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### Social justice as epidemic control

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# **SOCIAL JUSTICE AS EPIDEMIC CONTROL: TWO LATIN AMERICAN CASE STUDIES**

**Alex Nading and Lucy Lowe**

In this article, we draw on two cases -- one of reproductive justice movements in the wake of the Latin American Zika epidemic, and one of an environmental justice movement spurred by an epidemic of chronic kidney disease among sugarcane workers -- to argue for social justice as an "elastic" technology of epidemic control. In its compressed form, social justice simply refers to the fair distribution of medical goods. In its expanded form, it emphasizes the recognition and representation not just of medical problems, but of entangled histories of racial, gendered, and economic inequity.

*Keywords: Latin America, epidemiology, health communication, race and gender, social movements, Zika*

**Running Title:** Social justice as epidemic control

**Media Teaser:** How do reproductive rights and environmental justice movements in Latin America engage with global health epidemics of Zika and chronic kidney disease?

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Medical anthropology can claim some credit for bringing questions of social justice into the mainstream of global health (Farmer 1999; Biehl and Petryna 2013). Today, global health institutions from the World Bank to the World Health Organization to the Gates Foundation couch their interventions as both technically effective and socially just. However, within global health circles, social justice tends to be conflated with distributive justice, as perhaps best captured in Paul Farmer's famous axiom that "there's nothing wrong with high-tech medicine except that there isn't enough of it to go around" (1999: 14). One advantage of thinking of social justice in distributive terms is that it allows a precise, quantitative accounting of health outcomes. More vaccines injected, more drugs administered, and more doctors and nurses in clinics can be (theoretically) correlated with lower rates of disease transmission. Success in distributing these goods can be correlated (again, theoretically) to lowered inequality at local, national, and global scales (see Adams 2016). Seen as a matter of distribution, social justice is epidemic control's intended outcome.

In this article, we argue that social justice is not just an intended outcome of epidemic control but one of its key technologies. In order to understand social justice as a technology of epidemic control, we draw on the work of the feminist political theorist Nancy Fraser (2010), who suggests that while *distribution* is a crucial component of justice, justice is also a matter of *representation* and *recognition*. Even though poor and marginalized people are often the targets of epidemic control efforts, they frequently struggle to have their experiences represented in policy and media narratives about those efforts. While states and supranational organizations have considerable say in how medical goods are distributed, representational justice transcends national borders. A view of justice as *representational* opens space to consider the roles of, for example, transnational reproductive or environmental activists in epidemic control. A view of justice as *recognition* calls attention to how such activists make their problems (political, legal, or

medical) legible to states, donors, and scientific experts. Claims to justice must, in the first instance, be recognized as such. In epidemic control, an over-emphasis on the need to distribute medical goods can mask recognition of ongoing racial, political, and gendered discrimination (Fassin 2012; Redfield 2013; Whiteford and Manderson 2000).

We are far from the first to suggest that there is more to social justice in epidemic control than merely distribution. In a recent study, Charles Briggs and Clara Mantini-Briggs (2016) trace how indigenous Warao people struggled to make the Venezuelan state recognize a rabies outbreak in their community, and to convince national and international media to accurately represent the epidemic to their audiences. The Warao were not entirely successful because, as Briggs and Mantini-Briggs argue, “communicative inequities” between the Warao, the state, and the media created “health inequities” (2016: 5). Where the Warao saw a lack of recognition in the Venezuelan state and a lack of representation in national and international media, the state and the media saw in the Warao only poverty and medical ignorance -- problems to be solved through distribution.

Drawing on two case studies, in this article we blend Fraser’s tripartite theory of justice with Briggs and Mantini-Briggs’ identification of a domain of communicative justice. First, we discuss how reproductive justice activists in Latin America confronted the recent Zika virus epidemic. Second, we discuss how sugarcane plantation workers in Nicaragua launched an environmental justice movement to address an ongoing epidemic of chronic kidney disease of unknown causes (CKDu). This comparison is based upon limited data about two fast-moving epidemics. Our objective is not to make a normative evaluation of interventions into these epidemics; rather, we aim to identify a dynamic tension among distributional, representational, and recognition-based approaches to social justice. Like epidemic technologies, methods of doing environmental and reproductive justice originate largely in the global North. North or

South, however, these manifestations of social justice constitute forms of what Michelle Murphy calls “counter-conduct.” They involve heterogeneous and multiple actions *within* epidemics, rather than a “unified reaction” *to* epidemics (Murphy 2012: 183). Like more familiar technologies of epidemic control such as vaccines, educational campaigns, and epidemiological surveillance, environmental and reproductive justice do not operate the same everywhere (Lock and Nguyen 2010). They are, in a word, *elastic*.

Our description of social justice as elastic echoes a principle of critical medical anthropology, namely, that “health is not some absolute state of being but an *elastic* concept that must be evaluated in a larger sociocultural context” (Baer, Singer, and Susser 2003: 4, emphasis added). Importantly, elasticity is not a synonym here for relativity. It is not the case that concepts like health or social justice simply mean different things in different contexts. According to the *Oxford English Dictionary*, the word “elastic” has its root in the Latin term *elastica virtus*, the “impulsive force of the atmosphere.” The elasticity of concepts like health and social justice, as anthropologists well know, does not prevent them from motivating people to act. To say that these concepts are elastic is to call attention their impulsive force, and to highlight how people harness that force in scientific, political, or other kinds of projects. In physics, elasticity is the capacity of materials to be compressed into small spaces, but their energy emanates from their capacity to expand. In the cases of the Zika and CDKu epidemics, states, supranational organizations, and transnational activists have tended compress the meaning of social justice to the mere distribution of goods. Movements for reproductive and environmental justice have worked to expand, or *decompress*, social justice to encompass questions of representation and recognition. This compression and decompression drives epidemic control.

We find evidence for the elasticity of social justice in communicative practices. In reproductive and environmental justice movements, communicative inequities have long played a

key role. In the aftermath of the Zika outbreak in Latin America, reproductive justice activists used a variety of communicative techniques, from legal arguments to both public and clandestine social media networking, to make epidemic control compatible with their expansive view of social justice. In our second case, that of CKDu in Nicaragua, things turned out differently. In that case, the communicative channels of law and social media were quickly coopted by transnational activists, journalists, and corporations, who downplayed Nicaraguan activists' concerns about the impact of plantation agriculture on the environment.

### ZIKA AND REPRODUCTIVE JUSTICE

The Zika virus typically causes a mild fever, rash, and joint pain, though many cases remain asymptomatic. It is primarily transmitted by *Aedes aegypti* mosquitoes, which also transmit dengue, chikungunya and yellow fever; when the outbreak emerged in Brazil it was believed to be a milder form of the more locally familiar dengue (Diniz 2017: 25). In 2015, however, it became clear that this outbreak of Zika infection was more serious, and in northeast Brazil, zika in pregnant women was linked to a rash of severe fetal abnormalities, including microcephaly, and elsewhere, to Guillain-Barré syndrome, seizures, swallowing problems, and hearing and sight deficits. By 2016, antenatal Zika infection was confirmed as a cause of miscarriage and stillbirth (Rasanathan et al. 2017: 525). It is now evident that Congenital Zika Syndrome (CZS), as these symptoms became classified, reaches far wider than the initial focus on microcephaly. Research into the first cohort of women with symptomatic Zika virus during their pregnancies suggests that “for each baby born with Zika-related microcephaly we can expect 12 cases of CZS” (Rodrigues 2017: 832).

Zika became a WHO-designated Public Health Emergency of International Concern (PHEIC) on 1 February 2016. In the days following the announcement, the United States

reported a case of sexually transmitted Zika, while Brazil confirmed a case of infection through the transmission of blood from an infected donor. With this declaration and in the wake of the Ebola crisis in West Africa, controlling Zika became, at least briefly, a global health cause célèbre. At some bureaucratic or political level, “the world” seemed to have come to an agreement that something must be done.

The story of the Zika crisis is now being thoroughly told by the social scientists, doctors, and affected women and families (see Diniz 2017). It is not our intention to rehash the events surrounding the epidemic, but it does seem fairly clear that the main reason that the WHO and the world rallied to address Zika was *not* that millions of people in Latin America were living in close proximity to dangerous, disease-carrying mosquitoes. Rather, the vigorous response to Zika seemed to be spurred in part by the possibility that it (unlike infection with dengue or chikungunya, for example) could lead to microcephaly and severe disability in children. Media images of such children, and the potential (no matter how unlikely) for migration and sexual transmission to spark a global epidemic, attracted international attention.

A leading ground for global action, then, was that allowing microcephaly to persist was unconscionable from a moral perspective. As stated by the members of the WHO Emergency Committee, the then-unproven theory that Zika and microcephaly were related was the compelling factor in their recommendation of the PHEIC declaration (Heymann et al. 2016: 719). The response to Zika seemed premised on the principle that children should not be born into severe neurological abnormalities, and on that basis, women should have access to relevant reproductive rights and services (Heymann et al. 2016: 720). In the context of the outbreak, the rights of any women,

whose fetus might be compromised by Zika infection, was worthy of protection. For some, control of Zika could become a pathway to social justice, seen as more equitable



distribution of access to reproductive and antenatal care.

Achieving such distribution—and converting a short-term global health emergency into equitable national-level reproductive health policies—was easier said than done. In most parts of Latin America, abortion remains illegal or difficult to obtain. What passes for women’s health often amounts to promoting (limited methods of) birth control and safer sex. Restrictions on access to contraception and antenatal care are exacerbated throughout Latin America by widespread prevalence of sexual violence and limited domestic authority among women, which contribute to high rates of unplanned pregnancies (Ali et al. 2017: 2). The early response to CZS from governments in the region was to curtail the impact of the virus not by preventing transmission, but by limiting the births of children who could potentially be affected by it.

In El Salvador, for example, women were advised to avoid pregnancy for two years (Rasanathan et al. 2017: 526). There, abortion is illegal in all cases, including incest, rape, and risk of life to the fetus or mother, and contraceptives are difficult to access. These restrictions reflect a largely conservative, Roman Catholic understanding of justice, now ascendant in Latin America, which is primarily concerned with the potentiality of the life of the fetus, rather than needs or concerns of the women and children who bear them (Ramírez and Morgan 2017). In Brazil, abortion is classified as a crime against the potential life of the fetus and is illegal in all cases except risk to maternal life, rape or incest, or anencephaly, a severe abnormality where the brain and skull of the fetus fail to develop properly (Diniz 2007). In 2012, Brazil’s Supreme Court classified anencephaly as akin to brain death, and affected fetuses as “without the potential for life” (Valente 2017: 1377). Terminating pregnancy, therefore, did not entail an abortion, understood as the ending of a potential life, but a merciful procedure to precipitate a foregone conclusion. The Government of Colombia, where access to contraceptives and abortions is amongst the most liberal in the region, also recommended delaying pregnancy for six to eight

months, but the Zika epidemic reached Colombia when the implications of the virus on developing fetuses was already apparent. The prevalence of routinized obstetric ultrasounds allowed Colombian women with fetuses indicating abnormalities to opt for terminations. This likely contributed to the relatively low number of infants born with microcephaly (McNeil and Cobb 2016).

A view of Zika as simply a moment for reconsidering the (re)distribution of reproductive resources, however, is insufficient for understanding grassroots efforts to adequately represent the struggles of poor women of color to achieve state recognition. In all of the affected countries, young, single women and girls of color remain the most acutely affected by the immediate and long-term implications of Zika (Human Rights Watch 2017a: 26). In Brazil, more than three-quarters of women who gave birth to babies with microcephaly between November 2015 and September 2016 identified as either “black” or “brown” (Human Rights Watch 2017a). These women were most likely to live in endemic areas and least likely to be able to protect themselves from either mosquitos or unplanned pregnancies. As Diniz points out, “until now, there have been no reports of affluent women giving birth to babies with Zika-related neurological disorders” (2016: 62). Prior to the Zika outbreak, research conducted in urban regions of Brazil highlighted that black women were more likely to have had an abortion, and that they were three times more likely to be admitted to hospital for post-abortion care than white women (Diniz and Medeiros 2012). Black women were also more likely to use dangerous methods to induce an abortion and were less likely to have any help (De Zordo 2014: 24). While the rural northeast of Brazil was most severely impacted, women in the favelas of Rio de Janeiro have a similar profile – they are poor and black (Diniz and Ambrogi 2017: 142). According to Human Rights Watch, “the Zika virus outbreak in Brazil disproportionately impacted women and girls and aggravated longstanding human rights problems, including inadequate access to water and sanitation, racial

and socioeconomic health disparities” (2017a: 2). Brazilians are not alone. Across Latin America, women’s experiences of Zika are bound up with other social justice struggles, for fair housing, cleaner environments, and freedom from racial discrimination (Vélez and Diniz 2016: 59).

Yet such struggles fade away once epidemics like Zika become about babies and reproduction *in general*, and not, say, Afro-Brazilian babies. Framed as either a mission to protect the unborn in an emergency-saturated present or as a long-term effort improve antenatal care and counselling services, the global approach to Zika took a remarkably compressed view of social justice in terms of the (limited) redistribution of reproductive technologies. Now that the acute phase of the epidemic is over, the long-term focus on mosquito elimination or the development of vaccines—also forms of distributive justice—risk further occluding the intersectional injustices experienced by low-income women of color (Johnson 2017: 5).

Yet the compression of social justice is never permanent. While reproductive rights continue to be the dominant thread of much academic and activist discourse in Latin America (Morgan and Roberts 2012), “reproductive justice,” which emerged among women of color activists in the US in the mid 1990s, emphasizes the relationship between reproductive rights and other forms of structural and economic inequality. Reproductive justice highlights “how the control, regulation, and stigmatization of female fertility, bodies, and sexuality are connected to the regulation of communities that are themselves based on race, class, gender, sexuality, and nationality” (Silliman et al. 2016: 10; Luna and Luker 2013). A principle of reproductive justice is that adequately *representing* women’s experiences of emergencies, whether political, environmental, or medical, means contextualizing those experiences in the social roles and physical environments women inhabit and perform (Murphy 2015).

Responses to CZS largely failed on this point. They failed to *recognize* the relationship

between epidemic control, reproductive health, and social and economic inequality that makes Zika a distinct problem for poor, undereducated women and girls of color. Consider the case of Brazil, which is still the epicenter of CZS. When a new bill was introduced in December 2015 to make abortion laws more restrictive, even in cases where women have become pregnant as a result of rape, activists and legislators seized the Zika crisis as an opportunity to address reproductive injustices. In August 2016, the Brazilian Supreme Court was petitioned to allow women who had contracted Zika virus access to abortions. Beyond this, the petition sought to expand social security and health care, including access to contraceptives (Collucci 2016). Just a year later, in December 2016, the Supreme Court decriminalized abortion in the first trimester, with Judge Luis Roberto Barroso emphasizing that a woman's right to decide was crucial to achieving equality (Glum 2016). However, state-level judicial claims to reproductive rights in highly visible contexts such as Zika lost traction when the global emergency posture faded away. In November 2017, one year after the PHEIC for Zika was lifted, a Brazilian Congressional Committee voted in favor of a constitutional amendment that would prohibit abortion in all cases (Human Rights Watch 2017b). Meanwhile, the Brazilian government continues to confiscate international deliveries of abortifacient pills and has considered longer minimum sentencing for women who are convicted of obtaining abortion in Zika-related cases (Harris, Silverman, and Marshall 2016: 2).

The gains from any legislative redistribution of reproductive rights, then, appear highly constrained, and reproductive rights have been quarantined as private issues (Johnson 2017). Dominant global responses have largely failed to address the private "perversities of the reproductive rights regimes that amplify the effects of Zika infection for pregnant women" (Johnson 2017: 7). Microcephaly is usually undetectable until well into the second trimester, making abortions in the first trimester, even if safe and accessible to low-income, marginalized

women, somewhat irrelevant in this context. Similarly, the rapid deployment of specialized microcephaly clinics in Brazil are of limited benefit to mothers who have been forced to give up their jobs in order to provide the constant care that their severely disabled children require, and who cannot afford transportation costs to the clinic (Stern 2016).

The rapid shift of reproductive questions to the rarefied world of courts and legislation constitutes a form of communicative inequity (Briggs and Mantini-Briggs 2016). Poor women of color, however, have not allowed this inequity to go unopposed. Their struggle for representation and recognition of the intersectional burdens of gender discrimination, racism, and poverty is a testament to the elasticity of social justice in epidemic control. Brazilian women with limited reproductive agency have been credited with grasping and acting upon the abortifacient properties of misoprostol (De Zordo 2016). Information about and access to abortion pills has shaped new transnational networks of health and justice, as demonstrated by the significantly higher rates of women across Latin America requesting them through online telemedicine groups, such as Women on Web, since the Zika outbreak began (Aiken et al. 2016). Women on Web describes itself as a “digital community” and an “international collective” ([womenonweb.org](http://womenonweb.org)) that provides abortion pills, contraceptives, and advice to women. In Brazil, reports of serious abortion complications dropped from around 80,000 to 33,000 between 1992 and 2009, a period that coincides with the illicit uptake of misoprostol to induce abortions. The sharpest decrease occurred before 1998, when the Brazilian government prohibited pharmacy access to misoprostol and restricted it to hospitals (Gomperts et al. 2014: 130). Access was further constrained in 2011 through strict limitations on the availability of online information about misoprostol in Brazil (Gomperts et al. 2014: 130). These legislative constraints led women to seek misoprostol through black market sources, which usually came with little or no advice on dosage, side effects, or complications. Through telephones and the internet, telemedicine groups such as Women on

Web, whose helplines are staffed by doctors, facilitate not only access to abortifacients but also crucial medical advice, so addressing a critical communicative inequity.

Though the demographics behind the spike in online requests for abortifacient drugs are unclear, they indicate the distinct possibility that dangerous illegal abortions in the region increased overall after the Zika outbreak. For Women on Web, this increase constituted a grave threat, especially to poor women of color. In Guatemala, approximately 21,000 of the roughly 65,000 women who sought illegal abortions in 2006 alone were hospitalized for complications (Singh, Prada, and Kestler 2006). In response to this Zika-related threat, activists from Women on Waves, the Dutch organization that is the parent of Women on Web, sailed to Guatemala, where they planned to provide services and care, primarily to poor and indigenous pregnant women, aboard a ship located at least twelve miles offshore, in international waters. When the vessel was detained by the Guatemalan military, a Women on Waves spokesperson told a reporter “abortion is a matter of social justice” (Davis 2017). The group’s aim, aside from providing medical services, was to give “women the tools to resist repressive cultures and laws” ([womenonwaves.org](http://womenonwaves.org)). Recognition and representation, in addition to the distribution of contraceptive technologies, are fundamental aspects of their activism.

Initially, then, the work of Women on Waves/Women on Web seems primarily distributive: the group provides advice and services to women. Yet the organization's work as an “international collective,” at sea and online, is premised on a deeper form of solidarity—one designed to give poor women the ability to effectively communicate with state institutions, with doctors, and with one another. Although it is nominally a Dutch organization, Women on Web works in partnership with doctors, activists, and women all over the world. It is part of a fast-expanding virtual and real communicative space in which women can share advice, experiences, and engage in activism, fostering a recognition of reproductive justice struggles that legal

channels occlude.

In parallel to the increased engagement with Women on Web, Brazilian families of children with microcephaly have been organizing campaigns and sharing advice through Facebook and Whatsapp groups (Rodrigues 2017: 833). In such groups, women “share terms of informed consent, discuss new opportunities of participation in scientific research, or the biomedical vocabulary used to describe their children” (Diniz and Ambrogi 2017: 143). In doing so, women are engaging in forms of care while building local and national collectives around the need for recognition and representation in health services. “If on the one hand women seem to be the main victims of Zika virus in Brazil,” Brazilian reproductive justice scholars Simone Diniz and Halana Andrezzo write, “on the other hand they emerge as leaders and entrepreneurs of supportive initiatives. They start to meet through the health services, keep in touch and organize themselves by social media – even the poorest ones have mobile phones” (2017: 23). Through social media, groups like the Union of Mothers of Angels are mobilizing for long-term care for CZS-affected children, as well as “against the social and economic inequities,” including environmental degradation, economic inequality, and human rights protection, “that fueled the epidemic and worsened in its wake” (Daryani 2018).

Latin American women’s engagements in harnessing the communicative tools internet and social media counterbalance the tendency in global responses to epidemics to compress social justice into the narrow realm of distribution. In the aftermath of Zika, women’s rights, antipoverty and antiracist movements, and global health are being blended together in a “decompressed” social justice struggle. Still, demands for access to abortion in cases of Zika infection continue to frame the issue as exclusively a concern with the potentiality of fetal life, rather than broader claims to women’s rights (Ramírez and Morgan 2017). This “misframing” of the issue (Fraser 2013: 197) precludes consideration of reproductive justice more broadly, as well

as of the needs of women who have already become mothers to children with CZS. Fraser suggests that globalization, particularly through digital media, has rendered such misframing visible by calling into question the position of the state as the site at which justice is sought and enacted (2013: 197-200). Women affected by Zika are seeking recognition through transnational feminist and anti-patriarchal movements, which use novel communicative channels to circumvent the role of the state in defining and addressing their concerns. As a form of communicative justice, these movements reframe Zika and CZS in a way that goes beyond prenatal care and contraception to include child care, and beyond the distribution of medical goods to include environmental and economic justice.

#### CHRONIC KIDNEY DISEASE AND ENVIRONMENTAL JUSTICE

To further explore the relationship between social justice and epidemic control, we now turn to environmental justice. Diseases related to environmental and occupational hazards—for example, pesticide exposure and proximity to waste facilities—have been key public health concerns in Europe and North America for decades but are relatively absent from global health agendas. One reason for this absence is that disorders resulting from exposure to chemicals, air pollution, and workplace hazards tend to be confronted more often by lawyers and activists—in actions often lumped under the wide-ranging framework of environmental justice—rather than by the biomedical experts who lead global health institutions (Mitman, Murphy, and Sellers 2004; cf. Petryna 2002; Fortun 2001).

Environmental justice can be conceived as a form of social justice in which the conditions of individual bodies or of racially, politically, or otherwise marginalized groups are at stake, but so too is the wider biophysical environments in which people, live, work, and raise children and animals (Bullard 2000; Checker 2005). As with reproductive justice, environmental justice



initially grew out of US civil rights and indigenous sovereignty movements. Like reproductive justice, environmental justice is driven by an impulse to seek not just the equitable distribution of goods (clean air and water, safe living and working conditions) but also the recognition and representation for people and places traditionally discounted by corporate, state, and academic powers.

In the global south, mounting environmental justice movements has been especially difficult (Schroeder et al. 2008). Nevertheless, indigenous, peasant, and women's groups have used a variety of strategies to link the conditions of nonhuman ecologies to human struggles for recognition and representation. These groups, Rob Nixon (2011: 4) explains, "can seldom afford to be single-issue activists: their green commitments are seamed through with other economic and cultural causes as they experience environmental threat not as a planetary abstraction but as a set of inhabited risks, some imminent, others obscurely long term." What Nixon (2011) calls "the environmentalism of the poor" is by definition broad and multifaceted. This makes it a poor partner for contemporary global health, which is dominated by "single issue" institutions and actors (the WHO, the Gates Foundation, medical schools, and so on).

In the past decade, however, environmental justice activists have put one disease, "chronic kidney disease of unknown causes" (CKDu), onto the agendas of global health policy makers. In Nicaragua, CKDu has been linked to thousands of deaths—nearly all among sugarcane plantation workers (Brooks and McLean 2012). Despite the high rates of morbidity and mortality, news of the epidemic did not reach global health officials via its statistics. Instead, CKDu became visible through a series of legal cases, protests, and media campaigns by Nicaraguan plantation workers and others who lived in the country's largest sugarcane producing region, in the northwestern departments of León and Chinandega. Thanks in large part to a movement that began in northwest Nicaragua, CKDu is now being addressed not just in Central

America but in Sri Lanka, India, and north Africa (Chatterjee 2016). The story of that movement is, like the story of women's transnational reproductive justice mobilization in the wake of Zika, instructive for understanding social justice as an elastic technology of epidemic control.

In 2008, the World Bank's International Finance Corporation (IFC) was preparing a \$55 million loan to enable Nicaragua's largest sugar company, Nicaragua Sugar Estates Limited (NSEL), to expand its plantations and construct an ethanol plant near the town of Chichigalpa, in the Department of Chinandega. Before the loan was approved, a group of workers living with CKDu and families of those who had died from it filed a legal grievance with the IFC's Compliance Advisor/Ombudsman (CAO 2008). The grievance was officially submitted to the World Bank by the US-based Center for International Environmental Law, in association with a citizens' group from León's predominantly indigenous Goyena district and a newly formed sugarcane workers' organization called the Chichigalpa Association for Life (*Asociación Chichigalpa para la Vida*, ASOCHIVIDA). Perhaps because its provenance was legal rather than medical, the grievance is rife with rights-talk. It alleges violations of people's "right to freedom of association, right to safe and healthy working conditions, right to health, and right to water." It tells about the deaths of indigenous peasant farmers' cattle due to contaminated groundwater; about the blockage of paths and roadways connecting villages, so limiting freedom of association; and about poor flood control, damage to small farms and gardens, air pollution from pesticides and burning sugar, *and* suspected kidney disease. The claims were thus not just about CKDu, but about the various ways in which quality of life in the sugarcane zone was deteriorating. The grievance was about work and kinship, subsistence agriculture and industrial farming, traditional land tenure, a fragile local economy, and shifts in a global sugar supply chain.

Despite the wide-ranging nature of the grievance, its narrative about kidney disease

seemed to resonate most with the CAO. As the grievance explained, while former NSEL workers were sick or dead, those who were seeking work on NSEL-owned plantations now routinely had their blood tested when they applied. If high levels of creatinine (a key biomarker for CKDu) were detected, they were refused work in the fields. Those who raised questions or tried to form unions not sanctioned by NSEL were silenced or, worse, physically threatened. The grievance also alleged that CKDu was likely associated with the increased usage of chemical pesticides.

The grievance succeeded in its objective of temporarily halting the IFC loan process. In late 2008, the sugar company, NSEL, and the workers' group, ASOCHIVIDA, negotiated a plan to appoint a US-based research team to study the kidney disease problem (Brooks and McLean 2012). Importantly, at this stage, the group representing the residents of Goyena—many small farmers who identified as indigenous Sutiaba people and were not directly employed by NSEL—ceased to be part of the grievance process. NSEL, international scientists, and the Nicaraguan state insisted that the problem before them was not multiple (threats to land tenure from expanding sugarcane plantations, deaths to cattle, or the enclosure of traditional footpaths and roads). The problem was singular: CKDu among sugarcane cutters.

This compression of the issue from many problems into one was engineered in part to establish common ground. It did seem likely that something in the environment—a new pesticide, perhaps—was the “unknown cause” in question. In the years since, however, epidemiologists have failed to find a link between kidney disease and pesticides in soil or water. It seems just as likely that increased exposure to heat (cutting sugarcane is incredibly hot, dehydrating work) is to blame for failing kidneys. Still, no single “smoking gun” has been identified (see Jimenez et al., 2016). As long as the causes remain unknown, NSEL and the Nicaraguan Government have continued to deflect blame for the epidemic and to claim that it

must be connected to genetic or behavioral factors, not the plantation conditions they have created.

The compression of the problem here is instructive. Even though the original grievance discussed limits to free public association, damage to water networks, and the deaths of family cows—the capacious stuff of environmental justice—a disease-centric narrative was extracted from the complaint, making it difficult for non-caneworkers such as the claimants from Goyena to be recognized. The notion that an exploitative company might dump pesticides on its workers, make them sick, and then fire them was certainly compelling. From a distributive justice perspective, a wrong needed to be addressed. But as soon as the pesticide-CKDu connection became difficult to sustain, NSEL and the Nicaraguan government gained an opening to counter with talk of proximal causes: genes and behaviors. In mid-2017, NSEL’s own website reprinted an article by a journalist who had earlier helped to publicize a movement to boycott the company’s signature product, Flor de Caña rum (Wei 2015; Hoebink 2014). In the article, the journalist partly repudiates that boycott, pointing to studies of an association between heat exposure, rising global temperatures, and CKDu in Central America, Sri Lanka, and India to argue that the disease was not a problem of Nicaraguan sugarcane production per se, but of global climate change (Wei 2017). NSEL has taken voluntary measures to protect workers’ kidneys by reducing exposure to sunlight and promoting hydration, but they continue to assert that CKDu is not a symptom of broader inequities.

NSEL’s decision to reprint the article illustrates what Briggs and Mantini-Briggs (2016: 273) call “health/communicative inequities.” In this case, as scientists, states, journalists, and corporations have seized the epidemic narrative, those with the least power—especially the residents of Goyena, whose claims were not disease-based—have seen their struggles with “big sugar” go misrepresented or simply unrecognized. In some ways, this outcome is tragically

typical of environmental justice claims (Checker 2005; Ottinger 2013). More importantly for our argument, the situation signals how a broad-reaching social justice claim can be compressed into a distributive social justice claim (Fraser 2010).

Scientific knowledge (and its absence) plays a role in this compression. One might expect a knowledge vacuum to create space for a multi-issue justice movement to thrive, but that did not happen in this case nor initially in the Zika case. Recall that the declaration of a PHEIC for Zika was declared in a context of epidemic uncertainty. The lack of knowledge about a causal connection between Zika and microcephaly was not a hindrance to the declaration (Heymann et al. 2016). In both cases, the push to establish an etiological (as opposed to a structural, historical, or more broadly ecological) line of causality became central to how global health and global media communicated about the epidemic.

Whereas social media and online platforms like Women on Web have become media for communication about Zika across scales of community, nationality, class, and race, online discussion of CKDu has had quite a different character. After the 2008 grievance settlement, international NGOs and journalists began flooding the internet with stories about the suffering of cane workers, and with calls to action. The naming of the problem as a “mystery” epidemic of “unknown” causes created a rallying point for journalists from *Vice*, *The New York Times*, and *The Guardian*, among others. In the absence of epidemiological certainty about what caused CKDu, web-based activists and journalists built up a fortress of moral certainty. The situation, as mediated online, recruited a broad range of transnational actors into the cause of saving sugarcane workers and solving the mystery. The fact that the precise cause of CKDu has not been determined has not prevented a distributive approach to social justice to predominate in global discourses about epidemic control. On the contrary, it *enabled* it to predominate. Solving an epidemic mystery, it seems, requires a re-distribution of expert resources.

Those affected by CKDu in Nicaragua find themselves in what environmental justice scholar Kim Fortun (2001) calls a “double-bind.” To draw attention to their struggle, they must try to occupy two contradictory positions at once. To have a voice before large corporations like NSEL, they must act as political subjects, with historical and geographical ties to a company and a place, and with legal entitlements to workplace protections, healthcare, and social security conferred to them as citizens of Nicaragua. To gain the attention of global health scientists and advocates, on the other hand, they must act as victims: passive subjects in need of a life-saving expert solution to the “mystery.” Many rightly wonder whether the search for that solution might be excusing the “slow violence” of decades of exploitation and environmental degradation in Nicaragua’s sugar plantation zone (Nixon 2011). They fear that the corporation might prey on the patience that they have thus far displayed—that it might hide behind the growing number of (as yet inconclusive) studies of CKDu and continue to sow epidemiological doubt along with its yearly crop of sugarcane. The advent of CKDu onto the global health scene, then, is potentially beneficial for many patients, but potentially harmful to the broader environmental justice movement of which they form a part.

Our aim is not to discount the achievements of the scientists who have worked to bring attention to CKDu and to find ways to prevent it. Rather we aim, as Michelle Murphy (2015: 722) characterizes her work on transnational reproductive justice, to “unsettle” the epidemic narrative -- to “challenge to gestures of rescue, sympathy, and occupation that too often recapitulate colonial legacies.” Based on a close reading of the original 2008 grievance, it is clear that the complainants in the Nicaragua case, like the women whose reproductive justice activities we discussed above, were not only interested in a single disease. Their demands were never simply for biomedical goods to be redistributed. Rather, the original complainants were asking for recognition from the dominant local industry, the state, and supranational

organizations. They were asking for representation in decision-making processes that went into shaping the future of their communities and regions.

This case reveals how, as medical problems become “globalized,” the power to “frame” the terms of the relationship between social justice and health can shift from the hands of those suffering (the cane cutters and their families, of course, but also their neighbors in Goyena) to the World Bank, the sugar companies, activists, and the state (Fraser 2013). In the work of “unsettling” epidemic narratives, access to the media is crucial (Briggs and Mantini-Briggs 2016). If experts, states, and well-connected journalists continue to dominate discussions of CKDu, justice for those living in Nicaragua’s sugarcane zone could be reduced to the provision of technical treatment and preventive measures. From the perspective of the people in Chichigalpa and Goyena who wrote the original grievance, justice amounts to a refusal to settle the question—a refusal to disaggregate suffering at the level of the body from oppression at the level of the state or degradation at the level of the regional and community environment.

### THE ELASTICITY OF SOCIAL JUSTICE

A starting point for this special issue of *Medical Anthropology* was the idea that techniques and technologies of epidemic control are never neutral tools. From vaccines to antiretroviral drugs to antibiotics to clinical trials, these technologies harbor embedded assumptions about the value of life, the nature of the body, and capacity of patients and providers to communicate (Redfield 2013; Petryna 2009; Lock and Nguyen 2010). But epidemiological technologies are not always material tools. Discourses about sex-positivity and status-consciousness for HIV treatment, or discourses of personal responsibility for managing obesity, hygiene, and metabolic disease, are kinds of epidemic control technologies, too (Yates-Doerr 2015; Pigg 2013; Nguyen 2010; Briggs and Briggs 2003). We suggest that social justice should also be seen as a technology of epidemic

control. The difference is that social justice is also a technology for addressing racial, gendered, and political struggles.

To take the example of Zika, social justice might mean finding ways to insulate *all* women and fetuses from mosquitoes, regardless of the circumstances that produce that exposure. Alternatively, social justice might mean finding ways to protect the urban poor specifically from mosquitoes and viruses, as well as from dangerous abortions. In this second approach, racial and class inequalities are obstacles to the distribution of mosquito controls, abortifacient drugs, and antenatal care. Such inequalities should not impede the rights to safe pregnancy any more than mosquitoes should. Still, even in this second approach, there is no logical need to ask *why* women are poor (or racially marginalized or politically oppressed). The mission becomes either to protect all women, globally, from harm, or to manage the problem of birth defects among a particularly vulnerable population. In the Zika case, an immediate concern for the rights of the unborn and the burden of CZS threatens to supersede longer-term struggles among women (not just mothers) for reproductive justice. Those struggles have gone largely unrecognized and misrepresented in courts of justice, in global health policy, and in the international media.

To see social justice as a technology of epidemic control, it is essential to consider how affected people work to counterbalance these communicative inequities (Briggs and Mantini-Briggs 2016). In the struggles of poor, black Latin American women to make reproductive justice out of the Zika situation, the mosquito, the abortion, the condom, the national law, and the World Wide Web no longer operate as distinct technologies of exposure or risk or mitigation. Rather, they are “animated” in a shared experience of suffering and creative political response (Murphy 2012: 176). What we have termed the “elasticity” of social justice is manifested in women’s mobilization in solidarity with international advocacy organizations like Women on Web and with one another. Through this mobilization, social justice is “decompressed.” Social



justice—a simultaneous demand for distribution, representation, and recognition—has become in the case of Zika not a desired result of epidemic control, but its very means.

But elasticity goes both ways. Social justice can always be recompressed. With CKDu, what started as a broad-based movement for environmental justice, with disease was an important but by no means singular concern, was compressed into a search for “unknown causes.” Along the way, the place-based concerns expressed by the people of Goyena and Chichigalpa were de-animated: they went unrecognized and under-represented by international activists, journalists, and epidemiologists (Murphy 2012). As CKDu was framed as a global health issue, it was retrofitted into global health’s distributive, expert-driven model of social justice.

Our brief overview of these two cases should not be taken to mean that environmental and reproductive justice are fatally incompatible with the vision of social justice that predominates in global health. Instead, a view of social justice as elastic permits a better understanding of how epidemic control is practiced not just from the top-down, by states and supranational organizations, but from below, by grassroots groups. The loose agglomeration of corporate and university research institutes, supranational organizations, and philanthropic organizations that constitute global health increasingly finds itself confronting complex epidemics like Zika and CKDu. Traditional approaches based on cause and effect, exposure and prophylaxis, need and distribution, do not fully explain these epidemics, nor do they seem to have brought them under control. Under these circumstances, more sophisticated medicines, clinical procedures, and epidemiological surveillance tools are certainly necessary. It is also necessary, we suggest, to attend to the multiplicity of ways in which those technical problems and technical fixes become linked to social justice. Social justice can easily seem like the ultimate aim of epidemic control, but it is perhaps better seen as an elastic (if also unwieldy) technology.

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