Building Trust through Lymphatic Filariasis Elimination: A Platform to Address Social Exclusion and Human Rights in the Dominican Republic

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Abstract

Hispaniola, the Caribbean island that includes the countries of Haiti and the Dominican Republic (DR),

Introduction

In the Western hemisphere, the story of lymphatic lariasis (LF)—or rather, the story of people who live with LF—begins with an ignoble chapter in human history.[1] Along with untold millions of enslaved Africans, the Atlantic slave trade brought the disease from Africa to the Caribbean island of Hispaniola.[2] e rst site of European conquest in the so-called New World witnessed the decimation of an indigenous population and a plantation system so ruthless that it was cheaper to import new slaves and let the sick or injured die.[3] Haiti arose out of this colonial furnace as the rst free black republic in the world. e Haitian Revolution (1791–1804) was so radical that, at the time, "not even the most extreme political le in France or England had a conceptual frame of reference" for what happened there: that African slaves would overthrow their masters, defeat a colonial army, and yearn for the same Enlightenment rights as white Europeans.[4] On Hispaniola, then, the long and conjoined relationship between human rights and this neglected tropical disease (NTD) goes deep.

LF is a mosquito-borne, parasitic disease with social and economic costs estimated at 2.8 million disability-adjusted life years (DALYs) globally.[5] LF is endemic in 72 countries, with 856 million people at risk for infection and 40 million currently su ering from the dis guring and disabling complications of lymphedema or hydrocele.[6] e World Health Organization (WHO) targets elimination of LF as a public health problem through annual mass drug administration (MDA) to interrupt parasite transmission and provision of morbidity management and disability prevention (MMDP) services to alleviate su ering for those already a ected.

At present, Hispaniola accounts for 90% of LF in the Americas.[7] Haiti, the poorest country in the hemisphere, bears a higher disease burden than the DR.[8] Haiti's poverty has largely driven labor migration to the DR. Over time, Haitian migrants have gradually replaced ethnic Dominicans and other immigrant groups on Dominican sugar plantations, living in adjacent company settlement villages called *bateyes*. In 2016, Haitian-born migrants were estimated to comprise 23.2% of the nationwide *batey* population.[9] LF is rare outside of *bateyes*, meaning that they have been the predominant foci of LF transmission, likely due to the regular in ux of Haitian migrants that may inadvertently import

university, participating in the formal economy, presenting legal claims in courts, or traveling within the country without risk of expulsion.[17]

ese downstream e ects point to how the 2013 *Sentencia* violates fundamental human rights already enshrined in Dominican law. For example, the Dominican Constitution contains articles on the rights to health (Art. 61) and equality (Art. 39) while the Criminal Code penalizes discrimination based on origin or race, among other distinctions (Art. 336).[18] Furthermore, the country has rati ed multiple international frameworks pertaining to discrimination, including the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). Just ve months before the *Sentencia* verdict, an ICERD country report for the DR expressed concern over legislative and judicial hurdles that block access to identity documents for dark-skinned people and the Haitian irregular migrant population.[19]

e far-reaching consequences of statelessness on human rights should be quoted in full. e 2015 report released by the Inter-American Commission on Human Rights (IACHR) states that loss of nationality has increased vulnerability to other rights violations, including:

> *the right to personal integrity, the right to the protection of their honor, dignity, and private life, the right to protection of the family and family life, the rights of the child, the right to education, the right to health, the right to work, the right to private property, the right to due process of law, the right to judicial protection, political rights, the right to movement and residence, as well as the right not to be arbitrarily deprived of their liberty, the right not to be expelled from the rifro16(l)5(l)ato otd oie rghaoifrhrpntet ano 7(r)0.23(v)4(em)7(en)-9.E31f their 0 (if)-8.16sor (s-8(r)19(oi s9.7(e r*

Haitian-descended population.[27] For example, in 2004, the Dominican legislature passed the Immigration Act, which adopted stricter nationality criteria; in 2007, administrative procedures were introduced to suspend or retain birth certi cates to those born to parents without Dominican residency; in 2011, a regulation added more requirements, many of which were nearly impossible to ful ll, to acquire legal status; and in 2013, the Constitutional Court issued the *Sentencia*.[28] ese legislative and judicial steps, coupled with the impoverished living conditions found in *bateyes*, have helped to create "a tragic cycle in which a future of poverty is almost inescapable."[29]

How, then, to account for the successful public health campaign to eliminate LF in *bateyes* amid a context of social and legal exclusion? is paper responds to this question f

relation to others, including both people "at the top" and street-level agents, those tasked with the "dirty work" of selecting "good" citizens from the "bad."[33] While he says that "we all" have come "from somewhere else" and "have the same rights," Victor recognizes his own positionality in an unequal social order.

Other *batey* residents shared Victor's diminished sense of personhood, that their lives were unimportant in the eyes of o cial institutions or authorities, whether sugar companies, the national government, or simply *gente de arriba*—"people at the top." For example, another interview participant, a Haitian man in his 30s working as a market vendor, was told by an issuing o ce that his permit would last ve years, only to discover that it was valid for only one. is bitter experience, along with not having enough time to comply with recent changes in documentation requirements, le him feeling that the Dominican government, "doesn't consider us people."

Being ignored or manipulated by public authorities has long been a part of life in *bateyes.* Antonio Guzman, a Dominican-born man who had risen to a supervisory role in the local sugar company in the north region before it closed over a decade ago, attributed a deep psychological wound to a lack of government concern:

> *What do you do when there's no work? You humiliate yourself, you grovel, beg, and plead.*

to be recognized as socially rati ed persons."[35]

"Public, because it's for everyone": e approach of PELF

In March 2016, Yulisa Cáceres, a *facilitadora* (facilitator) and laboratory analyst for PELF, arrived late at night in a *batey* and knocked on the wooden door of a small, cinderblock structure. Earlier, this little home had been selected in the malaria and LF survey. Gertrude, a young Haitian woman who was living there with her husband and two children, had tested positive for LF antigen. Because antigen can persist a er infection has cleared, night-time testing is required to test for the presence of LF parasites, which circulate in the blood stream primarily at night.

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migrants have expressed disappointment at the inability to form these support groups due to the transitory nature of migration or perceived misunderstanding with Dominican neighbors.[36] Still, in some *bateyes*, it appeared that residents tried to form groups like *tèt ansanm*, no matter how informal. For example, interview participants described *recolectas*, or collection drives, to help pay for medical care or food for those in need. "We live by the strength of our hands," said a shop owner in one *batey*.

Collaboration with these support groups is central to the work of PELF. MDA efficacy is highly dependent on MDA coverage.[37] Thus, PELF extends drug coverage to as many eligible individuals as possible (excluding those who are pregnant or under two years of age), regardless of legal status, ability to pay, or seek care at a formal health structure.[38] One health promoter in the southwest emphasized the importance of reaching all persons in her work, particularly newly arrived Haitian migrants, who are often in dire need: "Some among them are sick, and they have nobody here to help them, no family, absolutely nothing." Speaking Haitian Kreyòl is not usually a problem, either, she explained, because, "Some came from [Haiti], so we learned to speak Kreyòl. We're joined together," [*estamos ligados*] "Dominican and Haitian."

Broadening the reach of MDA campaigns requires significant labor and resources, of course. Consequently, PELF engages with the community throughout the entire process: from initiating contact at *juntas de vecinos*, to conducting educative talks in the *bateyes*, to recruiting and training local volunteer *medicadores*, or medication administrators who go house to house.

The first step in this process involves identifying leaders at the neighborhood association or elsewhere and asking their permission to enter their communities. Working with these leaders, the PELF team then organizes larger meetings to explain the purpose of the MDA campaign and answer any questions. Yulisa and Wilson, another facilitator who has worked within PELF since 2002, underscore the need to explain everything in advance, including details of exactly how many tablets would be administered per person, so that, as Yulisa says, "there will not be any surprises." She goes further: "What is most important is community participation. […] The person must feel like they are their own protagonist for their health."

However, both Yulisa and Wilson emphasize that PELF does not broach the *tema caliente* ("hot topic") of the *Sentencia*. While it is not within PELF's mandate to address complex political issues directly, it was not lost on the PELF team that their work confronts problems tied up in a broader context of social injustice. As one figure within PELF confided, the situation of *bateyes* revolved around profit: "Exploitation would be far less if Haitians had rights," because, as he went on, with legal status, they could then access social services and health insurance funded by employers and the government.

When entering *bateyes*, Yulisa explained that they take caution to explain that LF is a health problem "that affects everyone," not just Haitians or Haitian migrants. Thus, everyone has a stake in resolving it. One community health volunteer echoed her perspective: "Because it's called 'public health,' 'public' means it's for everyone."

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in Dominican society. From a judicial perspective, the 2013 *Sentencia* reclassified entire generations of Dominican-born, Haitian-descended people as non-citizens. In effect, the *Sentencia* relocated exclusionary practices to the bureaucratic office, where digital registry lists determine who may have access to documents, and consequently, to life chances.[39] This "modernizing" shift in tactics, of course, follows a historical trajectory. In the early 20th century, the illegal status of Haitian migrant cane cutters formed the basis for increased state control over their labor, leading to physical confinement on *bateyes* and periodic expulsions going well into the 1990s.[40] From a historical perspective, the *Sentencia* was but the latest strategy to enlarge the proletarian sub-class.[41]

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study among Haitian migrants in the Dominican Republic,"