Angry, they demanded to know why their children had been ‘mistreated’. Cáceres defended RHS, reassuring parents that autopsies were performed in order to yield the evidence needed for diagnosis. Cáceres repeatedly requested but never received the results. Time passed. The answers never came. Trust in him and his medicine suffered, and many parents refused even to take infants with respiratory or diarrheal diseases to the clinic, fearing that they would end up in coffins.

You see, we did all of this [investigation], but there was no mercury.
It wasn’t lead or anything like that.
– Dr. Yolanda Othegui

Epidemiologists came to Mukoboina again and again after Adalia Florín died in the intensive care unit of the Dr. Manuel Núñez Tovar Hospital in Maturín, the nearest metropolitan hospital; a toxicologist and pediatrician suspected mercury poisoning. The regional epidemiologist soon left the state capital for Mukoboina, accompanied by an epidemiologist assigned to the local area, a sanitary engineer, a bioanalyst, a laboratory assistant, and a motorboat operator. Shortly afterwards, the state’s food sanitation coordinator, a public health inspector, and an employee of the Ministry of the Environment came. Then a Cuban epidemiologist associated with Mission Barrio Adentro, a program launched by the Cuban and Venezuelan governments,[3] brought two other Cuban doctors, the local physician, a dentist, boat operators, translators, schoolteachers, and community leaders.

Physicians examined children exhibiting other symptoms during these visits, but the focus was squarely on evidence. The visitors questioned 'the family members of the deceased and members of the community, in addition to undertaking very close inspections of available foods, utensils, vessels for the storage of water and food, the areas around houses, food residues as well as those of their respective containers'.[4] One epidemiologist said that she climbed thatched roofs searching for containers of mercury left over from small-scale mining operations. Epidemiologists took nasal swabs and samples of blood, water from the river, and food. The Cuban commission generated particularly detailed evidence, 'looking for data of Hygienic-Epidemiological interest' (Coordinacion de Epidemiologia 2007, 1). For each death, they provided the name, age, gender, date on onset of symptoms, date of death, and brief observations. Commission members gave 'educational talks'.

Despite efforts to find evidence of mercury poisoning, water samples and blood tests were negative. Another hypothesis centered on lead poisoning; one report indicated vaguely that lead levels were 'above normal'. No sources of lead poisoning were found, and no one was treated for this condition. The Cuban epidemiologist rather suspected 'a highly virulent kind of modified adenovirus, or an enterovirus of the Coxsackie type, or another type of germ that uses this route of tranmission' (Coordinación de Epidemiología 2007, 4). To date, no official diagnosis has been presented.

> We *wisidatu* think that this disease is too dangerous. . . .
> When there is *hebu* sickness, we extract it, and patients recover.
> But when we treat these patients, nothing happens.
> – Inocencio Torres

The lower delta includes healers representing a diversity of specialties; some children were treated by as many as a dozen. Like Cáceres, healers expressed frustration, sadness, and a sense of failure when they could neither diagnose nor treat patients. Like bilingual nurses but unlike physicians and epidemiologists, healers knew a great deal about the strange cases

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[3] On Mission Barrio Adentro, see Muntaner et al. 2006; Briggs and Mantini-Briggs 2009.

[4] This information comes from a report (*informe*) dated 6 February 2008 by the regional epidemiologist.

before patients arrived by listening to '*radio warao*', informal transmission of news around the lower delta. Their observations of patients was supplemented by what they learned from family members and other healers. Some persisted in trying to make sense of the epidemic. Several traced the epidemic to social conflict, citing disagreements between neighbors as prompting 'bad medicine'. Others drew attention to the role of government contractors from outside the delta who had been hired to build bridges or houses: friction with residents over projects left incomplete and unpaid wages owed to local workers reportedly resulted in unfamiliar types of 'bad medicine' that delta healers could not treat.

Becoming a healer involves mastery of an extensive mythic corpus, and many healers connected myths, symptoms, and contemporary events in compiling evidence. One symptom, hydrophobia (fear of water), led healer Paulino Zapata to link the epidemic to the parallel underwater world, citing myths in which water spirits introduced illness and death among humans and pan-Amazonic traditions of water spirits. Team member and healer Tirso Gómez questioned the relegation of vampire bats to a disease vector in the team's own epidemiological formulation by performing the myth of the bat, pointing to a much longer and more intimate history of multispecies relations.

Venezuelan public health physician Dr. Clara Mantini-Briggs and I stumbled onto the epidemic in July 2008 while working with residents to establish a new model for health care. Health Committee President Conrado Moraleda had been pressing health officials since August 2007 to take more concerted steps. Frustrated by RHS's efforts to render the third wave of cases invisible, he joined his brother Enrique in launching an investigation, recruiting us to participate as physician and anthropologist. Creating a complex knowledge-production process that drew on political oratory, indigenous medicine, dispute mediation, parents' narratives, epidemiology, and clinical medicine, we documented thirty-eight deaths in fourteen settlements. The symptoms reported were fever, headache, body aches, a feeling of itching in the feet that turned to numbness and then paralysis that ascended, difficulty swallowing, hydrophobia, seizures, strange dreams or hallucinations, and excessive salivation, resulting in death. A strong indication of rabies was supported by examining a patient, Elbia Torres Rivas, for several days until the time of her death, even as we provided palliative care. Our own search for evidence led us to find that most patients had been bitten nocturnally by vampire bats approximately one and one-half months before the onset of symptoms.[5]

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[5] We document the epidemic and the team's work in Briggs and Mantini-Briggs 2016.

Ecologies of evidence

Evidence: Lots was produced. Everyone wanted it. Everyone wanted it to turn magically into a diagnosis and an end to the epidemic. The same dying and dead bodies became recognized sites for producing evidence for physicians, epidemiologists, healers, and parents. Evidence circulated like crazy throughout the delta and among health professionals in the capital during each wave. And yet this evidence proved to be lethally inefficacious: it did not add up to a diagnosis prior to August 2008. After officials angrily dismissed bat-transmitted rabies, the evidence they collected provided fodder for rendering the epidemic officially invisible again. One way to think about this situation would be to examine the cultural conventions (Trostle 2005) and the modes of classification (Bowker and Star 1999) that epidemiologists used in turning bodies into numbers, into diagnostic categories and statistical tables imbued with authority and mobility (Latour 1999). We could also follow how clinical medicine and epidemiology turned parents' and healers' evidence into nonknowledge (Geissler 2013). Another key dimension would be how particular evidential features – particularly hydrophobia – became boundary objects that fit into different frameworks. Such a course of action would, however, reproduce epidemiology's claims to autonomy, decontextualizing it from the broader ecologies of evidence that constituted the epidemic. Exploring these ecologies ethnographically, I would like to suggest four ways that evidence production thwarted diagnosis rather than fostering efficacious health policies and practices.

First, Latour's notion of immutable mobiles (1988) and his characterization of circulating reference (1999) would seem to suggest that the production of scientific evidence is oriented towards enhancing its mobility. Yet the practices emerging in the epidemic produced very limited and specific forms of mobility and a great deal of immobility. Cáceres's one-page summaries were meant to be read only by hospital physicians who provided higher levels of care to the same patient. He hoped that they would spark an evidentiary exchange, counter-referrals that would inform his efforts to diagnose and treat future patients. Despite requests made by two-way radio, during trips to RHS's headquarters, and in letters to his superiors summarizing evidence about the epidemic and soliciting clinical and laboratory results, no evidence was forthcoming. The director reportedly told him that further efforts to initiate evidentiary exchanges might cost him his career. Epidemiologists incorporated brief summaries of Cáceres's clinical evidence into their reports, but these were documents destined for very limited routes of circulation and specified endpoints: the inboxes and file cabinets of RHS's director and regional epidemiologist. The final report on the epidemic was sealed in the offices of RHS's director and the national epidemiologist; no one can view it. Ecologies of evidence are thus structured as much around the production of what I would call 'mutable *im*mobiles' as immutable mobiles. The team's desire to enable its own account to become sufficiently mobile so as to reach national officials, thereby circumventing efforts by regional health authorities to hide the epidemic, similarly required us to make some accounts, such as those regarding 'bad medicine', immobile.

Second, barriers to the collaborative production and circulation of evidence proliferated. Regarding one of the children, Cáceres wrote: 'the treating physician decided to refer her [to a hospital in the state capital], but the parents refused and proceeded to discharge the patient against medical advice', instead taking her 'to the wasiratu [sic]', referring to a type of healer. When our team presented its findings to the national epidemiologist – after a standoff witnessed by national and international journalists – Delta Amacuro's government criminalized our efforts to produce evidence. Healers also erected their own barriers: their evidence was couched in specialized terms not shared by nonhealers, circulating mainly among themselves.

Third, evidence production was not limited to sites of caregiving. After repeated appeals to RHS officials failed to spark a more robust response, Conrado Moraleda presented evidence of the strange deaths to state legislators, leading to a confrontation with RHS covered by the local newspaper. Countering this purported attack on their monopoly on the production of health evidence, RHS officials circulated statements through rumors, radio broadcasts, and press conferences that projected the consumption of poisoned fruit or fish or garbage or mistreatment by local healers as possible causes. The assistant regional epidemiologist then launched a massive seven-day investigation that produced masses of statistical evidence; the final report mentioned only 'diarrheas and vomiting', not symptoms identified by Cáceres and epidemiologists (Lopez 2008, 1). The investigation ended with a visit by journalists and the vice-minister from the Ministry for Popular Power in Health. How epidemiology is imbricated in this broader ecology of evidence becomes apparent here. Moraleda's evidence, produced in collaboration with the local physician, sparked denigrating rumors and epidemiological research. Rather than the circulation of biomedical evidence through 'the media', these events formed part of a broader process of what we have called 'biomediatization', the coproduction of health knowledge by media and health professionals and laypersons in a variety of sites (Briggs and Mantini-Briggs 2016). Like laboratory and clinical evidence of pharmaceuticals (see Dumit 2012), this evidence was biomedical and mediatized from the start.

Finally, the parents' role in this ecology of evidence helps indicate why it failed to produce an official diagnosis. Parents wanted to know what was killing their children, and they desperately sought to prevent further deaths. They had observed symptoms, tried forms of care, and asked healers, nurses, and physicians to extend care and share evidence. The parents' observations were as crucial to these ecologies of evidence as their children's bodies. All practitioners extracted fragments of the parents' observations, but their questions and interpretations followed from etiological frames and discursive practices that limited the parents' input to responses to their queries. None expressed interest in the parents' practices for producing evidence or their narratives.

The encounters between epidemiologists and Mukoboina residents are striking. Framing these visits as exchanges, the parents assembled, anxious to share their narratives and evidence. Epidemiologists, however, had no interest in attending community meetings or hearing parents' narratives, only in getting answers to questions and making observations. Parents rejected passive and subordinate roles in evidence production. Epidemiologists misconstrued residents' frustration as evidence of 'the community's closed nature', as refusal to share evidence. The situation worsened when parents asked epidemiologists to share their evidence and hypotheses; they left without responding and never sent any information. Their evidence was produced for health officials, not clinicians or residents.

Conclusion

These ecologies of evidence thus positioned the parents vis-à-vis multiple inequities. Care and the production and communication of evidence were deeply imbricated: parents mobilized archives of evidence along with the bodies of their dying children. Caregivers, including healers, exploited the details parents provided but denigrated their status as producers of evidence. Parents' efforts to pursue all possible sites of evidence production and care were disparaged, particularly when they crossed ontological borders. As they moved progressively through higher levels of care – from nurses to Cáceres to the hospital in the state capital to metropolitan intensive care units – parents' efforts to pass along evidence they had amassed were increasingly sidelined until they were rendered mute in urban hospitals. Exacerbating deplorable 'normal' health conditions, the epidemic exemplified the sorts of health inequities targeted by global health programs. By examining how they were enmeshed in ecologies of evidence, I have explored the way health inequities are coproduced with what I refer to as 'health/communicative inequities': health inequities and health/communicative inequities came together at each site in which care was sought, in epidemiological investigations, and in denigrating stories in newspapers and on radio stations.

The epidemic also richly illustrated possibilities for transforming health/communicative inequities. Health and health/communicative inequities were massively coproduced in the area in 1992–1993 during a cholera epidemic that killed some five hundred people.[6] Their fusion produced a stereotype of 'the Warao indigenous ethnic group' as a homogeneous

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[6] See Briggs and Mantini-Briggs 2003.

population incapable of grasping basic hygienic principles or understanding what doctors tell them. A decade and a half later, Conrado and Enrique Moraleda challenged these stereotypes by creating a team to investigate a new epidemic and producing evidence for presentation to national health officials. Angered by collaborations between health officials and regional journalists in February 2008 that resulted in the same sort of denigrating press coverage that characterized the cholera epidemic, the four 'Warao' members of the team made articulate statements to national and international journalists, which were then circulated in some thirty thousand stories worldwide. Their desire to highlight their own process of producing evidence and the vision of critical global health that lay behind it prompted a book, *Una efermedad monstruo: Indígenas derribando el cerco de la discriminación en salud*[7] based on and structured around conversations between team members. The remarkable insights that emerged from efforts by Conrado Moraleda, Enrique Moraleda, Norbelys Gómez, and Tirso Gómez suggest that perspectives in global health will fail to become fully critical unless they attend to health/communicative inequities and how they structure ecologies of evidence.[8]

About the author

Charles L. Briggs teaches in the Department of Anthropology of the University of California, Berkeley. He researches complex interactions between medicine, healing, death, race, media, and communicative practices, primarily in Latin America and the United States. His publications include *Learning How to Ask* (1986), *Stories in the Time of Cholera* (with Clara Mantini-Briggs, 2002), *Voices of Modernity* (with Richard Bauman, 2003), *Making Health Public: How News Coverage Is Remaking Media, Medicine, and Contemporary Life* (with Daniel Hallin, 2016), and *Tell Me Why My Children Died: Rabies, Indigenous Knowledge and Communicative Justice* (with Clara Mantini-Briggs, 2016).

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[7] The English translation is: A monster disease: indigenous peoples breaking down the wall of health-based discrimination. See Briggs et al. 2015.

[8] Briggs and Mantini-Briggs 2016 presents an analytic framework for identifying health/communicative inequities.

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