



Uncovering a tragic flaw in revolutionary health policies: From health and communicative inequities to communicative justice in health

Descubriendo una falla trágica en las políticas revolucionarias de salud: desde las inequidades en salud y comunicación a la justicia comunicativa en salud

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ABSTRACT This article analyzes a contradiction facing efforts by left-leaning governments in Latin America to transform health into a fundamental social right. Policies and practices that confront health inequities generally fail to address *health/communicative inequities*, hierarchical distributions of rights to shape what counts as legitimate knowledge of health. This ethnographic analysis focuses on an epidemic of a mysterious disease – identified clinically as bat-transmitted rabies – in the Delta Amacuro rainforest of Venezuela in 2007-2008, tracing how parents who lost 1-3 children faced acute health/communicative inequities in clinical settings, epidemiological investigations, work with healers, news coverage, health policy, and health communication. Taking as a point of departure rainforest residents' demands for *communicative justice in health*, the analysis draws on Menéndez's notion of *autoatención* in exploring how health/communicative labor is co-produced with the labor of care.

KEY WORDS Healthcare Inequalities; Epidemiology; Communication Barriers; Communications Media; Venezuela.

RESUMEN Este artículo analiza una contradicción enfrentada por los gobiernos de izquierda de América Latina en sus esfuerzos por transformar la salud en un derecho social fundamental. Las políticas y prácticas que confrontan las desigualdades en salud, en general, no llegan a dirigirse a las *inequidades en salud y comunicación*; las distribuciones jerárquicas de los derechos dan forma al conocimiento legítimo en salud. El artículo presenta un análisis etnográfico sobre la epidemia de una enfermedad misteriosa –identificada clínicamente como rabia transmitida por murciélagos– en la selva del Delta Amacuro en Venezuela, en 2007-2008, centrado en cómo los padres y las madres que perdieron entre 1 y 3 hijos e hijas lidian con inequidades agudas en salud y comunicación en entornos clínicos, investigaciones epidemiológicas, trabajo con sanadores/as, la cobertura de las noticias, las políticas de salud y la comunicación en salud. A partir de demandas por parte de los y las residentes de la selva por una *justicia comunicativa en salud*, el análisis utiliza la noción de *autoatención* propuesta por Menéndez para explorar cómo la labor en salud y comunicación se coproduce con la labor de cuidado.

PALABRAS CLAVES Desigualdades en Atención de la Salud; Epidemiología; Barreras de Comunicación; Medios de Comunicación; Venezuela.

INTRODUCTION

Breathing new life into the spirits of Rudolph Virchow and Salvador Allende, remarkable revolutions in health emerged in Latin America in the new millennium. Constitutions written in Bolivia, Ecuador, and Venezuela cast healthcare as a fundamental social right. National policies have countered a decades-long process of commodifying and privatizing public health. In Bolivia and Ecuador, *sumak kawsay* placed indigenous conceptions of wellbeing at the center not just of health but of relations between humans, others species, and environments. Under attack by forces from the right – sometimes literally – these efforts to make health a locus of justice and equality constantly face the threat that a conservative government might dismantle them, practically overnight.

I suggest here that such efforts are also constantly challenged by a fundamental contradiction *within* progressive health scholarship, policymaking, and practice. Extending my engagement with Latin American Social Medicine and critical epidemiology and embracing their call to identify presuppositions that reproduce the hegemony of biomedicine and its role in deepening social and political-economic inequities, I use the powerful tool offered by an anthropology of health in the Americas – ethnography – to open up a new issue regarding equity and justice in health. My focus is the binary opposition between health/disease/healthcare *versus* communication/media. I argue that construing communication and mediatization as processes that exist apart from biomedical subjects and objects undermines efforts to radically rethink and reconfigure health. Rather than arguing in purely abstract terms or focusing on what are generally considered to be media and communication, I work ethnographically on a case that falls squarely within what are deemed biomedical issues by analyzing a mysterious epidemic that killed 38 members of an indigenous population in Delta Amacuro State, which took place during Venezuela's Bolivarian socialist revolution in 2007-2008.

I explore why efforts by clinicians, epidemiologists, and healers to diagnose the disease failed for over a year. Untangling this puzzle requires, I suggest, ethnographically scrutinizing how the seeming separation of communication to biomedicine and the subordination of the former to the latter was produced and how it thwarted clinical medicine and epidemiology, turning revolutionary public health into a site of oppression – as well as of creativity and struggle. My assessment is that this example reveals the most hidden – and possibly the most crucial – factor that undermines attempts to achieve equity and justice in health.

I want to emphasize from the outset the collaborative nature of this project. The fundamental insights on which I build are those of local leaders Conrado Moraleda and Enrique Moraleda. They recruited me, along with healer Tirso Gómez, nurse Norbelys Gómez, and public health physician Clara Mantini-Briggs, to join them in advancing President Hugo Chávez Frías' ideas regarding health and justice.

Long before the “social and economic determinants of health” became central to U.S. public health scholarship, scholars and practitioners of social medicine and critical epidemiology in Latin America focused on social inequality as central to structuring health, disease, and social relations. Unlike most North American scholars – but see Krieger⁽¹⁾ – they emphasized analyzing how political economy shapes ideologies and practices and influences the structural effects of health inequities. Jaime Breilh⁽²⁾ criticizes perspectives that simply describe “directly observable health,” emphasizing the need to analyze inequities by identifying the factors that produce fundamental political-economic and social dimensions of the distribution of resources and power. Breilh emphasizes

...the effects of the triple inequity in shaping health: inequities of social class, gender inequities, and ethnic inequities.”
[Translation from: *los efectos de la triple inequidad en la determinación de la salud: inequidad de clase social, inequidad de género e inequidad étnica.*]⁽²⁾

Eduardo Menéndez's relational perspective examines how alternative, indigenous, and popular health sectors are defined through opposition and subordination to biomedicine,⁽³⁾ evaluated through features of what he calls the Hegemonic Biomedical Model [*Modelo Médico Hegemónico*], such as biological reductionism, rationality, scientism, individuality, and focus on clinical efficacy.⁽⁴⁾ Menéndez thus develops anthropologically an epidemiology of forms of medical knowledge as they extend across subjects, sites, and illness trajectories.

A central focus for Menéndez is "*autoatención*", the work of care undertaken by laypersons beyond the direct control of health professionals as they examine their own bodies and those of family members, friends, and co-workers for evidence of health or illness, try to figure out what is happening, use forms of care available to them, make decisions about seeking assistance from professional caregivers, procure resources needed to access this treatment, transport patients, answer questions posed by caregivers, and provide post-clinical care. He argues that *autoatención* is the key locus of lay agency and knowledge in health, and that biomedicine is dependent upon it. Nevertheless, health professionals are taught – usually informally – to reduce *autoatención* to self-medication and the latter to unauthorized ingestion of pharmaceuticals,

...deeming it to be a product of lack of education or ignorance, and tend to identify it with the behavior of the lowest social strata. [Translation from: ...*producto de la falta de educación o de la ignorancia, y tiende a identificarla como un comportamiento de los estratos sociales más bajos.*]⁽⁴⁾

Bringing linguistic and medical anthropology together can greatly extend our understanding of how forms of medical knowledge [*saberes médicos*] are tied to practices of *autoatención*, illuminating ethnographically how the subordination of *autoatención* to professionalized forms of caregiving emerges

and why it is so consequential. I start with Walter Benjamin's exposition of stories, labor, and craft.⁽⁵⁾ Benjamin positions medieval craftsmen as exemplars of storytelling; he suggests that they learned repertoires of stories while acquiring their trade. In workshops, production and storytelling became "practical interests" that transformed the individual experiences of teller and audience into ways of illuminating the world. Rather than isolating labor and materiality from communication, Benjamin joins them as forms of labor in which stories become material and materialities are narratively informed. I would like to extend his analysis to contemporary forms of care and narration. Physicians and nurses learn how to provide particular forms of care and produce specific types of stories in the course of their training, even as laypersons learn communication practices as fundamental facets of *autoatención*. Materialities, bodies, and stories are co-produced in *autoatención*, clinical medicine, and epidemiology. As patients move between sites, what I call acts of *health/communicative labor* get stacked up with acts of care. As we look at bodies, speak with patients, report symptoms, and ask for advice or material assistance, we extract details for inclusion in increasingly complex narratives. Acts of care and of communication are thus coproduced at each site, proliferating as patients and relatives attempt to recount these increasingly embedded acts of care and of communication to clinicians; the latter's words and actions become woven into the narratives transported with patients.

Here I extend these insights ethnographically. Just as access to healthcare and power over clinical interactions is shaped by health inequities, health/communicative inequities structure who gets to speak and write, whose speech and writing becomes biomedical symbolic capital. How do these two axes of health/disease/healthcare interact? How might health/communicative inequities become causal factors that produce and structure health inequities? Do progressive health policies targeting health inequities necessarily ameliorate health/communicative inequities? Here, I suggest, is a central task for an

anthropology of health in the Americas, a key for addressing perhaps the most flagrant shortcoming and the most important obstacle to revolutionary health policies.

DEATH AND COMMUNICATIVE INEQUITIES IN A MYSTERIOUS EPIDEMIC

The prehistory of the events of 2007-2008 lies in a cholera epidemic that killed some 500 people in Venezuela's Delta Amacuro rainforest in 1992-1993. High morbidity and mortality from a preventable and treatable bacterial infection revealed the inadequacy of health infrastructures and the Regional Health Service (RHS)'s failure to prepare for an epidemic. Officials responded both by providing medical personnel, supplies, and transportation and by coproducing – with regional and national journalists – a narrative that blamed the epidemic on the “culture of the indigenous Warao ethnic group”: people classified as indigenous purportedly could not understand biomedicine due to the persistence of “ancient” beliefs in spirits and reliance on shamans. This narrative engendered a health-based ethnic binary that reproduced vast economic, political, and health inequities through clinical medicine, epidemiology, and public health.⁽⁶⁾ Eventually, anger over denigrating news stories and the persistence of unconscionable everyday health conditions led members of the delta's indigenous social movement to place health at the top of its agenda.

In recounting the mysterious epidemic that took place in 2007 and 2008, parents, community leaders, healers, and nurses asked us to use their real names – and particularly those of the children who died – in publications. Our fellow team members team decided, however, that it would be best to use pseudonyms for physicians and epidemiologists.

The beginning of the mysterious epidemic in 2007 came in the midst of Chávez's Bolivarian socialist revolution, which positioned the health of low-income Venezuelans

and indigenous rights as central foci. In July 2007, children began to die in Mukoboina, a settlement of some eighty residents (Figure 1).^(7,8) A fever was followed by a headache that was unresponsive to antipyretics or herbal treatments, initiating a desperate search for a diagnosis and cure, generally starting with Mukoboina's *wisidatu* healer and local representative, Inocencio Torres. A bizarre itching in the legs followed, then numbness ascending to the hips. Soon patients couldn't swallow food and, later, fluids. They experienced anxiety, strange dreams and hallucinations, and often seizures. The first child died after visiting various types of healers; parents then took children to the local nurse and a clinic with a resident physician. Bilingual nurses and a newly-graduated physician tried antibiotics, antipyretics, inhalers, and analgesics. The children salivated profusely, and most experienced hydrophobia. Parents incurred heavy debts for use of motorized canoes, oil, and gasoline. The doctor referred patients to the hospital in the state capital, where physicians sent them along to intensive care units (ICUs) and specialists in metropolitan areas; all returned in coffins. Seven Mukoboinan children died between July and September of 2007, nearly 10 percent of the population. A second wave of cases began in January 2008. June 2008 ushered in a third wave over an even broader area – sixteen deaths in two months. Overall, 32 children and 6 young adults died in the lower delta. Epidemiologists visited Mukoboina repeatedly but couldn't figure it out.

Residents believed that regional officials were indifferent. When parents demanded action, Health Committee President Conrado Moraleda presented evidence of the epidemic to the state legislature and journalists. Enraged that people classified as indigenous challenged their authority, health officials focused on covering up the epidemic. With the third wave, Conrado and brother Enrique launched their own investigation, bringing Clara, Tirso Gómez, Norbelys Gómez, and me on board. As we travelled to each settlement where unusual deaths had taken place, we held meetings that included parents and



Figure 1. Mukoboina Village, Delta Amacuro, Venezuela; 2007.

other residents. The parents' *testimonios* [testimonies] – along with clinical examination of one patient – permitted Clara to provide a presumptive diagnosis of rabies; most patients had been bitten nocturnally by vampire bats one to two months before developing symptoms, indicating a likely route of transmission.

The preceding describes the epidemic in biomedical, functionalist, and linear terms. My focus in this article is rather on how forms of care performed by healers, biomedical professionals, and laypersons were imbricated with complex, interlocking health/communicative practices – and how some got authorized and others denigrated. Menéndez calls for an epidemiology of forms of medical knowledge,⁽⁴⁾ for documenting all perspectives and practices relating to health, disease, and healthcare. What is equally

necessary is an *epidemiology of health/communicative practices*. I adopt Menéndez's ethnographic refusal to structure and restrict one's inquiry in advance by confining it to the examination of an a priori object⁽⁹⁾; here I question a priori definitions of "media" and "communication"⁽¹⁰⁾ along with clinical medicine, epidemiology, and healing. I argued elsewhere that hegemonic notions of media and communication are embedded in critical epidemiology and social medicine, thereby limiting their ability to afford emancipatory frameworks.⁽¹¹⁾ My goal in analyzing the epidemic is to extend this argument ethnographically, examining how health/communicative inequities can structure clinical medicine, epidemiology, healing, policymaking, health communication, and health media, thereby thwarting efforts to achieve revolutionary transformations.

TOWARDS AN EPIDEMIOLOGY OF HEALTH/COMMUNICATIVE VIOLENCE

Excitement and expectation were palpable as our small boat reached Mukoboina. As other team members crossed the dock and entered the house of Inocencio Torres, community leader and *wisidatu* healer, he joined me in the boat. Stopping at each house, we invited residents to a meeting. Having spoken with families at the clinic and at funerals, Conrado knew that parents who had lost children in the epidemic sought a forum for recounting knowledge they had amassed while taking their children from place to place, practitioner to practitioner. They had similarly assembled when epidemiologists arrived, only to be frustrated when the visitors declined to hear their accounts. One by one, parents – in all but one case fathers – walked to the center of the house and recounted efforts to save one, two, or three children.

Graciano Florín is heavier-set than most Mukoboinans, with fluffy, short brown hair, a wide face, and a hint of moustache. In their early 30s, Graciano and wife Matilse Carasqueño had three children in July 2007. Ángel Gabriel was 11, Adalia was 6, and Mary was only a few months old. Ángel Gabriel was the third child to develop the “strange fever”; his symptoms were fever, sore throat, headache, and body aches followed, on day three, by profuse salivation. The parents consulted Inocencio, but, having tried unsuccessfully to treat two children with identical symptoms, he suggested:

We wisidatus think that this disease is too dangerous – too many are getting sick and dying. When there is hebu sickness, we extract it, and patients recover. But when we treat these patients, nothing happens. The doctors have medicines, we should take the patients to them. [Translation from Warao]

Graciano and Matilse took Ángel Gabriel to the nurse across the river, José Pérez. As

with a previous patient, two-year-old Yuri Torres, José used analgesics and an IV, but the fever remained.

I thought, what's going on? Around here when I see cases like this I give them analgesics, the fever comes down, and in two days it's gone. But with this strong fever, even with medicines, they are just the same, just the same, they get even worse. [Translation from: Yo pensé, ¿qué será eso? Aquí llegan casos de fiebre. Yo les bajo la fiebre con un analgésico, y a los dos días no les da más fiebre. Pero fue una fiebre que con la medicina, igualito, igualito y hasta más, que se empeoraba más.]

He took the family to the clinic in Nabasanuka, hoping that the doctor and nurses could save Ángel Gabriel and tell him how to treat similar cases.

When they appeared in the nurse's house, José's questions to Matilse and Graciano went beyond filling a few entries in his patient log: he listened to their observations as he lay Ángel Gabriel in a hammock and started the IV. When their account of the symptoms matched Yuri's, however, he asked few additional questions. Things were different at the clinic. The bilingual nurses conversed mainly with José, quickly calling Dr. Ricardo Cáceres next door, relying on the parents only for Ángel Gabriel's name and age. Dr. Ricardo's only observation based on the parents' account was that he could see “*that the parents were very worried because they knew that their son was going to die.* [Translation from: *la preocupación del familiar de saber que su hijo se va a morir.*” He directed his questions to Pérez, who recounted the patient's history, his diagnostic and treatment efforts; the official production of knowledge about the case was limited to Dr. Ricardo's observations and those provided by his nurses. He reported (in an interview) that Ángel Gabriel

...arrived with a very high fever, intense headache, chest pain, was delirious,

and had similar pathologies. [Translation from: ...vino con una fiebre altísima, mucha cefalea, dolor torácico, delirios, otras patologías así.]

He decided to refer the patient to the hospital in Tucupita. There was little space in his narrative for Matilse's and Graciano's observations.

Although deemed unimportant by clinicians, Graciano and Matilse did not suspend their own archiving of observations on the labor of care and health/communication. They watched Dr. Ricardo and the nurses closely. Dr. Ricardo and the parents did not share a language in common, given that he spoke virtually no Warao and they relatively little Spanish; he asked the bilingual nurses for only scant translation. Admitting defeat, Dr. Ricardo requested permission to transport Ángel Gabriel to Tucupita, where more advanced care might provide answers. Matilse and Graciano's inventory of *saberes médicos* might well have led them to conclude that if they had consulted three different rankings of biomedical specialists (lower and higher ranking nurses and a physician) but only a low-ranking healer representing one specialty, their next step should be to access more skilled specialist healers. Nevertheless, they knew that Zoila and Wilmer Torres had made precisely this calculation with Yuri, taking her to several renowned healers, only to sense Dr. Ricardo's anger when they "asked to discharge her against medical advice" and then watch her die after returning to the clinic the next morning.

When Matilse and Graciano accepted his decision, Dr. Ricardo and the Health Committee arranged transportation to the maternal-pediatric wing of the Tucupita Hospital. Rather than asking the couple questions, physicians consulted the one-page referral sheet Dr. Ricardo provided. During the day and a half that Ángel Gabriel was in the hospital, clinicians did not explain anything to the parents. Acute linguistic inequities helped shape these acute health/communicative inequities, but clinical staff did not ask for help from an employee who translates between

Spanish and Warao. The only words that seemed to have been directed at them indicated that physicians planned to take Ángel Gabriel to the Dr. Manuel Núñez Tovar Hospital in Maturín, where he was placed in the ICU and seen by specialists. When he died there on August 31, a week after symptoms appeared, the parents were simply told "your son is dead," without a word of explanation or condolence. Regarding what caused Ángel Gabriel's death, Graciano noted, a year later,

...I don't know. They didn't tell us. I have no idea. They just gave us the boy and we came back here. [Translation from Warao]

Initially, the couple appreciated the caregivers' work. Care was never withheld, all services were free, and all parties shared a single goal: saving Ángel Gabriel's life. Nevertheless, each leg of the journey from Nurse José's house to the ICU involved an increase in both what is characterized, in biomedical terms, as the level of care and an augmentation of health/communicative inequities. With each step, Graciano's and Matilse's knowledge was increasingly devalued, they were involved in fewer and fewer conversations, were given less and less scope for volunteering observations or asking questions. How they perceived the care provided for Ángel Gabriel was inseparable from health/communicative inequities with which it was co-produced. The couple's insights into how health inequities and health/communicative inequities are produced turned into bitterness and anger upon opening Ángel Gabriel's coffin in Mukoboina. An autopsy had been performed in the hospital without consent, explanation, or conveying any findings. They read the professionals' silence about the autopsies not as a lack of communication but as what Roman Jakobson referred to as a "zero sign," as a clear communicative signal that conveyed its meaning by the lack of a signifier.⁽¹²⁾

In this and many other *testimonios*, parents spoke eloquently – sometimes bitterly – about how acts of care were co-produced with acts of health/communicative

injustice. This pattern extended beyond clinics and hospitals. Healers of various specialties participated actively in our investigation, and I interviewed many of them after the epidemic, tracing their continuing efforts to make sense of why their interventions had failed. I was surprised to see that they similarly disvalued the parents' observations. They asked questions, and some were more opening to listening to the parents' accounts. Nevertheless, they did not regard them as partners in knowledge production, only as relatively uninformed and unreliable sources of details that healers could transform into diagnostically-relevant knowledge. Menéndez⁽⁴⁾ makes similar observations.

Upon returning home with Ángel Gabriel's body, Graciano and Matilse learned that his six-year-old sister, Adalia, left in her grandmother's care, had "the same fever." Despite doubts about the care Ángel Gabriel received, they took her to the kind young doctor and accepted – after consulting several high-ranking specialist healers – another journey to urban hospitals. When she died in the ICU in Maturín, pediatricians and toxicologists suspected mercury poisoning; samples were sent to the National Institute of Hygiene in Caracas, but were reportedly lost. The Regional Epidemiologist, Froilán Godoy, organized a commission and departed immediately for Mukoboina. He focused on mercury poisoning, searching houses for possible sources from thatched roofs to refuse piles. Mukoboina's status as epidemiological ground zero prompted additional visits. A team consisting of Cuban health professionals associated with Misión Barrio Adentro, the parallel health system established jointly by the Cuban and Venezuelan governments, compiled particularly good data on the first ten cases.

Epidemiological investigations were structured by health/communicative inequities. When the visitors arrived, residents expected to engage in a knowledge exchange. They gathered excitedly, ready to share accounts detailing their observations, the forms of care their children had received, and the embedded layers of health/communicative labor that extended from home to nurse to

clinic to hospitals. The epidemiologists, nevertheless, were not interested in listening to their stories; they asked fill-in-the-blank epidemiological questions (the name, age, sex, symptoms, date of onset, and date of death) regarding each child, looked for "data of Hygienic-Epidemiological interest," and "examined the surroundings."⁽¹³⁾ Being denied the status of knowledge producers angered Mukoboinan parents; deeming the visitors refusal to hear their narratives as another sign zero – a powerful communicative hiatus – and the visits as another form of health/communicative violence, they became less and less willing to help each new commission. Epidemiologists, in turn, attributed their own failure to solve the puzzle to

...difficulty acquiring information due to the closed character of the community. [Translation from: *dificultades para acceder a esta información por lo cerrado de la comunidad.*]⁽¹⁴⁾

Health/communicative inequities – and demands for health/communicative justice – were not limited to biomedical sites. When Conrado Moraleda pressed for action in the state capital in February 2008, the local newspaper reported his visit to the Legislative Council.⁽¹⁵⁾ In countering this challenge to their monopoly over the production of public health knowledge, officials spread rumors, including over the radio, that the epidemic was caused by the parents themselves – by feeding garbage or poisoned fruit or fish to their children – or by healers mistreating their patients. Responding to these assertions in the newspaper provided officials with opportunities to reclaim their authority. Visual dimensions were at least as important as textual aspects here. The first article pictured a delta resident, Conrado, on the front page holding a document and interpreting its contents for politicians and officials (Figure 2).

In the second, people classified as "indigenous" were confined to the space of the delta, visible only in archival shots of a rainforest settlement and a "traditional Warao doctor"

smoking a palm-leaf cigar; the three top health officials were shown seated in the state capital, engaged in a sober, measured conversation. Only they were quoted (Figure 3).⁽¹⁶⁾

Another article featured RHS director Dr. Guillermo Rendón as “informing the delta community” that a massive, week-long epidemiological investigation and a new Strategic Plan for Epidemiological Intervention:

...had been able to control the emergency situation in which people are living at this moment, achieving a level of epidemiological security. [Translation from: *han podido controlar la situación de emergencia que se estaba viviendo en este momento, logrando un nivel de seguridad epidemiológica.*]⁽¹⁷⁾



Figure 2. Newspaper article regarding the epidemic featuring local delta resident. Delta Amacuro, Venezuela; 2008.

Note: The title reads “Emergency due to infectious outbreak in the Lower Delta.”

NOTIDIARIO
 Información / Pág. 9
 viernes 22 de febrero de 2008

Aseguran autoridades de salud regional Wisidatus no causan muerte de niños indígenas

Se investigan causas exactas de muertes en el Bajo Delta

■ Freddy León Jr

Tucupita.- El epidemiólogo regional, Oswaldo Méndez observa con mucha preocupación algunos comentarios suscitados por la muerte de niños indígenas en la comunidad de Mucoboina parroquia Nabasanuka municipio Tucupita, defunciones que están siendo investigadas el origen de sus causas, acotando que los Wisidatus (médico tradicional warao) no tienen nada que ver con esta lamentable situación.

Explicó Méndez, que toda la sintomatología que presentaban los pacientes dicho por los toxicólogos de la ciudad de Maturín, era como de una especie de intoxicación, producido por una sustancia desconocida. "Nosotros el año pasado acudimos a la referida comunidad, donde fueron tomadas muestras de sangre, cenefalo raquídeo entre otras, esas muestras fueron enviadas al Instituto Nacional de Higiene, laboratorio de referencia de nuestro estado".

Todos los resultados obtenidos en el aislamiento viral y bacteriano reportaron negativo, igualmente se tomaron muestras de aguas por parte del Ministerio del Ambiente, este notifico que no había intoxicación por mercurio. Este año nuevamente se acudió en el sector de Mucoboina, donde se tomaron muestras de las personas que tuvieron contacto con los niños fallecidos, para seguir investigando la causa de un posible producto tóxico natural. "Pero en ningún momento se esta acusando a los médicos tradicionales waraos".

Por su parte el adjunto a la oficina de epidemiología Dr Reinaldo Márquez ratificó, que como técnico en salud manejan hipótesis que progresivamente se tienen que ir descartando, por lo cual se están buscando sustancias toxicidad en algunos de los pacientes afectados y ratificar el hecho que en ningún momento, han logrado dilucidar toda esta presunciones que se han formulados, por lo cual desmienten algunos comentarios sobre una posible culpabilidad de los Wisidatus, en estos decesos.

"Nosotros creemos en el comportamiento de los médicos waraos, quienes poseen una cultura milenaria que siempre ha existido, por ello sentimos respeto y admiración por esa noble y altísima responsabilidad que viene cumpliendo en el trascurso de los años, en donde se han hecho esfuerzos para trabajar conjuntamente la medicina occidental con la tradicional. Creemos que esa

será la garantía para seguirle dando solución a los problemas de salud que puedan presentar los habitantes de las comunidades indígenas", dijo Márquez

El año pasado se realizó un congreso médico tradicional warao, donde hubo intercambio de conocimientos y experiencias, en la búsqueda de la integración del wisidatus y médico criollo, esa es una muestra que creemos en ellos.

Igualmente el Director Regional de Salud Dr. Luis Gómez manifestó, que desde el Ministerio de salud a través de la coordinación nacional indígena, ratificó su posición de apoyo a los wisidatus, con quien a compartido, y se ha elaborado un proyecto para continuar tratando el tema de incorporación de los médicos tradicionales waraos, al sistema nacional de salud. "Esto hace ver la importancia que representan a nivel de las comunidades. Por ende en ningún momento están efectuando algún señalamiento en su contra, por el contrario los alientan a que continúen trabajando por el bienestar del colectivo".



Director regional de salud acompañado de los epidemiólogos regionales.



Médico tradicional warao.



Comunidades indígenas son atendidas.

Figure 3. Newspaper article regarding the epidemic. Delta Amacuro, Venezuela; 2008.

Note: The title reads "Regional health authorities affirm that Wisidatus [traditional Warao healers] are not causing the death of indigenous children."

This might seem to represent an important example of health/communicative justice, epidemiological and policy responses to parents' and local leaders' demands for answers. Neither media stories nor the official report made mention, however, of the strange epidemic, focusing instead on diarrheal diseases. Rather than listening to residents' observations and concerns, the epidemiological effort included "a series of educational activities undertaken house-by-house," that, the report specified, consisted of "talks to communities about the handling of water and environmental sanitation."⁽¹⁸⁾

The policy, investigation, and intervention were staged as a performance for journalists, brought along to witness the enthusiasm of the vice-minister of the Ministry of Popular Power for Health for the plan and her "personal inspection of the activities undertaken by this multidisciplinary working group."⁽¹⁷⁾

The entourage was carefully shielded from the parents, ensuring that the only words its members heard were spoken by RHS officials. Health Committee President Conrado recalls bitterly that he was "kidnapped" the day of the visit by the assistant regional epidemiologist to prevent him from speaking

with the vice-minister and reporters. Health communication, policymaking, epidemiology, and media coverage thus all provided sites that, like clinical medicine, transformed efforts to produce knowledge about the epidemic and demands for health and health/communicative justice into a highly visible reinscription of the stereotype of “the indigenous Warao ethnic group” as individually and collectively responsible for deplorable health conditions due to purported ignorance and lack of hygiene. It constituted, in short, an official reiteration of the stereotype that emerged from the cholera epidemic.

HEALTH/COMMUNICATIVE INEQUITIES AND REVOLUTIONARY HEALTH POLICIES

Anthropologists and medical historians argue that epidemics X-ray social relations and forms of inequality.^(19,20) In the cholera epidemic, projecting a pervasive cultural logic that purportedly prevented people classified as “indigenous” from embracing rationality and biomedicine in favor of spirits and “shamans” could be used to rationalize high mortality resulting from a complex intersection between geopolitics, hydrology, the Venezuelan petro-state,⁽²¹⁾ and public health policies that provided virtually no sanitary infrastructures. Cholera’s aftermath was the creation of an epidemiological apparatus in which public health institutions assumed a key ideological and institutional role in the surveillance and policing of “indigenous” delta residents. Although this intersection of ethnicity and health relates to a particular regional political economy, it reveals much about other regions where ethnic inequities are tied to health inequities about how racialized logics inform public health policies.⁽²²⁾

The 2007-2008 epidemic lay at the intersection of two powerful narratives, shared by delta residents and regional elites. An ethnic narrative that projects a chasm between indigenous and non-indigenous people cast the 2007-2008 epidemic in the terms that

emerged in 1992-1993: as further proof, according to officials, of “indigenous” cultural difference and, for delta residents, of the discriminatory effects of public health policies. A second centered on revolutionary efforts to redefine health as a “fundamental social right” and to afford all Venezuelans access to healthcare. If evocation of the first narrative in the epidemic seemed over-determined, the effects of the second were equally pervasive but more unsettled and unsettling.

At the center of the second narrative lay *Misión Barrio Adentro*,^(23,24) which I have discussed previously in this journal. The first three years of Chávez’s presidency failed to transform a public health system debilitated by decades of disinvestment and privatization. *Barrio Adentro* arose through horizontally-organized, creative conversations in Caracas’ Libertador municipality between residents, a sociologist, and community workers. Prioritizing health, participants suggested that doctors should live and work in *barrios* [low-income neighborhoods] consisting largely of informal housing build on hillsides. When Venezuelan physicians expressed reluctance, the mayor asked the Cuban Medical Mission to send physicians. Ethnographic work on *Barrio Adentro* indicated that two aspects – in addition to gaining access to healthcare – most impressed residents. First, the Libertador team helped establish health committees, including many individuals without previous leadership experience; they assumed active roles in planning, identifying needs, organizing patient visits, procuring resources, daily problem-solving, house-to-house visits, and emergency calls. Second, patients were struck from the start by the egalitarian forms of address adopted by Cuban physicians, who displayed respect, for example, by using the second-person formal pronoun *usted*.

Thus, *Barrio Adentro* was organized around principles of health/communicative equality and justice from its inception, as reflected in the conversations that generated it, doctor-patient interactions, and health committees. Addressing health inequities and health/communicative inequities

simultaneously was truly revolutionary. The design of Cuban medical education and public health as a mode of ameliorating class differences and narrowing social gaps between physicians and patient populations⁽²⁵⁾ is clearly relevant, but the centrality of health/communicative justice emerged organically with Barrio Adentro's humble beginnings. When Chávez quickly nationalized Plan Barrio Adentro as Misión Barrio Adentro, a single design was implemented top-down throughout the country, excluding the sort of local dialogues that had placed health/communicative equality at its core. The emphasis on health/communicative justice remained, unfortunately, almost invisible to Cuban and Venezuelan policy-makers, and it was largely lost as Barrio Adentro's emphasis shifted to infrastructural projects: building clinics, rebuilding hospitals, and supplying them with advanced medical technologies.

Why? Venezuelan physicians were largely drawn from the middle class. The inequalities that inflected their perceptions of and interactions with working-class patients were exacerbated by medical training, which positions health/communicative inequities at the center, both in students' subordination to their professors and clinical supervisors and how they learn to interact with patients. Successful diagnosis and treatment seems to *require* health/communicative inequities, which become thoroughly naturalized. For working-class patients, health/communicative inequities similarly infuse perceptions of clinical medicine, albeit often through feelings of pain and/or anger. During the decades of privatization, treating patients unequally in public facilities formed a key mechanism – alongside infrastructural decay and staff shortages – through which physicians tried to push their patients into the private clinics in which they also practiced and could secure fees for service. Interviews suggested that Barrio Adentro helped to denaturalize connections between health inequities and health/communicative inequities, turning what Raymond Williams⁽²⁶⁾ called structures of feeling – elements that are not unconscious but difficult to formulate

explicitly – into a site for revolutionary consciousness and action by demonstrating that health/communicative justice can structure clinical medicine and public health.

Conrado Moraleta extended this revolutionary transformation in 2007-2008. As health committee president, he visited the clinic when each strange case appeared, observing clinical interactions and – being bilingual – speaking with patients, family members, nurses, and physicians. He witnessed multiple health/communicative inequities, including *both* Dr. Ricardo's virtual exclusion of the parents' knowledge and his angry reactions when they visited healers and how his requests for guidance from and further action from health officials resulted in silence, rebukes, and warnings. Conrado thus saw that doctors experience health/communicative inequities from both sides. Observing epidemiologists in Mukoboina and the events of February 2008 – including the “kidnapping” that prevented him from carrying out plans for a meeting between residents, national officials, and journalists – made him painfully aware that health/communicative inequities move across scales and beyond clinical interactions. Conrado carried a dog-eared brown folder containing the February 2008 newspaper articles. When he showed them to the parents, translating accusations that they were killing their own children, the articles sparked conversations in which parents connected the denigrating, health-based stereotypes reproduced by health officials and journalists with their experiences in urban hospitals.

Beginning in 1998, Conrado and Enrique listened closely to President Chávez's addresses via satellite television, including how he framed health as a fundamental social right. Bringing Chávez's words into discussions in Nabsanuka led them to conclude that health should figure centrally in the indigenous social movement's agenda. The epidemic prompted them to declare that “*the revolution in health has not come to the lower delta.*” The epidemic illuminated how health/communicative inequities simultaneously infect clinical medicine, epidemiology, public health policy, and news coverage. Going

beyond confronting the epidemic, organizing their own investigation and taking a report to Caracas formed an articulate demand for health/communicative justice. Tacitly accepting their classification as “indigenous,” they challenged the centrality of health/communicative inequities to the indigenous/non-indigenous binary, suggesting that delta residents – far from being too ignorant to understand and implement what doctors tell them – could produce knowledge when health professionals had failed. The brothers thus exposed how the two dominant narratives of health had come together fatally, how the ethnic binary had seemingly disqualified people classified as “indigenous” from active participation in the revolution in health. They created a new juxtaposition of these narratives, asserting that the struggle for racial justice required participation as revolutionary health citizens.

I would like to draw out several dimensions of how the parents, Conrado, Enrique, Norbelys, and Tirso extended Barrio Adentro’s health/communicative justice agenda. First, they demonstrated that all Venezuelans – despite assignment to a subordinate social category or lack of medical training – are producers of potentially valuable medical knowledge. Second, they demanded the right to enter into public debates about health, disrupting RHS’s monopolistic claims. Third, their efforts drew attention to the need to extend a key insight of Barrio Adentro across contexts and scales, to base not just clinical interactions but public health policies, epidemiological investigations, health communication, and media coverage on the principle of health/communicative justice. Fourth, the parents’ experience revealed that a fundamental social right to health must include health/communicative rights, that justice in health cannot emerge in the face of persistent health/communicative injustice. In attempting to hold the revolutionary government accountable on the basis of its own fundamental principles, the parents and our fellow team members exposed a central contradiction, demonstrating how failure to target both health/communicative inequities and health inequities simultaneously undermines revolutionary health

policies and practices. Their goal was not to criticize Chávez’s socialist agenda – which they embraced – nor to provide the political opposition with symbolic capital (they refused) but to positively model this broader agenda, to extend the revolution in health.

As Allende’s example painfully shows, structural contradictions are not resolved overnight, and people with unequal access to power – including health professionals – seldom accept more equal relations without struggle. RHS’s director reacted angrily to our visit to Caracas. Asserting that only RHS had the authority to investigate health conditions and make public statements, he criminalized the team’s work. Clara Mantini-Briggs was questioned for three days by a local prosecutor, and Conrado, Enrique, Norbelys, and Tirso were harassed and threatened. After denying that any epidemic had occurred, RHS’s director collaborated with national officials in attacking the team’s work, questioning the statistics (largely by ignoring cases that had not received medical attention or had been misdiagnosed), and denying Clara’s clinically-based presumptive diagnosis. To this day, the Ministry has never provided a diagnosis, a continuing source of pain and anger for the parents. The minister, in a rare press conference, simultaneously denied that the epidemic existed, questioned our numbers and diagnosis, and explained the deaths by asserting that “indigenous people have different customs,” thus reproducing the culturalist logic that emerged from the cholera epidemic. He then suggested that I – being a U.S. citizen – had made up the whole affair to discredit the revolution, overlooking my appearance on Chávez’s own television program, our research on Barrio Adentro, and over two decades of collaboration with delta residents. Thus, regional and national public health officials used both ethnic difference and socialist narratives to reject demands for health/communicative justice. Nevertheless, the government’s two national television channels portrayed Conrado, Enrique, Norbelys, and Tirso’s efforts positively, prompting a national debate and challenging stereotypes of people classified as indigenous.

CONCLUSION: TOWARD COMMUNICATIVE JUSTICE IN HEALTH

Having previously addressed hegemonic “communicative” assumptions in theoretical terms,⁽¹¹⁾ I have worked here ethnographically. This choice is tactical. Relying primarily on academic theory to explain insights developed by the parents, Conrado, Enrique, Norbelys, and Tirso would reduce them to the status of “informants” who produce “data” and turn ethnography into a tool for augmenting health/communicative inequities and ethnic binaries. The team’s work was rather based on a horizontally-organized dialogic process, one that is portrayed in a book that attempts to extend their demand for communicative justice in health, *Una enfermedad monstruo* [A monster sickness].⁽⁷⁾ In this article I have simply used my experience as a member of the team and my ethnographic and conceptual abilities to draw attention to their analytical work.

Now it is time to reflect on how we can build on these insights in exploring how to achieve communicative justice in health. Health/communicative inequities unravel revolutionary attempts to promote health justice at every turn. Even when care is structured around equality and inclusion, health/communicative inequities contradict these principles, announcing “not really!” If, following Breilh,⁽²⁾ the goal is to identify and counter the factors that produce health inequalities, emancipatory epidemiology and clinical medicine require identifying where health/communicative inequities lie and the effects they produce. Howard Waitzkin⁽²⁷⁾ and others have pushed study of health/communicative inequities in what is generally called “doctor-patient interaction” beyond narrowly-delimited positivistic analyses that reify measures of clinical effectiveness. Mohan Dutta⁽²⁸⁾ demonstrates how health communication programs extend global hierarchies of nations, populations, and *saberes médicos* to local settings. Becoming proper biomedical citizens and learning abstract,

impersonal definitions of life and health and one’s sovereign obligation to protect them require unquestioning accepting of one’s assigned placed in health/communicative hierarchies.⁽²⁹⁾

A major problem, as I have suggested, is that forms of socialization and practice render health professionals poorly equipped to collaborate effectively in efforts to identify health/communicative inequities and achieve health/communicative justice. A key desideratum is to revise training programs in schools of medicine, nursing, and public health to produce something other than ever finer attunement to and compliance with each professional’s present location in health/communicative hierarchies and the obligation to reproduce them. Nevertheless, reforming elite sectors alone will not do the job. Like attention to “doctor-patient interaction,” locating efforts to achieve health/communicative justice exclusively in these sectors will be likely to produce new ways of reifying biomedical authority, forms of evidence, and measures of effectiveness. If health/communicative inequities are more cognitively accessible to the people for whom engaging in *autoatención* requires everyday tactics for dealing with them, collaboration across lay/professional lines will be needed to begin to work towards health/communicative justice.

What are needed, accordingly, are the sorts of collaborations that produced Barrio Adentro and that shaped the team’s investigation of the epidemic. Just as popular epidemiology is crucial for challenging hegemonic epidemiologies, we need *popular health/communicative epidemiologies* to turn everyday awareness of health/communicative inequities into systematic inventories of where they are located in clinical, epidemiology, policy-making, and journalistic settings and the effects that accrue to them. In my case, it was only working alongside low-income urban residents who helped design and implement Barrio Adentro and delta residents during the cholera and rabies epidemics that rendered health/communicative inequities visible to me. My own training in

linguistic and medical anthropology were crucial in giving me something to contribute, but no amount of theory or methodology would have enabled me to grasp these issues on my own. I thus continue to insist that I am extending their insights here, not claiming credit for them.

A major goal of this essay has been to contribute to revolutionary efforts to promote justice in health. The forms of health/communicative labor that produced Barrio Adentro and to figure out what was causing the strange epidemic and bring it to an end have implications for scholarship, practice, and popular struggle everywhere. To claim that I have provided a formula that can be implemented everywhere would convict me of having failed to learn the lessons given me by residents of barrios and rainforests, the importance of horizontally-organized dialogues between laypersons and professionals. Each setting requires new efforts to identify *saberes médicos*, health inequities and health/communicative inequities and to creatively explore ways of addressing them. Nevertheless,

these experiences do suggest a few basic principles. First, a binary opposition between health and communication, medicine and media will reproduce dominant health/communicative inequities. Definitions of health, healthcare, healing, and biomedicine must be revised to see how the sorts of communicative dimensions I have discussed here lie deep within them, not in separate, peripheral spheres. Second, any attempt to achieve justice in health must be based from the get-go on the principle of communicative justice in health. Collaborative efforts to structure how the labor of care and the labor of health communication come together through notions of equality and justice provide a crucial first step. Third, communicative justice in health should not become just another slogan used to make small adjustments designed to maintain existing relations of power but, following the proposal advanced by Conrado, Enrique, Norbelys, Tirso, and mothers and fathers in the delta, to enable us to imagine, debate, and construct alternative social worlds that are truly more just and equal.

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