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Publication date 2020 Document Version Final published version License Other

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Citation for published version (APA):

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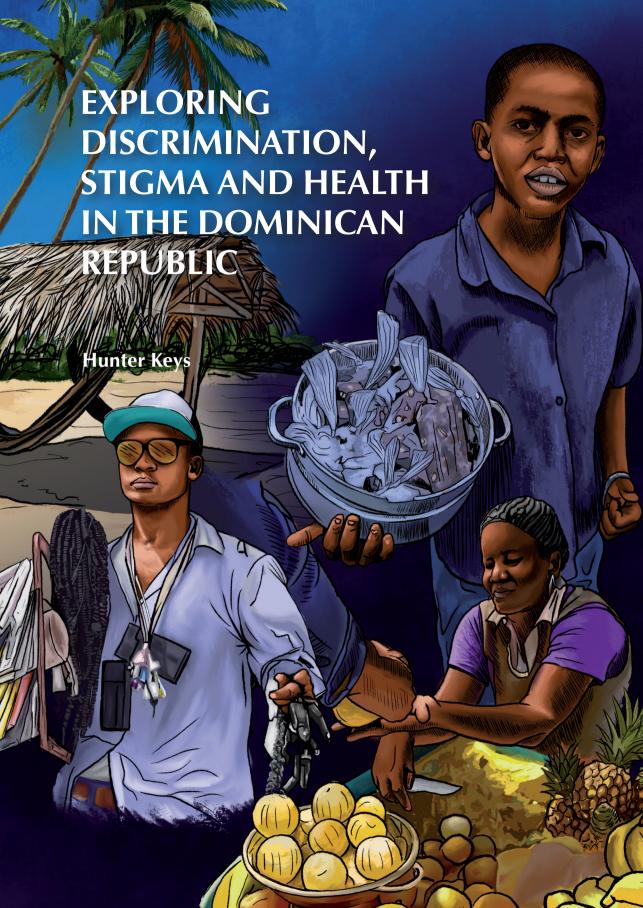
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# EXPLORING DISCRIMINATION, STIGMA AND HEALTH IN THE DOMINICAN REPUBLIC

Hunter Keys

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Design: Waarlé Grafische Vormgeving, Amsterdam, t.waarle@planet.nl

Print: Ipskamp Printing, Enschede

# EXPLORING DISCRIMINATION, STIGMA AND HEALTH IN THE DOMINICAN REPUBLIC

#### ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de Universiteit van Amsterdam op gezag van de Rector Magnificus prof. dr. ir. K.I.J. Maex ten overstaan van een door het College voor Promoties ingestelde commissie, in het openbaar te verdedigen in de Agnietenkapel op maandag 19 oktober 2020, te 14:00 uur door Hunter Masengill Keys geboren te Georgia

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#### **ACKNOWLEDGEMENTS**

Foremost, I thank the individuals who shared their time with me and the research team in the Dominican Republic.

I would not have come into anthropology were it not for Bonnie Kaiser, Brandon Kohrt, and Jenny Foster. They nurtured the seed of self-confidence that grew into what you now hold.

Ulric Dorval and Wilfrid Jean taught me about life in Haiti.

Rosa Burgos Minaya was constant in her support and love. Doña Altagracia and Manuel Vargas opened their doors to me on my first visit; everything else followed.

I thank Greg Noland and Steve Blount at The Carter Center. They continue to set the example for me. I am sure that they, too, are grateful for the evenings we shared with our colleagues Madsen Beau De Rochars and Luccene Desir on the Plaza de España.

Brandon Kohrt introduced me to Anita Hardon, who helped me apply for a Research Talent Award from The Netherlands Organization for Scientific Research. This award dramatically opened up new possibilities for me.

In 2018, I suffered a major medical setback while in the Dominican Republic. Dr. Jimenez was my chest surgeon who cared for me in a tender and refreshingly humorous way. I thank the Hospiten nursing staff in Santo Domingo. Doña Yumina and Arturo Medrano were my homestay parents prior to this unfortunate event; they stayed by my bedside. In Georgia, Dr. Chad Statton definitively repaired my lung. I thank my friends and colleagues at Piedmont Newnan Hospital. Craig Withers and Kenya Casey at The Carter Center made sure I got home.

Keyla Ureña and Domingo Cabral provided much support in Santo Domingo.

The Hotel Bahia Blanca in Rio San Juan was a place of refuge and wonder.

In Amsterdam, I thank my friends and paranymphs Mark Hann and Arsenii Alenichev. In no particular order, I am also grateful for the kindness of Carola Tize, Jos Bartman, Lex Kuiper, Tanja Ahlin, Eva Vernooij, Hanna Henao Vanegas, Kevin Singh, Daniel Gómez Uribe, Nathan Trousdell, Javier Garcia-Bernardo, and Natashe Lemos Dekker. Janus Oomen at AISSR was always helpful. I thank River Martin for our friendship in Ghent. Ashley Witcher helped me get this across the finish line.

Some of the proverbs preceding each chapter are borrowed from Amy Wilentz' splendid work, *Farewell, Fred Voodoo*. Others I discovered on my own while on "the imagined island."

This work came to completion thanks to the encouragement, clarity, and poise of Robert Pool and Rene Gerrets.

In a time of turbulence and pain, the mountains, fog, sea, and life of Akutan, Alaska helped me recover a sense of calm and ease.

The Donders family gave me their love. They now see this work come to a close. Jhefres Augustín Reyes has been my friend and guide since the beginning.

Much joy comes from my friendship with Maralyn Hazelgrove.

Other friends, near and far, helped me get here.

Dad, the stroke took away your speech and mobility, but as you know, we get along fine with our eyes. Yours still speak of your pride for me. I am grateful for your love.

Logan, you are a bedrock for the family you have created. I am grateful that you are my sister. Lauren, you and I have grown apart, but perhaps we will grow towards each other later.

Mom, your strength and unbounded love have allowed Logan, Lauren, and me to become who we are today. The home you and Charlie have made is one of comfort and sustenance. I would not have come to this point in my life were it not for you.

Thank you all

#### **SUMMARY**

The Caribbean island of Hispaniola, shared by Haiti and the Dominican Republic, has been called "the imagined island" for its long history as a contested space of identity, nationalism, and meaning-making. This ongoing process of differentiating self and other has continued since European colonists, indigenous people, and African slaves converged on the island in the late 15<sup>th</sup> century. In the Dominican Republic, contemporary forms of discrimination and stigma against the Haitian and Haitian-descended minority are rooted in the two countries' intertwined histories, in which ideas of race, nationality, and class shape how people understand themselves and each other in a fraught and at times injurious social world.

This dissertation is the culmination of nearly 10 years of intermittent fieldwork on "the imagined island," most of that time in the Dominican Republic, where I sought to understand discrimination, stigma, and consequences for health among the Haitian and Haitian-descended minority. I did not begin with a single, overarching research question that would lead to a doctoral dissertation in medical anthropology. Rather, the research evolved over time, responding to findings in the field, my own intellectual growth, and my changing professional roles and institutional affiliations. Nonetheless, along this winding path, there were key guiding questions that tied together these projects and the publications that resulted from them:

- How is discrimination said to occur, and why?
- How can we describe the burden of perceived discrimination?
- How are perceived discrimination and health related?
- How do these findings fit into broader systems of power and history?
- What are implications for public health programs and interventions?

To answer these questions, I drew on a suite of mixed methods: in-depth ethnographies; interviews and focus groups; and cross-sectional surveys and epidemiology. I found my theoretical bedrock in both anthropology and history. It was impossible, in my mind, to obtain a cross-cultural understanding of discrimination and stigma – nor quantify certain health outcomes – without accounting for how the two countries came to be, particularly through economic change, geopolitical relationships, and ideas of race and difference. I approached these topics from the perspective of public health, since I trained first in nursing and epidemiology. I was supported by public health and academic institutions committed to applying the research findings. Consequently, the question of "so what?" was always in the back of my mind.

The <u>Introduction</u> provides an overview of how I came into this research and considers my own positionality in relation to the fieldwork. I then recount the history of

the two countries and how historical legacies of race, class, and territorial expansion figure into contemporary ways of "seeing" the other. Following this historical summary, I discuss the key, theoretical frameworks of discrimination and stigma that influenced this body of work. Lastly, I foreshadow implications for public health, which I take up in more detail later.

<u>Chapter One</u> provides a snapshot of perceived discrimination and mental health among Haitian migrants in one of the country's largest cities, San Francisco de Macorís. This mixed-methods study used a cross-sectional survey and in-depth interviews to find that among Haitian migrants, feelings of mistreatment by Dominicans were associated with greater depression, anxiety, and functional impairment. Importantly, this study also uncovered the evocative Kreyòl idiom *imilyasyon* (humiliation), explored in subsequent fieldwork. <u>Chapter Two</u> is also based on this initial round of fieldwork and examines links between social support and mental health within this population.

<u>Chapter Three</u> considers how three theoretical pathways of discrimination (institutional, interpersonal, and internalized) figure into the life of a Haitian woman in the Dominican Republic, and how public health programs can use these findings to counteract discrimination. <u>Chapter Four</u> steps back from this setting to provide a broader explanation of our methods in understanding the role of language, measurement, and structural violence and their relationship with mental health needs in both Haiti and Dominican Republic.

<u>Chapter Five</u> returns to San Francisco de Macorís in the wake of the cholera epidemic that began shortly after the devastating 2010 earthquake that struck Port-au-Prince. Based on focus groups, this qualitative study examines how narratives about cholera – how it spreads, what can be done about it, and who is to blame – fit into longstanding tropes about the Haitian minority in the country, and how Haitians communicate material and psychosocial hardships through idioms of distress. The chapter provides recommendations for health messages and social mobilization in these communities.

Changing field sites (and professional roles and institutional affiliation), <u>Chapter Six</u> is based on in-depth interviews with residents of *bateyes*, agricultural shantytowns that historically hosted Haitian migrant laborers for sugar cultivation. Today, *bateyes* are home to a mix of Haitian, Haitian-descended, and Dominican people – a testament to how cross-cultural exchange, intermarriage, and familial bonds remain a defining part of life there. This chapter uncovers how recent legal and bureaucratic modes of exclusion contrast with the inclusive approach of the country's lymphatic filariasis program, which has long worked in the *bateyes*.

Finally, <u>Chapter Seven</u> uses epidemiological data from a nationwide, cross-sectional survey in the *bateyes*. This survey was linked to a larger project interested

in prevalence of malaria and lymphatic filariasis, two mosquito-borne, parasitic diseases that are endemic to the island and slated for elimination. As part of the survey, I incorporated the Everyday Discrimination Scale, a well-known measure of perceived discrimination, and investigated its associations with ethnicity and reasons for interpersonal discrimination. I then consider how these findings can assist the disease elimination programs in their work.

In the <u>Conclusion</u>, I return to issues of positionality by briefly sharing three examples, taken from reflections and field notes, of how my relation to "the field" encountered unexpected surprises. The fieldwork that went into each of these chapters contained a complicated mixture of excitement, self-doubt, growing confidence, and nostalgia. Looking back, I could not have foreseen where this work would lead, nor the intellectual and emotional growth that would occur along the way.

For me, perhaps the most insightful and deeply moving aspects to this work were the ways in which people talked about discrimination and stigma – two words, in fact, that I found to have little resonance in their direct translation. Instead, people talked about feeling humiliated, not being seen, not being recognized, or feeling worthless. This was not always tied to race or nationality, but sometimes to distinctions of class and labor – "it is us, always bent over doing the *travay mikwòb* [dirty work]," as one Haitian farm laborer said. I draw together these findings through the helpful lens of ecosocial theory, in which dualisms of past and present, biology and history, and individual and society are inseparable when considering patterns of health outcomes and associations with discrimination. I close by articulating several ways for public health practitioners to carry this work forward in the long task of closing the health disparities gap.

#### SAMENVATTING

Het Caribische eiland Hispaniola, dat zich op grondgebied van zowel Haïti als de Dominicaanse Republiek bevindt, wordt ook wel "het Ingebeelde Eiland" genoemd door diens lange geschiedenis met kwesties als identiteit, nationalisme en betekenisgeving. Dit proces van onderscheiden tussen de zelf en de ander duurt voort sinds de Europese kolonisten, inheemse bevolking en Afrikaanse tot slaaf gemaakten daar convergeerden aan het einde van de 15° eeuw. Huidige vormen van discriminatie en stigma ten opzichte van de Haïtiaanse, en de van Haïti afstammende minderheid in de Dominicaanse Republiek, vinden hun wortels in de vervlochten geschiedenis van de twee landen, waarin ideeën over ras, nationaliteit en klasse vormen hoe mensen zichzelf en anderen zien in een beladen en soms ook schadelijke sociale wereld.

Deze dissertatie is de climax van bijna tien jaar aan periodiek veldwerk op "het Ingebeelde Eiland", grotendeels in de Dominicaanse Republiek, waar ik discriminatie, stigma en de consequenties hiervan voor gezondheid onder de Haïtiaanse, en de van Haïti afstammende minderheid, probeerde te begrijpen. Ik begon echter niet met een enkele, overkoepelende onderzoeksvraag die zou leiden tot een doctorale thesis in medische antropologie. Het onderzoek ontwikkelde over tijd, waarin ik reageerde op bevindingen in het veld, mijn eigen intellectuele groei en mijn veranderende professionele rollen en institutionele affiliaties. Desondanks waren er leidende sleutelvragen op dit kronkelende pad die deze projecten en de publicaties die hieruit voortvloeiden met elkaar verbonden:

- Hoe vindt discriminatie plaats, en waarom?
- Hoe kunnen we de last van ervaren discriminatie<sup>1</sup> beschrijven?
- Hoe zijn ervaren discriminatie en gezondheid gerelateerd?
- Hoe zijn deze bevindingen onderdeel van grotere structuren van macht, en geschiedenis?
- Wat zijn de implicaties voor volksgezondheidsprogramma's?

Om deze vragen te beantwoorden, putte ik uit een reeks *mixed methods:* diepte-etnografieën; interviews en focusgroepen; en transversale enquêtes en epidemiologie. Ik vond mijn theoretische basis in antropologie en geschiedenis. Het leek mij onmogelijk om een intercultureel inzicht te krijgen in discriminatie en stigma, en evenmin om bepaalde gezondheidsuitkomsten te kwantificeren, zonder in acht te nemen hoe

<sup>1</sup> Origineel: *perceived discrimination*. Deze term verwijst naar de perceptie van slachtoffers van discriminatie. In de vertaling is gekozen voor 'ervaren' in plaats van 'waargenomen', omdat laatstgenoemde een positivistische connotatie heeft waar *perceived discrimination* juist een licht schijnt op de ervaren, affectieve dimensie van discriminatie.

de twee landen tot stand kwamen, met name als rekening wordt gehouden met economische verandering, geopolitieke relaties en ideeën over ras en verschil. Ik benaderde deze onderwerpen vanuit het perspectief van volksgezondheid, aangezien ik in eerste instantie ben opgeleid in verpleegkunde en epidemiologie. Ik werd ondersteund door volksgezondheids- en academische instituties die toegewijd waren aan het toepassen van de onderzoeksbevindingen. Zodoende speelde de vraag "en wat dan nog?" altijd in mijn achterhoofd.

De <u>introductie</u> biedt een overzicht van hoe ik bij dit onderzoek terecht kwam en beschouwt mijn eigen positie in verhouding tot het veldwerk. Daarnaast weid ik uit over de historie van de twee landen en hoe historische erfenissen met betrekking tot ras, klasse en territoriale expansie een rol spelen in hedendaagse manieren van de ander "zien". In navolging van dit historische overzicht, zet ik het theoretische kader over discriminatie en stigma uiteen dat van belang is geweest bij deze dissertatie. Tot slot, ga ik in op de implicaties voor volksgezondheid, waarover ik later in meer detail treed.

Hoofdstuk Een toont een momentopname van ervaren discriminatie en mentale gezondheid onder Haïtiaanse migranten in een van de grootste steden van het land: San Franscisco de Macorís. In deze *mixed-method* studie maakte ik gebruik van een transversale enquête en diepte-interviews die aantoonden dat onder Haïtiaanse migranten ervaringen van mishandeling door Dominicanen werden geassocieerd met grotere depressie, angst, en functionele beperking. Bovenal onthult dit onderzoek ook het evocatieve Kreyòl idioom *imilyasyon* (vernedering), wat verder wordt onderzocht in navolgend veldwerk. Hoofdstuk Twee is tevens gebaseerd op dit initiële veldwerk en onderzoekt de link tussen sociale ondersteuning en volksgezondheid binnen deze populatie.

<u>Hoofdstuk Drie</u> overweegt hoe drie theoretische benaderingen van discriminatie (institutioneel, interpersoonlijk en geïnternaliseerd) een rol spelen in het leven van een Haïtiaanse vrouw in de Dominicaanse Republiek en hoe volksgezondheidsprogramma's deze resultaten kunnen gebruiken om discriminatie tegen te gaan. <u>Hoofdstuk Vier</u> neemt een stap terug uit deze setting om een bredere verklaring te geven van onze methoden in het begrijpen van de rol van taal, meten en structureel geweld en hun relatie tot gezondheidsbehoeftes in zowel Haïti als de Dominicaanse Republiek.

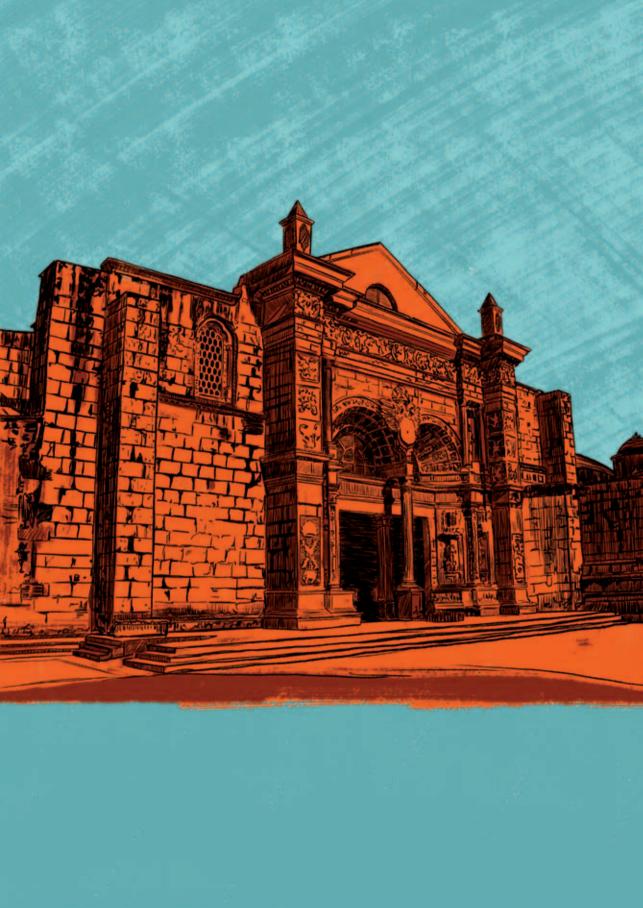
Hoofdstuk Vijf keert terug naar San Franscisco de Macorís gedurende de nasleep van de cholera-epidemie. Deze begon na de verwoestende aardbeving die Port-au-Prince trof in 2010. Gebaseerd op focusgroepen, onderzoekt deze kwalitatieve studie hoe verhalen over cholera – hoe het verspreidt, wat eraan gedaan kan worden, en wiens schuld het is – passen bij de lang bestaande tropen over de Haïtiaanse minderheid in het land, en hoe Haïtianen materiële en psychosociale ontberingen communiceren via idiomen van pijn en leed. Het hoofdstuk biedt aanbevelingen voor gezondheidsmededelingen en sociale mobilisatie in deze gemeenschappen.

Na het veranderen van onderzoekslocatie (en ook professionele rol en institutionele affiliatie), is <u>Hoofdstuk Zes</u> gebaseerd op diepte-interviews met bewoners van *bateyes* (agrarische sloppenwijken waar historisch gezien Haïtiaanse migrantenarbeiders woonden voor de suikerteelt). Vandaag de dag woont er een mengelmoes van Haïtianen, afstammelingen van Haïtianen, en Dominicanen in *bateyes* -- een bewijs van hoe interculturele uitwisseling, gemengde huwelijken en familiale banden een bepalend onderdeel zijn van het leven daar. Dit hoofdstuk laat zien hoe recente legale en bureaucratische manieren van uitsluiting contrasteren met de inclusieve aanpak van het land zijn lymfatische filariasisprogramma, dat al lang werkt in de *bateyes*.

Tot slot gebruikt <u>Hoofdstuk Zeven</u> epidemiologische data van een landelijke, transversale enquête in de *bateyes*. Deze enquête was gelinkt aan een groter project dat geïnteresseerd was in de prevalentie van malaria en lymfatische filariasis, twee door muggen overgedragen parasitaire ziekten die endemisch zijn voor het eiland en op het punt staan om uitgeroeid te worden. Als onderdeel van de enquête, incorporeerde ik de *Everyday Discrimination Scale*, een bekend middel om ervaren discriminatie te meten, en onderzocht ik de associaties bij etniciteit en de redenen voor interpersoonlijke discriminatie. Daarna overwoog ik hoe deze bevindingen kunnen bijdragen aan de programma's die ziekten willen elimineren.

In de <u>Conclusie</u> keer ik terug naar de problematiek van positionaliteit door kort drie voorbeelden te delen uit mijn reflecties en veldwerknotities, over hoe mijn verhouding tot "het veld" onverwachte verassingen veroorzaakte. Het veldwerk dat nodig was voor elk van de hoofdstukken ging gepaard met een mengeling van enthousiasme, zelftwijfel, toenemend zelfvertrouwen en nostalgie. Terugkijkend, had ik niet kunnen voorspellen waar dit werk heen zou leiden, noch wat voor intellectuele en emotionele groei ik onderweg zou ondervinden.

De meest verhelderende en diepst ontroerende momenten van dit werk waren voor mij de manieren waarop mensen over discriminatie en stigma praatten – twee woorden, in feite, die tekortschieten in hun letterlijke vertaling. In plaats daarvan praatten mensen over een gevoel van vernedering, niet gezien worden, niet erkend worden, of over zich waardeloos voelen. Dit was niet altijd gelinkt aan ras of nationaliteit, maar soms aan onderscheidingen met betrekking tot klasse en arbeid. "Wij zijn altijd voorover gebukt om het *travay mikwòb* [vuile werk] te doen," zei een Haïtiaanse landarbeider. Ik breng deze bevindingen samen, door een nuttige lens van *ecosocial theory*, waarin dualismen van verleden en heden, biologie en geschiedenis, en individu en samenleving onlosmakelijk met elkaar verbonden zijn wanneer men het heeft over patronen van gezondheidsuitkomsten en associaties met discriminatie. Tot slot articuleer ik een aantal manieren voor volksgezondheidswerkers om hun werk voort te zetten met de langdurige taak om de kloof op gezondheidsgebied te dichten.



# Introduction

"The Dominicans do not want to see us," Sylvie, a young Haitian woman and market vendor told me while standing next to her little stall, where she sold soaps, toiletries, and knock-off brand sneakers. Tucked into a busy section of San Francisco de Macorís, one of the largest cities in the Dominican Republic, the market was a cacophony of noise, smells, and sights: plantains and coconuts piled in giant heaps; people yelling and bargaining over prices; butchers slaughtering chickens; and pick-up trucks carrying enormous speakers blasting bachata and merengue music. Speaking in Haitian Kreyol, her phrasing was direct and matter-of-fact: *yo pa vle we nou –* "they do not want to see us," implying a feeling of invisibility.

And yet, as Sylvie went on, Haitians like her sometimes felt all too visible. For example, what of the way Dominicans reacted to cholera as it spread across the border from Haiti?

They say it's us who have brought this illness, but I say, Who are we? We are not God who can create these things. And now they think the illness can be transported in the clothes that we sell, so now people are afraid to buy clothing from us.

I recall this conversation distinctly because it was one of the first I had in the Dominican Republic as an anthropologist-in-training. I met Sylvie in March, 2011, during my first in-depth investigation of perceived discrimination and mental health of Haitian migrants in the Dominican Republic. At the time, I was a nursing and public health student at Emory University in Atlanta, Georgia. I had the good fortune to fall under the guidance of anthropologists Dr. Brandon Kohrt and (now Dr.) Bonnie Kaiser the previous summer, when they recruited a team of graduate students to explore mental health in neighboring Haiti. I joined the first field team to Haiti in summer, 2010, just a few months after the devastating earthquake that struck Port-au-Prince. In the immediate aftermath, there was a buzz of academic and professional interest in mental health, trauma, and resilience.

As I came to learn, the discipline of anthropology questioned the very underpinnings of those concepts: what do we really mean when we use the terms, "mental health," "post-traumatic stress," or "coping?" I became immersed in ideas of ethnopsychology, concepts of personhood, and the cultural roots of how we understand mind and body. That summer, I gained my first "field experience" in a desperately poor but inspiring community of rural Haiti. I picked up the rudiments of anthropological tech-

niques. More importantly, I came to appreciate the sense of awe that accompanies, in the words of Geertz, "perceiving other people's perceivings" (Geertz, 2003, p. 30).

Unquestionably, that summer in Haiti left an indelible imprint on me. Before that summer, I already felt a strong pull to work in humanitarian settings, and considered nursing a useful skillset. Anthropology provided new intellectual guideposts. In addition to reading the literature on cross-cultural mental health, I plunged into the writings of Paul Farmer, Didier Fassin, and Arthur Kleinman. Long holding an appreciation for history, I quickly latched onto the concept of structural violence as a powerful, explanatory tool: here was a way to discern present-day social injustice and health disparities by recognizing not only their *patterns* across social groups but also the *historical antecedents* that led up to them.

In short, structural violence theory had a major role in helping me make sense of what I saw and heard in the field, first in Haiti and later in the Dominican Republic. Less than a year after that summer in Haiti, I applied the same methods to investigate symptoms of depression and anxiety among Haitian migrants in the Dominican Republic. That project would subsequently lead to another the following year (2012), when our team explored the impact of cholera from multi-disciplinary angles: from public health, with its emphasis on epidemiological risk factors; to the legal, with its interest in migration policy and documentation; to the ethnographic, with a focus on meaning in local explanations of the epidemic. Cholera had far less an impact in the Dominican Republic compared to Haiti, but it nonetheless held imaginative power that fed into narratives of blame.

Studying mental health of Haitian migrants in the Dominican Republic led me to recognize the centrality of perceived discrimination. In Haiti, depression or anxiety are often communicated through idioms of distress like thinking too much (*reflechi twop*), having a "loaded head" (*tet chaje*), "head that has left" (*tet pati*), or heartache (*ke fe mal*) (Keys, Kaiser, Kohrt, et al., 2012; Nichter, 2010). These experiences were said to arise from, for example, the grinding reality of extreme poverty, loss of a loved one, or traumatic events. In the Dominican Republic, I heard the same idioms among Haitians who had crossed the border; now, they linked these idioms to the way they were treated in Dominican society: being called names, doing only the "dirty work" (*travay mikwob*) of stoop labor, lacking legal documentation, and feeling humiliated (*imilyasyon*). "If our country was good, we would not come here to be humiliated by the Dominicans," said one Haitian man, a laborer in a rice field. This was "violence that works on the soul" (Galtung, 1969, p. 169): of internalizing the feeling that as Haitians, they *pa gen vale* – are worthless.

These explanations had an intense, searing quality to them. By then, I was becoming more familiar with the literature on Haitian-Dominican relations, cross-border migration, and identity on the island. At the same time, I strove to account for the perspectives of Dominicans, including those living in the same community as migrants, those who employed them or worked alongside them, and the clinicians who cared for them. Throughout it all, I developed friendships and professional relationships with Dominican colleagues, without whom I would not have been able to undertake these projects. Part of the research process was sharing these findings in different ways: informally, as a small group of colleagues, as well as in more formal settings, such as gatherings in local clinics, where I talked about what we were hearing.

Most Dominicans bristle at the accusation that their country, or the Dominican people in general, are racist towards their Haitian neighbors, an accusation that surfaces periodically in international media or human rights investigations. A common retort was, "Look at your own country and what it does to the Mexicans!" The Dominican Republic was the first country to send aid, including brigades of medical teams, to Haiti in the aftermath of the earthquake. There is ample literature on shared cultural customs that transcend political boundaries, while the presence of mixed families will always challenge rigid conceptualizations of race. It is a fallacy to assume that both countries are somehow incompatible, locked in an existential struggle (Martinez, 2003).

So how was I to contextualize this idiom of *imilyasyon* – humiliation? Did it pertain only to the interpersonal realm, or did it speak to deeper, social and institutional structures of identity and class? I went further into the literature. There was a world to discover in the works of scholars from the island itself. Haitian scholars were at the vanguard of the anthropology discipline in its infancy. Anténor Firmin, Haitian politician and anthropologist, shook the establishment with his 1885 book, On the Equality of Human Races, which, as the title suggests, argued that all races possess the same intrinsic qualities and took to task prevailing notions of phrenology. In Thus Spoke the Uncle (1928), Jean Price-Mars traveled the Haitian countryside recording the customs and beliefs of rural Haitian peasants - long cast as superstitious and backwards - finding them deserving of admiration and praise. In Silencing the Past (1995), Haitian anthropologist Michel-Rolph Trouillot examined historical erasure. For Trouillot, any discussion of the Caribbean region should recall that it was the symbolic and material space for Europe to construct an image of the Savage Other and the site of a growing creole population, one "whose very existence questioned the West/non-West dichotomy" (Trouillot, 1992, p. 21).

Among works produced on the Dominican side of the island, it is hard to exaggerate the influence of Samuel Martinez, whose *Peripheral Migrants: Haitians and Dominican Republic Sugar Plantations* (1995) was one of the first books I read on the subject. Historian Lauren Derby's work on Haitian-Dominican borderlands in

the early 20<sup>th</sup> century helped me better comprehend the formation of the Dominican nation-state in relation to Haiti. While the elite sought to delimit a body politic according to differences, the "people below" engaged across a porous border, a hybrid space of racial and cultural mixture (Derby, 1994). This idea of divergent ideologies between an elite and the "common people" crystalized further after reading works by Harry Hoetink and Michiel Baud, Dutch scholars who conducted fieldwork in the Dominican Republic, and Pedro San Miguel, professor of history at the University of Puerto Rico.

In particular, Hoetink ties together ideas of social stratification based on desirable physical traits. However, he reminds us that demonizing the "African component" is not something intrinsic to Dominican society but pervasive wherever blacks were subordinate to whites (Hoetink, 2000). In his literary history The Imagined Island (2005), San Miguel uncovers how elites and popular classes on both sides of the island struggled over who belongs in the nation, whether in Haiti, where the mulatto elite rejected the African heritage of the masses, or in the Dominican Republic, where the Spanish-descended political class viewed the rural population as an obstacle to development. In their nation-building projects, ethnicity, culture, and race became virtually synonymous (San Miguel, 2005). Thus, a legacy of imposing ideologies onto to the masses complicates the ugly history of anti-haitianismo (anti-Haitianism) in the Dominican Republic; one must ask whether, and to what degree, everyday Dominicans really share such hostile sentiments. Nonetheless, while social scientists "may repeat time and again that racial and ethnic prejudices are scientifically untenable" (Baud, 1996, p. 122), such prejudice clearly has a psychosocial reality (Hoetink, 1967); race may not exist, but the effects of racism certainly do.

Midway through my fieldwork, in 2013, the Dominican Constitutional Court issued a verdict colloquially known as *La Sentencia*, rendering upwards of 200,000 Haitian-descended, Dominican-born persons stateless by stripping them of their birthright citizenship (Inter-American Commission on Human Rights (IACHR), 2015). This decision expanded the near-permanent underclass to include not only the undocumented migrant population but also those who, just previously, were Dominican citizens. Under a veneer of legality, the administrative state could more effectively decide who is "made to live" and who is "let to die" (Foucault, 2003). Foucault's concept of biopower was evocatively conveyed by one man I met in 2016: without legal documentation, people were *muerto con vida*, or "dead but alive," relegated to the lower rungs of society with little job mobility, educational chances, or decent healthcare.

The *Sentencia* was but the latest example of how institutions within the Dominican Republic operationalize an ideology of exclusion (Martínez & Wooding, 2017). My fieldwork continued into 2016 after the Carter Center, a health and human rights non-governmental organization, invited me to assist their work in the country. Under the guidance of Dr. Greg Noland, epidemiologist and Senior Associate

Program Director, I oversaw a nationwide household survey of malaria and lymphatic filariasis, two mosquito-borne diseases on the island (Keys et al., 2019). Through this work, I had the chance to travel across the country and visit some of its most marginalized communities, the *bateyes* (discussed in detail below). In addition to providing technical support for the survey, I interviewed nearly 30 residents of *bateyes*. In these conversations, I was struck by phrases in both Spanish and Kreyòl that alluded to loss of personhood: people affected by *La Sentencia* said that they wanted to be *reconocido* – recognized; Kreyòl speakers said that without legal status, an individual is not *yon moun*, a person. In many ways, this fieldwork in the *bateyes* confirmed a key, earlier finding: that the self-perpetuating cycle of poverty was linked to a devalued sense of who they considered themselves to be. "Where do you put a day's work for 400 gourdes [approximately \$10 USD]?" exclaimed one rice farm laborer whom I met in 2011; "You can't send your kids to school. They all have to bend down right there in the dirt. They do the same thing that the father is doing. Once the child is grown, that's what the child will end up doing too."

Studying processes of inclusion and exclusion had to be approached beyond a juridical point-of-view; there were historical and sociocultural dimensions that reflected how the Dominican Republic, on the one hand, strives to promote universal rights – such as the right to health, according to Article 61 of its Constitution – while articulating its identity, often in opposition to Haiti (or what is understood to be Haitian). The othering of the Haitian and Haitian-descended minority led me into the vast literature on stigma, starting with Erving Goffman's classic Stigma: Notes on the Management of a Spoiled Identity (1963) and winding into public health, where I discovered the work of sociologists Bruce Link and Jo Phelan, who connect stigma to broader systems of power (Link & Phelan, 2001, 2014), and anthropologist Arthur Kleinman, who argues that in local worlds, stigma threatens "what matter most" relationships, life chances, a job, social status, religious experience, or health, for example (Yang et al., 2007). Based on these readings, I came to interpret humiliation as a moral experience, one in which stigmatizers (the dominant group) attempt to defend what matters most for them; in turn, the stigmatized (minority group) suffer diminished social standing and consequently cannot obtain or participate in what matters most to them (Yang et al., 2014).

In the end, this PhD dissertation is interested in how people in the Dominican Republic see themselves and each other. It is about people's perceptions of difference, the interpretation of hurtful, interpersonal experiences, and consequences for bodily and psychosocial well-being. The Haitian-Dominican binary is a persistent thread throughout these articles; after all, it formed my grounding analytical approach to matters of perceived discrimination in the country. However, without blunting the very real effects of anti-Haitian discrimination, I encourage a broader recognition of what is at play: structural violence and stigma that harm people of both nationalities.

The contemporary political moment in which we find ourselves should compel us to think of "collective sentiments, judgments, and prejudices as products of long historical processes and pervasive structures" (Hoetink, 2000, p. 223). On Hispaniola, those processes and structures create a shared struggle on both sides of the border, a border that, in the words of a Dominican poet and playwright, "divides the land but not the misery of the people" (Blonda, 1968, p. 168).

#### HISPANIOLA: "THE IMAGINED ISLAND"

The title of San Miguel's work *The Imagined Island* speaks to imagined identities on the island shared by Haiti and the Dominican Republic. Even coming to an acceptable term to designate the island has its pitfalls. In general, Haitians use the word *Ayiti*, an indigenous Taíno word meaning "land of high mountains," to refer to both their country and the island as a whole. Haitians call the Dominican Republic *Sendomeng*, a clear reference to the capital, Santo Domingo, only with a twist: the French had named its colony, which later became Haiti, *Saint Domingue*. Despite its neocolonial undertones, Hispaniola, a Latinized version of the Spanish *Española*, is considered less biased towards one or the other country and will be used here (Fumagalli, 2018). That such distinctions in terminology persist are further evidence of the fraught and complicated histories of both countries, their peoples, and territorial nationalism rooted in the imaginary (Mitchell, 2000).

Bearing in mind that less powerful voices are generally unheard in historical reviews, let us begin with a stirring remark from Caribbean anthropologist Sidney Mintz: that the millions of enslaved Africans who arrived in the New World could bring only "whatever they could carry in their minds" (Mintz, 1970, p. 6). The enslavement, Middle Passage, and plantation life awaiting them destroyed a staggering amount of cultural material. Their knowledge of how and why things were done, according to their ancestral customs, was eroded. Suddenly and violently, their bedrock for interpreting experience, for making and understanding meaning, was pulled out from under them. "They were no longer going anywhere - they had, as it were, arrived" (Mintz, 1998, p. 119). Life expectancy on Caribbean sugar plantations was short; it was cheaper to import new slaves into Saint Domingue and let the sick or injured die (Dubois, 2012). This urgency and disorientation compelled large numbers of ordinary people to find solutions to their problems. In other words, they had "to figure out how to retain their humanity and rebuild a way of life, under what probably were the most trying conditions in world history" (Mintz, 2008, p. 257). Out of this colonial furnace entirely new social institutions emerged: new languages; new mixtures of cultural customs and religious beliefs; and the creation of mixed "races" in which African origin was always an ingredient (Mintz, 2008; Vega, 2007 [1981]).

For these reasons, anthropologists have had a difficult time engaging with the Caribbean region. It is neither "civilized enough" nor "primitive enough" (Trouillot, 1992). The irony runs thick, for it was through its first contact with the Caribbean peoples that the West came to know itself as such. The indigenous Taínos who encountered the small fleet of Spanish ships in 1492 had already been present there for nearly 6,000 years (Roorda, Derby, & Gonzalez, 2014). Initially numbering around 1 million on the island, they were nearly extinct by the close of the 16<sup>th</sup> century. A year after his first contact, Columbus returned to the island with the first cohort of enslaved Africans, inaugurating a new global circuit of capital (Mintz, 1998; Trouillot, 2001). If anthropology has historically preferred "pre-contact" situations, "the Caribbean is nothing but contact" (Trouillot, 1992, p. 22).

The plantation colonies that emerged on the island diverged sharply in their modes of profit-making, with crucial implications for the ways in which the people living there came to construct shared identities. While the Spanish had initially "discovered" the island, they were drawn to the mainland in their pursuit for gold. In 1697, Spain ceded the western third of the island to France, which had already established a plantation economy there. The eastern side of the island became a backwater colony for Spain while the other side of the island generated stupefying wealth for France. By the close of the 18th century, the plantation economy had reached its zenith in Saint Domingue, where a minority master class presided over a vast population of slaves. Meanwhile, in the east, Spain's neglect and uneven economic changes had led to the preponderance of more freed people than enslaved. This, too, is ironic, in that it was the Spanish who had introduced slavery and sugar plantations to the New World (Mintz, 2008), yet their first colony became a site of less rigid social hierarchies, more mixing among Spanish, African, and indigenous people, and relative racial harmony (Roorda et al., 2014; San Miguel, 2005; Vega, 2007 [1981]).

The Haitian Revolution (1791-1804) completely upended dominant notions of race relations (San Miguel, 2005). How radical indeed that former slaves could defeat the Napoleonic army! Napoleon himself lost his brother-in-law to the fighting, and more French soldiers died trying to retain the colony than at the battle of Waterloo. Yet from the vantage of Enlightenment Europe – busy debating new ideas on the nature and rights of Man – the slave uprising was less a revolution and more an aberration, referred to as *les troubles de Saint Domingue*. After all, resistance to domination is a *human* quality, and the ontology of the day held that slaves were anything but; "to acknowledge resistance as a mass phenomenon is to acknowledge the possibility that something is wrong with the system" (Trouillot, 1995, p. 84). Given the prevailing ideas of the time, the Haitian Revolution was met with fear among the Spanish-speaking population to the east; the slave, the one "supposed to obey," was transformed into a "blood-thirsty menace" (San Miguel, 2005, p. 45).

The Haitian army's twenty-year incursion onto the eastern side of the island – which, at that point, was only a few short months into its "ephemeral independence" from Spain – further cemented suspicion, fear, and hostility among the Spanishspeaking inhabitants. Historical narratives convey what matters most to those who tell them (Trouillot, 1995). Depending on one's historical reference, the period 1822-1844 can be seen as an attempt at unification of the entire island in order to prevent potential re-invasion (and re-enslavement) by a European power. After all, abolishing slavery on the island was the first decree issued by then-President of Haiti Jean-Pierre Boyer in 1822. From another historical angle, the Haitian military presence was seen as an occupation, in which taxes, confiscation of property, and an imperviousness to the people on that side of the island fomented nationalist sentiment (San Miguel, 2005). It was anathema for the Spanish-descended elites on the eastern side of the island to maintain such close ties to a largely black, African population. The colonial paradigm provided a cognitive roadmap to reject the Haitian presence. Like other emerging Creole nations, the political leadership in the Dominican Republic "had at their disposal only the racial thought and the idea of progress that the former colonial regime bequeathed to them" (Torres-Saillant, 2006, p. 182). By defeating the Haitian army, the Dominican Republic declared its independence from Haiti, rather than its colonial motherland, Spain.

As Martinez (1997) notes, the emphasis on Spanish roots seems to set the Dominican Republic apart in Latin America, where founding myths tend to embrace the creation of new *razas*, a term that encompasses not only race but also culture and nation. For the Dominican elite, *raza* aligned with Spain and whiteness, an ideology that distanced the elite from the majority, darker-skinned population. To launch the country into a new era of *progreso*, the elite faced two fundamental obstacles: a mostly underdeveloped, rural economy and the presence of an ethnically hybrid population whose African roots were seen as an impediment to self-rule.

Among all Caribbean nations, the Dominican Republic was unique in that large-scale sugar plantations expanded *after* the abolition of slavery (Hoetink, 2000). The newly formed nation lacked the capital necessary to launch large-scale agriculture and export production; until then, the colonial economy was based around free-range cattle herding and communal ownership and use of land (Vega, 2007 [1981]). For the elite, economic growth depended on a controllable labor force. Over time, the presence of a largely migrant Haitian workforce on sugar plantations conveniently served two ends: to generate economic growth and consolidate ideas of Dominican nationhood (Baud, 1992; Martinez, 1999). The Dominican government of the latter half of the 19<sup>th</sup> century pursued a "modernizing" formula that welcomed Cuban and American capital to stimulate production of sugar (Baud, 1987). The expectation was that the expansion of sugar *ingenios* (companies) would transform the country's mostly rural, peasant economy. Sugar production was a labor-intensive undertaking.

At first, the rural Dominican population flocked to the *ingenios*, which in turn depopulated the interior of the country, led to a precipitous drop in food production, and drove up food prices (Baud, 1987). Cane-cutting wages could not keep up, while Dominican braceros (cane-cutters) resisted the domination of the planter class. Sugar companies looked elsewhere, eventually recruiting an almost entirely foreign-born workforce, initially among migrants from islands such as St. Kitts, Nevis, Antigua, and St. Martin (Martinez, 1999). Private investors worked hand-in-hand with state authorities to create this disciplined labor force, which eventually became actively managed by the Dominican government (Baud, 1992; Martinez, 1999). By the 1930s, Haitians comprised the majority of the labor force for sugar cane harvesting (Martinez, 1999).

The United States military occupations of both Haiti (1915-1934) and Dominican Republic (1916-1924) helped to consolidate private-sector investment and further channeled Haitian braceros into the sugar estates, where they were housed in isolated labor towns called bateyes. By the time of the American military withdrawal, North American corporations owned 11 out of 21 sugar mills; 98% of all sugar exports were absorbed into the American market (Fumagalli, 2018). These developments came along with increased centralization of the Dominican state, which implemented a national police force, anti-vagrancy laws, mandatory primary education, tax collection, and infrastructure projects (Mayes, 2014).

Together with these "modernizing" projects were attempts to populate the country with "national" citizens (Baud, 2000). The Haitian-Dominican borderland, long an area of market exchange, ethnic mixture, and human movement (Derby, 1994; Turits, 2002), undercut the blatantly racist, nationalist scheme advanced by the Trujillo dictatorship (1930-1961). In various "whitening" projects, Trujillo attempted to entice immigrants from Europe to settle in the Dominican countryside (Turits, 2002). Trujillo and his propagandists diffused an anti-Haitian ideology through mass media, public schools, and national holidays – all while exerting more control over the importation of Haitian cane laborers (Martinez, 2003). Unquestionably, the fullest, most murderous expression of anti-haitianismo was the 1937 ethnic cleansing of mostly darkerskinned peasants on the frontier. For Trujillo, the massacre of upwards of 12,000 people – distinguished on the basis of skin color and linguistic difference – was a necessary counter-measure to the blending of both peoples (Derby, 1994). Haitians in the Dominican Republic were essential as laborers yet also a threat to dominicanidad ("Dominican-ness").

Yet one of the most crucial points to consider when discussing anti-haitianismo is whether, and to what degree, it actually resonates with las clases populares (the largely poor majority). As Hoetink wrote in the year 2000, "the ladder of stratification [has grown] longer and wider" in the time since Trujillo (Hoetink, 2000, p. 230). A Dominican elite continues to hold the levers of political and economic power; investment has shifted from sugar plantations to the tourism, free trade zone, and service

industry sectors; and yet the movement of predominantly lower-class people from the western side of the island to the east is unchanged. Of course, this is not a surprising pattern, given the vast macro-economic differences between the two countries.

In conservative political circles, anti-Haitianism lurks behind calls to "protect the labor market," prevent crime, or else defend cultural values or national sovereignty. More overtly, the Dominican state has engaged in various anti-Haitian legal tactics, tightening requirements for legal documents, arbitrarily denying birth certificates to children born on Dominican soil to Haitian mothers, and conducting episodic, forced expulsions of Haitians and "Haitian-looking" persons (Fletcher & Miller, 2004; Martínez & Wooding, 2017). The 2013 Constitutional Court decision nicknamed La Sentencia was but the culmination of a decade's worth of legal "reforms" that constricted rights of mostly Haitian-descended, Dominican-born persons. Upheld by the nation's highest court, this astonishing retroactive decree – going back to 1929 – stripped an estimated 200,000 people of their Dominican citizenship, in effect creating a sub-class of people who are "culturally Dominican" but henceforth foreign (i.e., Haitian) (Martínez & Wooding, 2017).

Yet no popular, expressly anti-Haitian political party has ever emerged in the country (Baud, 1996), nor any semblance of a hate group akin to the Ku Klux Klan. Indeed, there is an interesting possibility that unlike other contexts, where racist ideas and attitudes against immigrants spring from poor and lower classes, the situation appears reversed in the Dominican Republic, where the political and economic elite recycle colonial-era tropes against the Haitian ("more black") segment of society (Baud, 1996). Furthermore, it must also be acknowledged that ideas of dominicanidad simultaneously denigrate the Haitian Other while also desiring and standing in awe of it (Baumann, 2004; Vega, 2007 [1981]). Ancestral and spiritual connections to vodou have long bestowed Haitians with a peculiar kind of power in the Dominican imaginary; while there exists a pantheon of Dominican "folk beliefs" and cosmology that bear similarities to Haitian vodou (Deive, 2007 [1981]), they are widely understood to have their limits that only Haitian spiritualists can surpass (Derby, 1994). Martinez reminds us that the supposedly "fatal conflict model" of the two peoples is actually a distraction from what is really at play: political power holders making an issue of "uncontrolled" immigration from Haiti, and economic power holders benefitting from an exploitable labor force (Martinez, 2003). In an evocative metaphor, Martinez compares Haitian-Dominican relations to a game of cat-and-mouse:

[T]he point is not to eliminate the mouse but to prolong its pursuit indefinitely. Doing away with the mouse would be counterproductive to the cat's larger ends, for a dead mouse would leave the cat with no one to blame for things going wrong in the house and no spectacle of pursuit with which to divert the attention of the residents from the dwindling stocks in the larder (Martinez, 2003, p. 94).

Dominican scholar Silvio Torres-Saillant argues that the story of anti-black or anti-Haitian racism in the Dominican Republic has long implicated an intelligentsia, one that "created the conceptual paradigms that facilitated the crimes" against the darkerskinned, lower classes (Torres-Saillant, 2005). From this viewpoint, court decisions like the 2013 Sentencia and other discriminatory practices are less expressions of popular opinion but rather mechanisms to uphold the interests of an elite.

It is important, too, to recall that anti-Haitianism reflects the racial paradigms of the dominant countries upon which the Dominican Republic has had to depend (Torres-Saillant, 1998). Since the country's founding in 1844 and into the late 19th century, the Dominican elite not only mythologized their European roots but pursued higher education there at a time when European thinkers were advancing blatantly racist theories of human society (Torres-Saillant, 1998). The United States military occupation in the early 20th century and the Trujillo dictatorship (working closely with the United States) circumscribed a symbolic space for Haitians that was morally and culturally inferior. At the same time, a "relative equality of poverty" among both Haitians and many Dominicans has fostered forms of mutual aid and solidarity, evident, for example, in practices of communal labor and land, sharing of resources in times of scarcity, collective resistance to power-holders, and other popular customs and folklore (Derby, 1994; Hintzen, 2016; Martinez, 2003; Vega, 2007 [1981]). The "imagined island" of Hispaniola remains an unfinished project of identity and meaning-making, a project in which the voices of those de abajo – from below – often go unheard (Trouillot, 1995).

### RACISM, DISCRIMINATION AND STIGMA: A CROSS-CULTURAL PERSPECTIVE

Like so many other nations in the Western hemisphere, the Dominican Republic "came into being as a result of racial crime" (Torres-Saillant, 2006): the genocide of an indigenous population and enslavement of Africans and their descendants. Yet racial identity in the Dominican Republic challenges North American constructs of blackness, which rely on African phenotypic features. The majority of people share some degree of African ancestry but do not consider themselves "black" as outsiders from North America or Europe may see them. Furthermore, as described above, the country's political independence from Haiti and colonial relationship with Spain continue to influence ideas of nationhood and culture (San Miguel, 2005). Race, of course, is a powerful operative variable because "it precisely captures the social classification of people in a race-conscious society" (Jones, 2000, p. 1212). Given its cultural and historical record, the Dominican Republic certainly qualifies as a "raceconscious society," but one where peculiarities of race, nationhood, and culture call on a cross-cultural perspective.

A few guiding points from the theoretical literature on racism, discrimination, and stigma help to contextualize the situation of Haitians and Haitian-descended people in the Dominican Republic. The first is that "race entails position" (Howard, 2007, p. 729; Paradies, 2006). The dialectic of privilege/oppression articulates how a dominant (privileged) group seeks to preserve its interests (Bonilla-Silva, 1996, p. 2). By attaching meaning to characteristics of the minority group – such as skin color, cultural customs, religion, language, gender, and sexuality – the dominant group not only distinguishes but also ranks human differences, thereby feeding worldviews that justify and maintain privilege. Racism is thus an ideological apparatus that structures *racialized social systems* in which power – economic, political, or social – is unevenly distributed among people grouped within racial categories (Bonilla-Silva, 1996). Because racism is premised on socially invented categories, the inequalities that result are both avoidable and reversible (Paradies et al., 2015). In the same vein, *discrimination* refers to the systematic oppression of minority groups to the advantage of dominant groups (Krieger, 1999).

This structural aspect of racism and discrimination is evident in institutional practices and policies. Stark examples include the racial segregation, unfair housing, and mass incarceration of black Americans (Coates, 2017; Williams & Mohammed, 2013) or diminished access to quality education, employment, healthcare, and a clean living environment among Native Americans (Walters et al., 2011). These contemporary examples point to how institutional policies breathe new life into historical injustices. It is precisely *because* of institutionalized racism that race and socioeconomic status are so strongly associated in the United States (Jones, 2000).

In the Dominican Republic, the 2013 *Sentencia* is a recent iteration of institutionalized anti-Haitian discrimination. By revoking the *jus soli* citizenship of thousands of Dominican-born, Haitian-descended persons, the court decision encoded into law longstanding administrative practices of denying legal documentation to persons of Haitian descent (IACHR, 2015). Undocumented individuals cannot perform basic civil functions such as register children at birth, obtain health insurance, enroll children in school, enter higher education, participate in the formal economy, present legal claims in court, or travel in the country without risk of expulsion (IACHR, 2015). In effect, the *Sentencia* is the latest "biopolitical turn" that delimits boundaries of citizenship while enlarging an exploitable labor pool (Martínez & Wooding, 2017).

In addition to structural mechanisms of privilege/oppression, a second theoretical insight is that racial – or more broadly, *social* – groups and their ranking are constituted in the interpersonal, symbolic space between actors, who, through their interactions, come to know a "sense of one's place" as well as a "sense of the place of others" (Bourdieu, 1989, p. 19). This "sense of place" also relates to dynamics of power and positionality. Social actors orient themselves to the world around them by perceiving and interpreting outward signs, practices, and dispositions among others like (and

unlike) themselves (Bourdieu, 1989). There is thus an objective-subjective dualism at work: signs and practices are objectively visible but acquire symbolic importance once *perceived by* actors in the social world (Bourdieu, 1989, p. 19). A crucial aspect to this process is that it can be hidden or unrecognized (Link & Phelan, 2014). Social actors may perceive, evaluate, and react to others based on implicit (unconscious) biases and scripts. Furthermore, symbolic power is not just about how people perceive others but also about how they perceive themselves – to some extent, some members of minority or oppressed social groups may in fact internalize the negative representations about themselves held by the dominant group, further contributing to their disadvantage, while members of the dominant group internalize self-reinforcing feelings of superiority (Kwate & Meyer, 2011). The potency of symbolic power lies in how it is often subtle and taken-for-granted (Link & Phelan, 2014).

Bourdieu's ideas of symbolic power provide a framework for conceptualizing stigma (Link & Phelan, 2014). A highly complex phenomenon, stigma is traditionally thought of as a process in which deeply discrediting marks or attributes disqualify individuals from their full-standing in society (Goffman, 1963). Although Goffman called for a "language of relationships, not attributes" (Goffman, 1963, p. 3), the bulk of stigma studies have focused on individual-level experience (Link & Phelan, 2001). To broaden this perspective, Link and Phelan identify interrelated components of stigma to implicate power relations: (1) labelling human differences; (2) stereotyping those differences; (3) separating "us" from "them"; and (4) experiencing status loss and discrimination. "It takes power to stigmatize", they note (Link & Phelan, 2001, p. 375); one may ask, then, who has the power to label differences and ensure that their negative attributes "stick?" How does labelling affect access to education, healthcare, jobs, and housing? In short, what are the power differences between people with those attributes and those without? In order to stigmatize, a crucial step is to build some cultural consensus about the meaning of certain negative attributes. This consensus is promoted and reinforced through modes of power in legal, economic, and cultural dimensions, becoming all the more total through symbolic power, or the capacity of a dominant group to impose its particular vision of the social world. Stigma, then, is hegemonic power that "keeps people down," "keeps people in" (within normative boundaries), and "keeps people away" (Link & Phelan, 2014).

An anthropological approach sheds additional light onto stigma's social aspects. Drawing on concepts of social suffering and the sociality of illness (Kleinman, 1988, 2006; Kleinman, Das, & Lock, 1997), this perspective shifts to local, moral worlds where "something is at stake," such as life chances, reputations, health, religious practice, wealth, or relationships (Yang et al., 2007, p. 1528). To be a moral person is to engage in activities that matter most in the cultural milieu (Yang et al., 2014). Stigma harms those it is directed against by jeopardizing the capacity to obtain or hold on to what matters most. At the same time, stigma appears to be a pragmatic,

even tactical response to protect what matters most to those doing the stigmatizing: "keeping people down," "in," or "away" is a powerful means to protect what is valued by the dominant group. Stigma is enacted and felt through interpersonal engagements among people who are, ultimately, "interpreting, living, and reacting with regard to what is vitally at stake and what is most crucially threatened" (Yang et al., 2007, p. 1530).

Attention to "what matters most" reveals culture-specific forms of stigma and its bodily, psychological, and social consequences. For example, in their work with Chinese persons with mental illness, Yang and Kleinman (2008) connect the moral experience of stigma to somatic manifestations. In this context, "face" represents one's moral standing in the community. The burden of mental illness stigma causes loss of face, threatens family lineage and honor, and causes shame. Stigma is thus moral-emotional and moral-somatic; the stigmatized lose moral standing in the eyes of others and themselves, leading to a range of psychosomatic feelings of shame and the sensation that one's face has "crumbled away" (Yang & Kleinman, 2008).

Discussed in detail later, humiliation among Haitians in the Dominican Republic carries a similar meaning. Being passed over for more respectable jobs, being denied legal documentation, and feeling belittled and resigned to hardships are said to result from their disadvantaged status, one composed of racial, national, and cultural elements. Not being able to obtain what is important to them is associated with negative affective states and poor mental health, including depression and anxiety symptoms and self-devaluation. Two perspectives can be taken to consider the use of stigma for the dominant group. At sites of institutional power, legal decisions like the Sentencia are said to defend national sovereignty and "regulate" a chaotic labor pool, an argument dressed in modernity-cum-rationality. In the "everyday" world of communities, where Haitians may attest to feeling humiliated, their Dominican neighbors express fear of contamination or contagion, loss of livelihoods amidst economic change, or "cultural differences" to explain the disparities between themselves and their Haitian neighbors. Stigma appears to simultaneously threaten and protect what matters most in this local world.

### IMPLICATIONS FOR PUBLIC HEALTH AND OVERVIEW **OF CHAPTERS**

Simply put, racism, discrimination, and stigma are bad for health. Racial disparities in health outcomes are well documented and persist over time despite overall gains in life expectancy. In other contexts, such as on the North American mainland, for example, black and Native Americans have higher age-specific mortality rates along the entire life span compared to whites, even after controlling for socioeconomic status (Williams & Mohammed, 2009). Institutional racism creates differential access to resources and shapes the clustering of risk factors for poor health, such as unemployment, poor quality housing, neighborhood violence, strained social support networks, and environmental contamination (Williams & Mohammed, 2013). Self-reported experiences of racism or discrimination are associated with poor mental and physical health, including depression and anxiety, cardiovascular and metabolic disease, cognitive impairment, substance abuse, and giving birth to lower-birth-weight infants (Kwate & Meyer, 2011; Paradies et al., 2015; Pascoe & Smart Richman, 2009; Williams & Mohammed, 2009). Stigma, too, can severely impact health because it can lead to delayed care-seeking and worsen disease conditions (Van Brakel, 2006). Feelings of hopelessness, low self-esteem, and impaired coping are also linked to perceived discrimination and stigma (Kwate & Meyer, 2011). Yet while it may seem self-evident that racism, discrimination, and stigma harm health, elucidating their causal pathways to "explain" health inequalities has been challenging for the epidemiology and public health disciplines.

This challenge stems largely from issues of conceptual clarity, measurement, and methods (Krieger, 1999). Racism, discrimination, and stigma are slippery constructs that transcend spatial and temporal scales. Discriminatory or racist experiences range from the almost mundane, "everyday" experiences of being treated unfairly in stores to less common but life-changing, terrifying hate crimes (Krieger, 1999). Furthermore, racism and discrimination are increasingly understood to be collective, cumulative, and intergenerational. Again, to take the example of North American Native Americans, centuries-long physical and cultural dislocation continues to shape alarming and persistent health disparities (Lock, 2015; Walters et al., 2011).

These features of discrimination complicate epidemiological methods that seek to isolate and measure discrete risk factors. A broader view comes from ecosocial theory, which considers social patterns of disease as expressions of embodiment, or the biological incorporation of the social and ecological context (Krieger, 1999). For example, that perceived discrimination is associated with a chronically activated stress response (Pascoe & Smart Richman, 2009) – which in turn leads to wear and tear on the body – illustrates how "external depredating situations literally transform the material body" (Lock, 2015, p. 152). Embodiment calls attention to how the physical body becomes "a register for, or site of, struggle against forms of domination" (Nguyen & Peschard, 2003, p. 467), since the distribution of disease mirrors social gradients of power (Marmot, 2005). Another insight is the theoretical deconstruction of the body along three axes: the individual body, which, in the time since Descartes, is said to experience life through a material body and immaterial mind; the social body, one engaged in relationships with other beings through nature and culture; and the body politic, subject to political control and discipline (Scheper-Hughes & Lock, 1987). According to ecosocial theory, the epidemiology of disease results from the complex interplay of individual experience and agency, relationships among human and non-human actors, and the unequal distribution of power.

It is impossible, then, for a single study to accurately measure every pathway of discrimination or racism at these various levels (cellular, individual, social, ecological) and across relevant time scales (as singular events or chronic exposures over the lifespan) (Krieger, 2012). Rather, as social epidemiologist Nancy Krieger says, "systematic theorizing about what is or is not measured, and how, can aid interpretation of study findings" to produce knowledge useful for reducing health disparities (Krieger, 1999; 2012, p. 936). In short, measurement is a crucial matter of concern when investigating racism, discrimination, or stigma and their impacts on health.

Empirical attempts to measure these phenomena often rely on quantitative surveys of self-reported experiences (Paradies et al., 2015; Pascoe & Smart Richman, 2009). The reliance on subjective reports results from the difficulty in objective measurement: to adhere to the scientific method, any particular experience cannot objectively be determined as discriminatory or racist without a comparison group in which all contextual elements of the situation or event are identical *except for* the race of the actors (Paradies, 2006). These empirical difficulties are further muddled by the critique that biomedical and epidemiological categories are socially constructed and not naturally given (Nguyen & Peschard, 2003). For the biomedical sciences, complex phenomena are made available for intervention only once they are operationalized as variables; the variables themselves are not "natural" but created through networks and power relations among institutions and bodies of technical knowledge (Latour, 1993).

Additionally, scientific reductionism and its emphasis on discrete risk factors can be seen as overly medicalizing suffering, thereby losing sight of the historical and social relations that constitute the body, health, and disease (Lock, 2015). This mode of knowledge production and implementation also tend to presume that the constructs to be measured are understood or experienced the same everywhere. Staying cognizant of "what is or is not measured" spurs reflection of how standardized survey instruments are in fact cultural artifacts of the milieu in which they were developed; typically, within the Western biomedical canon. In a sense, such instruments measure only what the investigators – who are often from outside the cultural context – conceptualize as the underlying construct, rather than what is understood and experienced by those to whom the questions are asked. Quantitative surveys are certainly useful and have captured remarkably similar findings across different cultural contexts (Van Brakel, 2006), but in-depth, qualitative analysis provides a complementary, fine-grained perspective because it focuses on local meaning. Thus, combining both quantitative and qualitative methods generates a fuller picture of discrimination, stigma and health in local contexts and can better inform public health interventions (Shariff-Marco et al., 2009).

Described in the final sub-section below, the methodologies that underpin this dissertation include quantitative as well as qualitative approaches. These mixedmethods sought to both characterize perceived discrimination and provide recommendations for public health programs in the country, with particular emphasis on principles of community engagement. Chapters 1-4 focus on perceived discrimination and mental health of Haitian migrants in and around San Francisco de Macorís, a large city in the country's Cibao region. To the best of my knowledge, these publications were the first, formal investigations of mental health of Haitian migrants in the country. At the time, I was a nursing student at Emory University School of Nursing, which had a research partnership with a Dominican university in San Francisco. The impetus to explore mental health of Haitian migrants was based on the acknowledgment that little was known about them, despite their significance as a patient population. My background in mental health in Haiti provided a foundation to launch an exploratory study of mental health and links to perceived discrimination. Quantitative methods uncovered a potentially high burden of mental illness symptoms that were indeed associated with perceived mistreatment by Dominicans. On the qualitative side, humiliation arose as a key finding, which would have gone missed had we relied exclusively on standardized questionnaires.

These findings inspired the next round of fieldwork. The study in <u>Chapter Five</u> was also based in San Francisco de Macorís and sought to link the emergent finding of humiliation to broader themes of discrimination and stigma amidst the spread of cholera. This qualitative study solicited explanations for the epidemic among both Haitian and Dominican community members. Study participants employed a repertoire of local idioms, cognitive scripts, and lived experiences to communicate what was at stake for them: the perceived (in)ability to act in the face of adverse, structural conditions or the perceived threat of contagion that arose from "cultural differences." This study provided contextual depth to a concurrent, quantitative survey of risk factors for cholera (Lund et al., 2015) by analyzing how host and migrant groups perceive the disease, the structures and behaviors that mitigate or exacerbate its spread, and how explanations were supported by, and fed into, narratives of blame.

In contrast to these studies, those in in <u>Chapters 6-7</u> concerned a different study setting and population but stayed focused on perceived discrimination and health. These articles were based on in-depth interviews, personal observations, and a nationwide, quantitative survey of residents in *bateyes*, or shantytowns that traditionally housed Haitian migrants working on nearby sugar plantations. Today, *bateyes* are home to not only Haitian migrants but also their Dominican-born descendants, many of whom were affected by the 2013 *Sentencia*. These articles came out of my work with the Carter Center, a health and human rights non-governmental organization supporting the Ministries of Health in both Haiti and Dominican Republic to eliminate malaria and lymphatic filariasis, mosquito-borne, parasitic diseases. Using quali-

tative data from interviews and observations, Chapter Six explores social exclusion through the eyes of batey residents and implications for disease programs. In essence, the country's filariasis program has had to navigate competing notions of recognition. While the Dominican Constitution stipulates the right to health for toda persona – every person – the government enacts increasingly harsh immigration and citizenship policies like the 2013 Sentencia. Given such a charged political backdrop, how might disease elimination be achieved and sustained? The article attempts to address this question.

The article in Chapter Seven was also based on the nationwide survey of batey residents and shares quantitative results from the Everyday Discrimination Scale, a well-known measure of perceived discrimination. While the qualitative study in Chapter 5 underscores the theme of recognition, this article provides an epidemiological profile of perceived discrimination among the different ethnic groups found there: Haitian-born, Dominican-born with Haitian descent, and Dominican-born without Haitian descent. Crucially, the study also explores given reasons for discriminatory experiences, ranging from one's poverty or lack of education to skin color, origin, or documentation status. As the article elaborates, findings were germane for disease programs that encourage participation or behavior change among people who experience the "hidden distress" of stigma and discrimination (Weiss, 2008).

In sum, the complexity of racism, discrimination, and stigma and their impacts on health in the Dominican Republic called for a mixed-methods approach. While these phenomena are widely considered "social determinants of health," a phrasing that positions them "upstream" from health outcomes, they are notoriously difficult to characterize, particularly given critiques of biomedical reductionism, an overemphasis on the individual, and presumed unidirectional causation. In response to these issues, I draw on core ideas from ecosocial theory, symbolic power, and stigma's effects in local, moral worlds. These theoretical frameworks reorient the line of inquiry away from a reductionist approach and towards a deeper awareness of subjectivities, history, and power and the ways they constitute the body, relationships, and health.

#### FINAL NOTES ON METHODOLOGY

The seven articles contained in this dissertation span a variety of field sites, methodologies, and institutional relationships. They also reflect how my own thinking about discrimination and stigma in the country evolved over time.

As mentioned above, my introduction to medical anthropology came about as a nursing and public health student at Emory University in Atlanta, Georgia. In summer of 2010, I joined a team of graduate students to begin formative research on mental health in Haiti. Under the guidance of Dr. Brandon Kohrt, our team cross-culturally adapted the Beck Depression and Beck Anxiety Inventories (BDI and BAI), a process detailed elsewhere (Kaiser et al., 2013). Additionally, we explored key idioms of distress used by Haitians to communicate psychosocial suffering (Keys et al., 2012).

This work laid the groundwork for studies in the neighboring Dominican Republic, where the School of Nursing had an ongoing research partnership with a Dominican university. At the School of Nursing, I fell under the guidance of Dr. Jenny Foster, herself a certified nurse midwife and medical anthropologist. She and her colleague in the Dominican Republic, Ms. Rosa Burgos, a nursing school instructor, helped me through the fieldwork process, managing a field team, and interpreting study findings. The articles shared in Chapters 1-5 were based in and around San Francisco de Macorís, where the Dominican university was based. San Francisco is the third largest city in the country; as a land-locked, crowded city, it is not what comes to mind when people think of the Dominican Republic as a tourist destination. Sites of data collection included densely-populated barrios and small, rural communities outside the city. Selecting these communities depended on, among other issues, attempts to identify areas where Haitian migrants lived; newly formed and evolving relationships with "gatekeepers;" logistics of accessing the communities; and random, systematic sampling (for surveying). Completing these projects would not have been possible were it not for the guidance, help, and hard work of Haitian and Dominican research assistants, mentors, and other colleagues "on the ground." My companions were committed to the work, shared their time with me, and never hesitated to say that they were always a su orden (at my service). Beyond the research, these relationships opened my eyes more broadly to the world around us and the implications of the work.

Shortly after graduation from Emory University in 2013, I was approached by The Carter Center, to assist in an upcoming nationwide survey of bateyes. Since 2008, The Carter Center has been present in the Dominican Republic and Haiti, where it assists the Ministries of Health in both countries to eliminate malaria and lymphatic filariasis. In early 2016, I supervised the collection of household-level questionnaires among a sample of nearly 780 adults living in bateyes across the country. This survey was interested in prevalence of both diseases as well as standard risk factors for transmission (Keys et al., 2019). Alongside this survey, I collected in-depth interviews among certain individuals in bateyes who were willing to share their thoughts about discrimination, health, and general life since the 2013 Sentencia. These interviews formed the basis for the article in Chapter Six. Finally, the survey incorporated the Everyday Discrimination Scale (EDS), the results of which are shared in Chapter Seven. In sum, the study sites comprising the articles shared here were mainly in and around a large city and scattered across the country's bateyes. The range of study sites reflect the various institutional relationships I had at the time, relationships that enabled me to approach research questions about discrimination and health across a range of social and geographic contexts.

Throughout these studies, I relied on the usual suite of data collection methods: in-depth interviews, cross-sectional surveys, focus groups, and personal observations and reflexive note-writing. I would like to think that my adeptness with these methods improved over time. I visited public hospitals and primary care clinics, where I spoke with clinicians and nurses and shadowed them in their work. I sat across the desk from administrators tasked with processing requests for legal documents. I went into people's homes where I was offered the only chair available. I spoke in Haitian Kreyòl and Spanish, sometimes in the same conversation. I ate meals and drank with friends and was invited to the beach. I bounced along in crowded, government pick-up trucks with public health teams, joining them in door-to-door surveillance activities, listening to their jokes and complaints. I followed up some conversations, sending WhatsApp messages, poking around street markets or offices, tagging along, hoping to learn more. Some of the people I keep in touch with today; with others, I have lost contact.

I have deferred an in-depth reflection of how my research evolved over time to the <u>Conclusion</u>. This, I feel, allows the reader the chance to go through the chapters in chronological order, and follow the threads that connect each study to the next. This was, after all, how I went about this work: iteratively, and always enmeshed in the institutional relationships and professional roles I had at the time. Thus, I prefer that the reader follow along and develop her own understanding of the "big picture," before arriving at my own explanation of how this research unfolded.

"Mixed-methods" conveys a certain degree of formality. It is a recognized term in the literature that is supposed to adequately capture all of the messiness of what was involved. Characterizing discrimination and publishing about it – and largely from the point-of-view of Haitians in the country, no less – was a delicate task at times. In the Conclusion, I share specific examples of what was sometimes left out of each Methods section: the personal and interpersonal experiences that shape how one comes to say, with any confidence, what life is like in a given place. Each methodology has its strengths and limitations; at the same time, such methods are "used" within a figurative space of power and positionality. Who's perspective counts in explaining social reality? What does "validity" mean, and to whom? How do alternative perspectives and ways of understanding the world find their way into the analysis? The precise language contained in each Methods section does not do enough justice to this complexity. Gradually, I came to appreciate that "the field" is not an easily demarcated space, because your life as an investigator becomes a part of those around you. In short, knowledge production occurs in a context of shared lives, values, and experiences. These articles are, in essence, what came of my attempts to wrap my head around what people were saying and doing; in other words, of my attempts at "perceiving other people's perceivings."

# TOU SA OU WE SE PA SA

EVERYTHING YOU SEE IS NOT WHAT IT SEEMS



# Perceived discrimination, humiliation, and mental health<sup>2</sup>

#### **ABSTRACT**

**OBJECTIVE** Many Haitian migrants live and work as undocumented laborers in the Dominican Republic. This study examines the legacy of anti-Haitian discrimination in the Dominican Republic and association of discrimination with mental health among Haitian migrants.

**DESIGN** This study used mixed methods to generate hypotheses for associations between discrimination and mental health of Haitian migrants in the Dominican Republic. In-depth interviews were conducted with 21 Haitian and 18 Dominican community members and clinicians. One hundred and twenty-seven Haitian migrants participated in a pilot cross-sectional community survey. Instruments included culturally adapted Kreyòl versions of the Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI) and a locally developed function impairment scale.

**RESULTS** Haitian migrants described humiliation (*imilyasyon*) as a reason for mental distress and barrier to health care. Dominicans reported that discrimination (*discriminación*) was not a current social problem and attributed negative social interactions to sociocultural, behavioral, and biological differences between Dominicans and Haitians. These qualitative findings were supported in the quantitative analyses. Perceived discrimination was significantly associated with depression severity and functional impairment. Perceived mistreatment by Dominicans was associated with a 6.6-point increase in BDI score (90% confidence interval [CI]: 3.29, 9.9). Knowing someone who was interrogated or deported was associated with a 3.4- point increase in BAI score (90% CI: 0.22, 6.64). **CONCLUSIONS** Both qualitative and quantitative methods suggest that perceived discrimination and the experience of humiliation contribute to Haitian migrant mental ill-health and limit access to health care. Future research should evaluate these associations and identify intervention pathways for both improved treatment access and reduction of discrimination-related health risk factors.

KEYWORDS: migration; mental health; discrimination; Dominican Republic; Haiti; undocumented

<sup>2</sup> Originally published as: Keys, H., Kaiser, B. N., Foster, J. W., Burgos, R. M., and Kohrt, B. A. 2015. "Perceived discrimination, humiliation, and mental health: a mixed-methods study among Haitian migrants in the Dominican Republic." *Ethnicity and Health* 20(3): 219-240. The text has been lightly edited.

## INTRODUCTION

The links among globalization, migration, and mental health have drawn increased scrutiny (Lindert et al. 2009; Bhugra et al. 2011). Every year, an estimated 214 million people migrate across national borders (IOM, 2013), often triggered by political, socioeconomic, or environmental pressures. An estimated 10-15% of international migrants are classified as "illegal," undocumented, unauthorized, or irregular.

"Migration on the periphery" refers to the movement of generally uneducated, rural residents of impoverished regions on the periphery of development to areas of marginally improved living standards, often making periodic return trips to their poorer sending communities (Martinez, 1995). Labor migrants often find themselves simultaneously needed but unwanted, indispensable to growing economies, yet deemed a threat to cultural and national identities. This bears important consequences for their health.

When host societies construct concepts of legitimacy and deservingness, those failing to meet such criteria are excluded from political and moral spheres, where their "lives, bodies, illnesses, and injuries" are considered less worthy (Willen, 2012a, p. 806). They undergo a stigmatizing process of being "othered," based on supposedly intrinsic differences between the dominant "us" and nondominant "them" (Grove & Zwi, 2006), the citizen and noncitizen (Bail et al. 2012), and the deserving and undeserving (Sargent, 2012). Newly arrived migrants must navigate these hierarchical categories, coming to recognize their own marginalized social status. For example, in contrast to their first-generation peers, second-generation Mexican immigrant women in the USA more readily reference their Mexican identity as a reason that stigmatizing practices are directed toward them, contributing to their psychosocial distress (Viruell-Fuentes, 2007; Viruell-Fuentes, Miranda, & Abdulrahim 2012).

#### Perceived discrimination and mental health

Perceived discrimination only exacerbates existing consequences of migration arising from diminished social support, exhaustion, exposure to trauma, and acculturative stress (Bhugra et al., 2011; Bhugra, Wojcik, & Gupta, 2011). The harmful impact of perceived discrimination on migrant mental health has been documented (Lin et al., 2011; Llácer et al., 2009). Chronic, everyday discrimination predicts poor mental health after controlling for other sources of distress and socioeconomic status

(Williams et al., 1997). There are three major pathways whereby perceived discrimination can affect mental health (Jones, 2000). The first is through institutional practices that restrict socioeconomic mobility. The second is through interpersonal experiences of discrimination. The third occurs when members of the minority group internalize stigmatizing attitudes and beliefs about themselves (Williams & Williams-Morris 2000). The last pathway is especially useful in understanding public regard, or the manner in which one racial or ethnic group perceives the attitudes of another group toward them (Sellers et al., 1998).

#### Haiti, the Dominican Republic, and anti-Haitianismo

Haiti and the Dominican Republic share the Caribbean island of Hispaniola, yet there are stark economic and human development disparities between the two (World Bank 2012a, 2012b). Indeed, poverty is a leading determinant of migration from Haiti to the Dominican Republic (Ministerio de Trabajo, 2011).

Today, there are an estimated 500,000 to 1.5 million Haitians and Haitian descendants in the Dominican Republic, the majority undocumented, and many having lived in the country for two or more generations (Canales et al., 2009). The imprecise population estimate of Haitian migrants in the Dominican Republic reflects the more fundamental – and political – nature of migrant Haitian–Dominican relations: although migrant workers have established themselves within Dominican society, they remain a largely marginalized and unrecognized population.

With roots in European colonialism, anti-Haitianism (anti-haitianismo) is a view of Haitians as more African, less civilized, superstitious practitioners of Vodou (Howard, 2007). Officially promulgated during the Trujillo dictatorship (1930–1961), anti-haitianismo is an ultra-nationalistic, overtly racist ideology; those appearing "more Haitian" occupy the lower strata in a racial-moral hierarchy (Bartlett, Jayaram, & Bonhomme, 2011). Nonetheless, race in Dominican culture is a complex construct, as the majority of Dominicans share some degree of African ancestry (Sagas & Inoa, 2003).

The purpose of our exploratory study was to formally investigate the relationship between perceived anti-Haitian discrimination and migrant mental health in the Dominican Republic.

#### **METHODS**

#### Setting

Data were collected during March-April 2011 in the Duarte Province, Dominican Republic (Figure 1). In 2008, Duarte Province had a population of 310,357 (SESPAS, 2008), mostly concentrated in urban and peri-urban areas. Lying two hours from the capitol Santo Domingo, San Francisco de Macorís is the province's largest city. Smaller com-

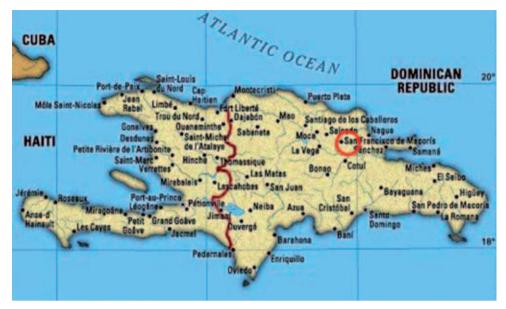


Figure 1. Map of Dominican Republic and Haiti with study site circled (source: image from Google Earth).

munities lie on the outskirts of San Francisco and throughout the province, where production of rice and cacao is common and where many Haitian migrants live and work.

Research was facilitated through a longstanding research partnership between Emory University, Universidad Autonoma de Santo Domingo, and the regional public Hospital Regional San Vicente de Paul. The partnership comprises community-based participatory research, engaging community members, community health workers (CHWs), and in-hospital staff to seek improved quality of care (Foster et al., 2010a; Foster et al., 2010b).

The study team comprised four multilingual (English-Spanish or Kreyòl-Spanish-French), locally hired research assistants (RAs), including one Dominican and three Haitians. The lead author, proficient in Kreyòl, French, and Spanish, coordinated the study. RAs were trained in obtaining verbal informed consent, confidentiality, and all data collection procedures.

Data collection sites included the public hospital, regional clinics, and six predominantly migrant Haitian communities in and around San Francisco de Macorís. We purposively selected Haitian migrant communities through discussions with professional partners in the Ministry of Health, Haitian community members, and Dominican clinical staff. One community was located within the urban core of the city, and the remaining five were located in rural settings. The study was approved by the Emory University Institutional Review Board and the Ethics Committee of the regional hospital. All participants gave verbal informed consent.

# Data collection: conceptual overview

We integrated qualitative and quantitative methods throughout the research process to explore migrant experiences and their mental health (Johnson, Onwuegbuzie, &Turner, 2007; Figure 2). Mixed-methods approaches have been used for studies of mental health and discrimination in both high-income and low-income country settings (Shariff-Marco et al., 2009; Kohrt, 2009; Kohrt et al., 2009). After identifying Haitian migrant communities, we used qualitative and quantitative methods to gather preliminary data and build rapport. Haitian RAs visited the communities to explain the project's purpose, conduct a household-level census, perform free-listing activities regarding daily tasks, and pilot a survey. After these activities, the team met to discuss results and overall impressions, challenges, and reactions in the community. During these debriefing sessions, we became aware of the centrality of perceived discrimination. Following this, the team met on an ongoing basis with research partners and community members to reevaluate the project's focus and methodology. Steps taken during this iterative process included development of two survey questions to target public regard among Haitian migrants and questions and probes for in-depth interviews with community members and clinicians.

# Qualitative data collection and analysis

For in-depth interviews, purposive sampling was used, with the aim of identifying individuals with a unique insight into the lived experience of Haitian migrants, perceptions and experiences of discrimination, and mental health (Table 1). These interviews explored perceptions, attitudes, and beliefs regarding migration from Haiti, perceptions and experiences of racism and discrimination, clinical experiences, treatmentseeking behavior, and causes and symptoms of mental distress. In-depth interviews lasted 30-60 minutes and were conducted by the lead author with a bilingual RA or by the RAs alone. To reduce bias and ensure comprehension and comfort among interview participants, a Dominican RA interviewed Dominican participants and Haitian RAs interviewed Haitian participants. All interviews were audio-recorded, transcribed in Kreyòl or Spanish by native-speaking RAs, and then translated into English by bilingual speakers.

A free-listing activity was utilized to develop a function impairment instrument for use in community surveys. Haitian RAs purposively sampled 21 men and 23 women in rural and urban communities. Participants listed important tasks in daily life. The 10 most frequently cited tasks by sex were included in the function impairment instrument (Bolton & Tang, 2002). During the community-level survey, participants rated their degree of difficulty in completing those tasks. Among 99 of 127 survey participants, reasons for functional difficulty were elicited and coded as perceived anti-Haitianism, economic difficulties, or other.

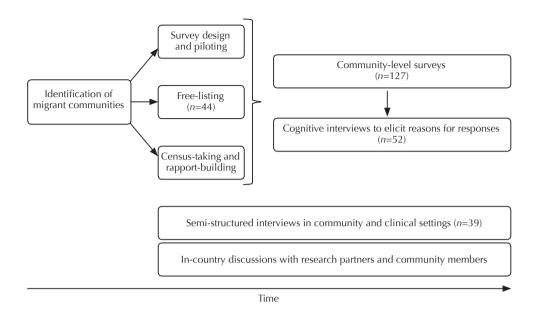


Figure 2. Chronological outline of mixed-methods data collection.

Brief (10–15 minutes) cognitive interviews were conducted among 52 of the 127 survey participants to better determine reasons for providing answers to survey items on the culturally adapted Kreyòl versions of the Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI). Participants were purposively selected based on severity of responses to certain survey items (e.g., feeling worthless, sadness, pessimism). Five cognitive interviews were audio-recorded, transcribed, and translated into English; the remaining were recorded in field notes taken by RAs, who wrote key words and phrases used by respondents.

An important challenge regarding these interviews was the inherent power imbalance between the research team and participants, particularly in migrant communities. Haitian migrants in the Dominican Republic are little recognized, and many live in fear and suspicion of outsiders. Given this context, the particularly sensitive topics of mental health and perceived discrimination, and the close proximity that qualitative methods bring to bear between researchers and participants, we strove to adhere to ethical principles requiring us to articulate the project's beneficence, ensure it minimized harm and maintained confidentiality, and strike a balance between our goals as researchers with the interests and potential repercussions felt among participants (Hennink, Hutter, & Bailey, 2011).

**TABLE 1:** In-depth interview participants (n=39).

Social group	ID	Occupation	Gender	Age range	
Migrant Haitian	MH01	Construction worker	Male	20s	
	MH02	Construction worker	Male	W	
	MH03	Market vendor	Female	20s	
	MH04	Market vendor	Female	20s	
	MH05	Market vendor	Female	W	
	MH06	Market vendor	Female	30s	
	MH07	Rice farm laborer	Male	40s	
	MH08	Rice farm laborer	Male	30s	
	MH09	Rice farm laborer	Male	20s	
	MH10	Rice farm laborer	Male	20s	
	MH11	Rice farm laborer	Male	30s	
	MH12	Rice farm laborer	Male	20s	
	MH13	Rice farm laborer	Male	40s	
	MH14	Rice farm laborer	Male	20s	
	MH14	Rice farm laborer	Male	20s	
	MH15	Rice farm laborer	Male	20s	
	MH16	Ice cream salesman	Male	20s	
	MH17	Student, market vendor	Female	20s	
	MH18	Mason	Male	30s	
	MH19	Unemployed	Female	30s	
	MH20	W	Male	30s	
	MH21	W	Male	20s	
Dominican	DM01	Medical doctor	Female	40s	
	DM02	Medical doctor	Male	20s	
	DM03	Medical doctor	Female	20s	
	DM04	Medical doctor	Male	W	
	DM05	Medical doctor	Male	W	
	DM06	Nurse	Female	30s	
	DM07	Nurse	Female	40s	
	DM08	Nurse	Female	50s	
	DM09	Nurse	Female	20s	
	DM10	Nurse	Female	W	
	DM11	Nurse	Female	30s	
	DM12	Nurse	Female	W	
	DM13	Nurse	Female	40s	
	DM14	Psychologist	Female	40s	
	DM15	Employer of migrants	Male	50s	
	DM16	Employer of migrants	Male	50s	
	DM17	Charity worker	Female	50s	
	DM18	Shop owner	Female	40s	

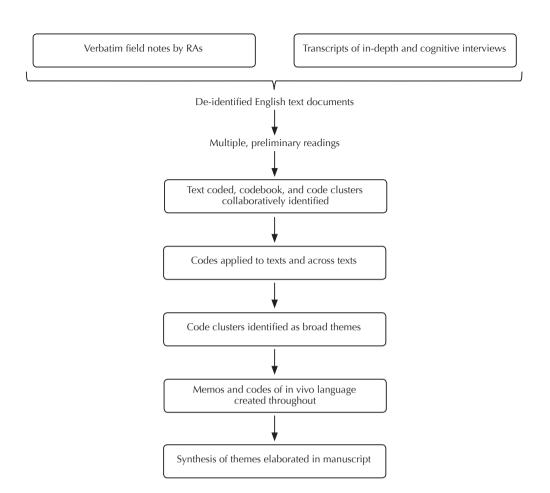
Note: W = missing information

At times, informal meetings were held with multiple gatekeepers within the communities. These contacts were facilitated by the locally hired Haitian RAs, themselves familiar with the communities. To build rapport with Dominican participants, we relied on well-established relationships at the administrative level in the public hospital and regional office of the Ministry of Health.

We pursued an exploratory-descriptive level of qualitative analysis (Figure 3; Sandelowski & Barroso, 2003). The lead author first reviewed all transcripts and field notes. Based on these initial readings, parent codes were created. All codes were compiled into a codebook with definitions, inclusion and exclusion criteria, and examples. The codebook was reviewed by the first and second authors for agreement. Codes were clustered to become parent codes around broadly prevalent themes, such as the migrant experience, sources and barriers to health care, perceptions of Haitians among Dominicans and vice versa, and causes of mental distress. Parent codes were applied to all texts, and additional sub-codes were created in a sequential manner through indexing of in vivo terms or memos about subjects that continually resurfaced under each parent code. MaxQDA10 software was used to manage the coding and analysis (VERBI, 1989–2010).

#### Quantitative instruments and analysis

Across the six communities, we conducted a pilot survey of migration and mental health experiences with 127 adult Haitian migrants. Each survey participant self-identified as Haitian and reported having migrated from Haiti to the Dominican Republic. Survey participants were identified through systematic random sampling. In each of the six migrant communities, we conducted a census of all Haitian households. We then used probability proportional to size to draw samples from each community so that each participant belonged to a different family.



**Figure 3.** Conceptual outline of qualitative data analysis pathway.

Each participant completed a migration history questionnaire, culturally adapted BDI and BAI, and the function impairment instrument for men or women. The BDI and BAI comprise 21 items and are based on experiences over the previous two weeks. Total score can range from 0 to 63; higher scores indicate greater severity (Beck, Ward, & Mendelsohn, 1961). For the BAI, item 20 (facial flushing) was found not to be applicable and was removed, so the highest possible score is 60 (Kaiser et al., 2013). The migration history questionnaire captured basic demographics, place of origin in Haiti, reason for leaving, length of time in the Dominican Republic, perceived discrimination, and public regard, all of which were developed and refined while in country after piloting and discussions with RAs.

The BDI and BAI have been culturally adapted for use with Haitian populations (Kaiser et al., 2013; Wagenaar et al., 2012). The instruments underwent a transcultural

translation and adaption process for psychiatric instruments (Kohrt et al., 2011; van Ommeren et al., 1999). The process involves several stages of translation and discussion involving bilingual lay individuals, bilingual professionals, general community members, and independent bilingual experts. This assures each item in the adapted instrument demonstrates semantic, technical, content, criterion, and conceptual equivalence (Flaherty et al., 1988). In the instrument development study, BDI mean (M) was 22.9, standard deviation (SD) was 12.2, and Cronbach's alpha ( $\alpha$ ) was 0.89; BAI M = 23.1, SD = 18.3, and  $\alpha$  = 0.94 (Kaiser et al., 2013).

All survey data were entered into Excel 2007, checked for data entry errors and implausible values, and analyzed using SAS 9.3 (SAS Institute Inc., 2011). Because this represents the first study of its kind among this population, quantitative analysis was exploratory. To account for small sample size, we calculated 90% confidence intervals (p < 0.10), as analysis was hypothesis generating rather than aiming to carry strong inferential weight. Multivariable linear regression models were constructed, with continuous depression total score, anxiety total score, and functional impairment total score as outcomes for separate models. Continuous outcomes were deemed more appropriate than categorical to optimize the variance of the small sample size and due to lack of validated categorical cut-offs for the instruments. BDI, BAI, and functional impairment scores were normally distributed. For individuals with missing or no response to instrument items, we imputed values by taking the individual's mean score for answered items and then multiplying by total items on the screener. Seventy-nine percent of observations were complete for the BDI, with 15% missing only one item (either item 10 or 11). Seventy-six percent were complete for the BAI, with 18% missing only one item and 5.5% missing two or more items. Ninety-two percent were complete for the function impairment instrument.

Exploratory analysis began with all likely predictive and confounding variables. Variables considered for inclusion in the models were age, sex, marital status, migrated alone, knew someone in the Dominican Republic prior to migrating, engages in periodic round-trips between Haiti and the Dominican Republic, number of household members, feels that Dominicans mistreat Haitians, feels that there are problems between Haitians and Dominicans, ever been interrogated or deported, and knew someone who had been interrogated or deported.

Backward selection procedures ( $\alpha$  < 0.10) were used to obtain final models. To establish significance of predictor variables, t-tests were used. Clustering effects were accounted for by creating dummy variables for each community. Cook's D, leverage values, jackknife residuals, and partial residual plots were examined in the final model to assess for effects on the values of regression coefficients, extremeness of observations in relation to independent predictors, outliers, and violations of the linearity assumption. Significant differences in functional impairment scores between men and women were computed through t-tests.

#### **RESULTS**

## **Quantitative findings**

The community survey sample was young (M = 33 years, range 18–58 years), largely uneducated (men's education M = 4.5 years, range 0–14 years; women's education M = 3.9 years, range 0–9 years), and mostly male (59%) (Table 2). Most individuals had migrated within the last 10 years (mean length of time 7.3 years, range 0.5–30 years), had known someone in the Dominican Republic before migrating (54%), and engaged in periodic round-trips between the two countries (79%). "Problems between Haitians and Dominicans" or that "Dominicans mistreat Haitians in this community" were reported by 26% and 29% of the sample, respectively. Twenty-nine percent reported a personal experience of having been interrogated or deported or of knowing someone who was.

**TABLE 2:** Demographics and migration characteristics of Haitian migrants (n=127).

Characteristic	N (%)
Female	53 (41.7)
Persons per household	4.42 (range 1-16)
Persons married	23 (18.4)
Persons with children	102 (80.9)
Primary reason for migration Economic insecurity Family Hunger/sickness Security/government	98 (81.0) 6 (5.0) 6 (5.0) 2 (1.7)
Other	9 (7.4)
Migrated with family	38 (30.4)
Migrated alone	46 (36.8)
First time in Dominican Republic at time of survey	26 (20.8)
Knew someone in Dominican Republic before migrating	67 (54.0)
Had job arranged in advance of migrating	16 (12.8)
Engage in periodic round-trips	100 (78.7)
Send remittances back to Haiti	100 (78.7)
Suffer >3 months of inadequate money to buy enough food for self or family	61 (48.0)
Access to a toilet or latrine	93 (76.9)
Obtain drinking water through purchase	71 (57.3)
Report that "there are problems between Dominicans and Haitians in my Community"	33 (26.2)
Cite being Haitian or "not being in my country" as a reason for difficulty in completing daily tasks	31 (31.3)
Past experience of interrogation or deportation – self	13 (10.4)
Past experience of interrogation or deportation – knowing another	31 (25.0)
Report past experience of being attacked or robbed	17 (13.9)

## BDI and perceived discrimination

Mean imputed BDI score for the sample was 27.11 (90% confidence interval [CI]: 25.23, 28.98; median 27;  $\alpha = 0.85$ ). The final linear model for depression had an  $r^2$ of 0.41 and revealed no significant multicollinearity (variance inflation factor [VIF] < 10). Significant covariates of BDI score were being married (protective effect; aß = -5.08; Cl -9.26, -0.9), migrating to the Dominican Republic alone (aß = 5.45; Cl 2.28, 8.62), feeling that Dominicans mistreat Haitians (aß = 6.59; Cl 3.29, 9.9), and having ever been personally interrogated or deported (aß = 5.22; Cl 0.14, 10.29; Table 3).

TABLE 3: Multivariable linear regression of Kreyòl Beck Depression Inventory (BDI) total score for Haitian migrants in the Dominican Republic, March–April 2011 (n = 119).

Covariate	aß (90% confidence interval)		
Married	-5.08 (-9.26, -0.90)		
Came alone	5.45 (2.28, 8.62)		
Reports that Dominicans mistreat Haitians in community	6.59 (3.29, 9.90)		
Ever interrogated or deported	5.22 (0.14, 10.29)		

# BAI and others' experiences of discrimination

Mean imputed BAI score was 16.17 (CI: 14.92, 17.42; median 16.33;  $\alpha = 0.85$ ). The final linear model for anxiety had an r<sup>2</sup> of 0.33 and revealed no significant multicollinearity (VIF < 10). Being married and having migrated to the Dominican Republic alone were associated with worse mental health ( $a\beta = 4.43$ , CI: 0.63, 8.24 and  $a\beta =$ 3.37, Cl: 0.24, 6.51, respectively). Having an acquaintance who had experienced interrogation or deportation was associated with higher anxiety score (a $\beta$  = 3.46, CI: 0.39, 6.53; Table 4). Additionally, participants living in communities that are remote or with more reports of violent retaliation by Dominicans against Haitians tended to have higher anxiety scores on average.

TABLE 4: Multivariable linear regression of Kreyòl Beck Anxiety Inventory (BAI) total score for Haitian migrants in the Dominican Republic, March–April 2011 (n = 119).

Covariate	aß (90% confidence interval)			
Married	4.43 (0.63, 8.24)			
Came alone	3.37 (0.24, 6.51)			
Knows someone who was interrogated or deported	3.43 (0.22, 6.64)			
Community*				
A	9.89 (4.67, 15.11)			
В	12.51 (7.71, 17.32)			
C	6.38 (-0.12, 12.88)			
D	4.84 (-0.04, 9.71)			
E	3.98 (-0.29, 8.26)			

<sup>\*</sup> Communities are anonymized in this table. To note, A was urban and B-E were rural.

## Functional impairment and perceived discrimination

Mean imputed functional impairment score for men was 17.44 (Cl: 15.99, 18.9; median: 18;  $\alpha = 0.75$ ), and for women it was 19.84 (Cl: 18.26, 21.41; median: 20;  $\alpha$ = 0.71). Scores were significantly different (p = 0.03). Of 99 observations for which a reason was cited for functional difficulty, 31 (31.3%) cited perceived anti-Haitianism as the main reason for difficulty.

The functional impairment regression model achieved good fit ( $r^2 = 0.19$ ) and had no significant multicollinearity (VIF < 10). Significant covariates of functional impairment were female sex (aß = 2.09; CI 0.13, 3.87) and feeling that Dominicans mistreat Haitians in the community (a $\beta$  = 2.72; Cl 0.65, 4.79; Table 5).

**TABLE 5:** Multivariable linear regression of functional impairment for Haitian migrants in the Dominican Republic, March–April 2011 (n=124).

Covariate	aß (90% confidence interval)		
Female	2.09 (0.13, 3.87)		
Reports that Dominicans mistreat Haitians in community	2.72 (0.65, 4.79)		

# Qualitative findings

"Us little miserable ones": reasons for migration and daily obstacles

When asked to explain why Haitians come to their country, Dominicans explained that Haiti's poverty, punctuated by the January 2010 earthquake, forces Haitians to look toward their neighbor. Haiti's instability, they explained, works synergistically with a Dominican economy dependent on cheap labor, such that migrants find a better life outside Haiti while fulfilling essential economic roles in the Dominican

Republic. An employer suggested that Haitians even depend on the Dominican Republic to survive: "They cross the border at any cost and come to work because they will die in their country [...] Where else can they go? Without us, they almost couldn't exist" (DM15, male).

Employers of migrants referenced how the Dominican economy has changed in a way that favors the influx of an undocumented workforce. Two employers in the agriculture sector described how Haitians come to do work that Dominicans no longer prefer because more Dominicans attend school. Both employers described that the nature of the work itself – typically "stoop labor" under the sun – was disagreeable. Another employer explained that rural Dominican farmers and small landowners face their own financial constraints and have little choice but to hire migrants willing to work for less. A different employer explained, "The government doesn't give priority to the rural farmer. The smaller farmer is buying more expensive products, the gasoline is more expensive, everything is more expensive, and then when [Haitians] go to harvest the rice, it's cheaper" (DM16, male).

Both migrants and Dominican farm employers – or the gran neg (big men) as the migrants called them – agreed that they had a good working relationship with each other. Contentious relationships were instead described between migrants and poor Dominicans. Whereas Dominican employers reported that Dominicans were uninterested in low-paying jobs, Haitian migrants reported that poor Dominicans were resentful of their presence, presumably because of competition for work: "The big men, we help them in their work. The Dominicans who don't have opportunities, who don't have money like the big men, they don't want to see us around" (MH07, male rice farm laborer).

Lack of legal documentation was cited as a major challenge in daily life. For most interviewed migrants, purchasing a passport and an accompanying cédula, or identity card granting authorized status, was unaffordable. Instead, many described passing anba fil, or "below the wire," a phrase for those who cross the border without paperwork, a process rife with corruption and theft.

Even for those with a passport or cédula, life was not always easier. One woman described arbitrary stops and exploitation:

You must show [immigration officials] your passport. Sometimes they will treat a Haitian like a little toy (yon ti jwèt), and they will make you spend what you have [...] They will take your passport and visa from you and sell it to another Haitian who might look like you. And then it's the same immigration person that will give you problems for not having your passport later. (MH04, market vendor)

For undocumented Haitians, legal paperwork represented the possibility for upward mobility while leaving some vulnerable to further exploitation.

The challenges to acquiring documents were perceived by some as an intentional arrangement to keep Haitians in low-paying jobs: "It's a way for them not to give a job to you, asking about the cédula," said one woman (MH03, market vendor). In a rural community, one man exclaimed:

Where do you put a day's work for 400 gourdes [approximately \$10 USD]? You can't send your kids to school. They all have to bend down right there in the dirt. They do the same thing that the father is doing; once the child is grown, that's what the child will end up doing too. (MH08, rice farm laborer)

While Dominican informants referenced economic drivers of migration, their accounts diverged from migrants when asked whether migrants succeeded in finding a better life. Employers felt that migrants benefited from an economic niche outside their home country, finding an opportunity for self-improvement. A migrant, on the other hand, summed up his experience this way: "If our country was good, we would not come here to be humiliated by the Dominicans" (MH08, rice farm laborer). Migrants described proximate, daily obstacles: lack of legal documentation, inability to find a sustainable income, and imilyasyon (humiliation). Haitians reported feeling powerless and belittled, sometimes referring to themselves as ti malere, "little miserable ones," and ti jwèt (little toys) stuck in a game whose main actors are the "big men" for whom they work or immigration officials, whose decisions seem arbitrary and exploitive.

#### "They humiliate us"

At the time of our fieldwork, cholera, which emerged in Haiti in October 2010, had been reported in the Dominican Republic (Tappero & Tauxe, 2011). One woman described the blame incurred by Haitians following the epidemic's spread: "[The Dominicans] say this is a problem only for Haitians to have [...] If a Dominican has cholera, they blame it on us Haitians" (MH04, market vendor). In these accounts, the epidemic appeared to further stigmatize migrants. She elaborated:

They say it's we who have brought this illness, but I say, Who are we? We are not God who can create these things. And now they think the illness can be transported in the clothes that we sell, so now people are afraid to buy clothing from us.

The fear and stigma of cholera exacerbated an already marginalized social space. Increased psychosocial stress and internalized stigma resulted from these "streetlevel" interactions where Dominicans passed over Haitians in the market or resorted to name-calling. A female Haitian market vendor said, "Because you're a Haitian, to [a Dominican] you are just like a dog, and you don't have much vale [value]. It's like

you're more animal than person. These words can make you reflect [and] you can become discouraged" (MH03).

Vale (value or worth) was a predominant theme in accounts by Haitian participants. Vale can represent both financial means and self-worth as a human being: "In life, when you have nothing, you're worth nothing (ou pa vo anyen). You're poor," stated one unemployed Haitian female (MH19). Being poor and Haitian in the Dominican Republic convinced some that as a collective body, Haitians pa gen vale, or "have no worth." BDI item 14 captured worthlessness, expressed as pa vo anyen – "not worth anything." Sixty-nine percent (n = 88) of the survey sample endorsed this item:

When I live in the Dominican Republic, they humiliate us (*yo imilye nou*) because we're not in our country. (MH18, male mason)

I don't see a way out of this misery because of how Dominicans say bad things to us. (MH21, male community member)

Dominicans humiliate me; they treat me like garbage [...] In the eyes of the Dominicans, I am worth nothing. (MH05, female market vendor)

In their use of vale, migrants connected the concrete and symbolic meanings of worth, represented by both a lack of money and being Haitians in another country.

The clinical experience: views of Haitian patients

Pierre (pseudonym; MH01, male construction worker) had been living in the Dominican Republic with members of his family for three years. At the time of our interview outside the public hospital, he was waiting for his sister, who was receiving treatment for postpartum hemorrhage. When asked how he and his sister were treated inside the hospital, he first commented on the time it took Dominican providers to attend to them:

In the hospital, they almost treat you the same as a Dominican, but it can be worse. I'll take the example of my sister. She's been sick, bleeding, and if I hadn't been diligent, the people in the hospital wouldn't have cared for her, they wouldn't have asked what was wrong with her. They take too much time to take up your case, so you're obligated to wait.

Even when that care arrived, it was apparently disjointed and poorly communicated, leaving Pierre resigned to accept whatever decision was made. Pierre said he avoids going to the public hospital because "it takes too long for them to care for a Haitian." He described how the hospital staff seemed to respond more quickly to the needs of nearby Dominican patients and concluded saying, "it's as if they take me for a little toy (yon ti jwèt)."

Pierre's sense of resignation at the public hospital was echoed by other migrants. In general, private clinics were said to be of better quality but too costly for most. However, alongside financial constraints in accessing care, Haitian participants implicated their nationality: "If you are Dominican, you can go [to the private clinic], but if you're Haitian, you can't go because you don't have money" (MH04, female market vendor). Much like Pierre's experience, this woman explained how Haitians are largely ignored at the hospital, since "they see you are a person without money, [and] they won't be eager to help you. Because we're Haitian, and we don't have value, we don't have money, [so] you sit there." Overcoming the language barrier did not always facilitate the matter: "Even if you speak Spanish, if they see you are Haitian, you call for them, but they won't take up your case because you're Haitian" (MH03, female market vendor). Thus, Haitian participants widely shared the perception that Dominicans not only could access better quality care but also received preferential treatment in the same clinical space as Haitians.

The clinical experience: views of Dominican health care professionals

Working in a large, publicly subsidized hospital and its outlying clinics granted Dominican interview participants a unique perspective on caring for Haitian patients. Clinicians attributed many of their patients' afflictions to circumstances not found among their Dominican patients.

Most interviewed clinicians reported that unsanitary, crowded living conditions in which many Haitians live were conducive to spreading disease. Some Dominicans in the community presumed that Haitians chose to live that way out of social or cultural custom: "That is the biggest difficulty they have – their way of life – so many of them live all together [...] Me, I like privacy" (DM18, Dominican female shop owner). Additionally, some Dominicans emphasized an ignorance of hygiene: "They don't take care of themselves so much, they don't know how to take care of themselves (no se saben cuidar)" (DM11, Dominican nurse). In this way, social and health disparities among Haitians could be explained away through ignorance, supposed preferences, or social practices, which could predispose them to disease:

They are people with less privacy than the Dominican[s], they have more sexual relations with consecutive people than the Dominicans [...] A Dominican woman is proud of having a husband, the Haitian no, she has many relationships. (DM11, Dominican nurse)

Building on the premise "the Haitian patient has another culture, other beliefs, other ideologies, and even another language" (DM11, Dominican nurse), one Dominican physician went even further to say Haitians had a different physical and mental constitution, which grants them unusual strength to cope with the difficulties they experience:

The Haitian is a human being who tolerates more than any other human being, because they are, let's just say, accustomed (acostumbrado) to living with anemia; they endure levels of hemoglobin that the books don't accept [...] The books tell you that with a hemoglobin of 5 one [should] die, [but] the Haitian goes [around] perfectly with a hemoglobin of 5, he goes around in the street, and then he is going around working, but how it doesn't give him motion sickness, or anything, that's just how they are. (DM01)

Another doctor in an outlying clinic agreed: "Haitian patients are, in a certain way, stronger with regards to health" (DM05). Thus, being acostumbrado to malnutrition, poverty, and hard work further differentiates Haitians from Dominicans: "They have strong minds and can resist the problems that they really have" (DM09, Dominican nurse). In this way, while Dominican clinicians may have intended to admirably characterize Haitians, their references to social, cultural, or even biological differences provided a means to overlook more complex structural factors at root, which seemed painfully obvious to their patients:

You have to carry a large sack of rice on your head [...] You have to get up early, which sometimes bring sickness that you never thought you would find in this life [...] You're poor, and when it gives you this illness, if you don't have means to go to the hospital, you may find yourself just having to deal with it. (MH08, male rice farm laborer)

Yet while multiple reasons were provided for the different ways Haitians acquire, experience, and seek care for disease, Dominican clinicians were adamant that all patients, regardless of nationality, were treated the same. Maintaining that they provide impartial care to everyone, clinicians said many Haitian patients incorrectly presume they are being discriminated against: "They believe even though you treat them well, they feel that you are maltreating them, they believe you are going to hurt them" (DM01, Dominican doctor). This misconception was said to reflect a historical misunderstanding between the two countries. The same doctor continued: "They have a resentment against the Dominican Republic, one that grows from Haiti; they feel that this part of the island is also theirs, because of the history of wars and the independence and all that (DM01)."

Another doctor further explained that while this "resentment" against the Dominicans "makes them feel like however you deal with them is bad, [...] that's not to say that's really how it is" (DM02). He went on:

Just because their country has its problems, they shouldn't feel ashamed [...] They should feel proud, because their problem isn't because of them but because of their politics.

According to him, Haitian patients, who unjustifiably feel "ashamed," are responsible for any misunderstanding with their Dominican clinicians. For this doctor, rather than feeling ashamed, worthless, or humiliated, Haitians should "feel proud." He concluded, "I don't see what the problem is, but that's getting into culture [...] That's a guestion of how they see it from their perspective, their point of view" (DM02).

Thus, competing pictures emerged from the clinical setting. From one perspective, Haitians cited the structural difficulties they endure in daily life - including their working conditions, lack of documentation, and financial constraints – and the perception that they were unimportant and relegated to a lower rung in the ordering of clinical priorities. Dominican clinicians differentiated their Haitian patients on the basis of cultural, social, or "bodily predispositions" (Holmes, 2012, p. 879) not found among Dominican patients. Those "predispositions" were considered responsible for their poor health and inability to grasp the good intentions of care providers.

#### **DISCUSSION**

Perceived discrimination is central in the self-reported experience of Haitian migrants in the Dominican Republic, is underrepresented in accounts by Dominicans, and is significantly associated with mental distress measured through both depressive and anxiety symptoms. While migrants and Dominicans cited similar drivers of migration, their accounts diverged when asked to describe the lived experience of migrants and root causes of their ill-health. Compared to Dominican informants, migrants grounded their explanations of distress within more proximate determinants, including the stress of migrating, trying to find work without legal documents, and feeling humiliated. This imilyasyon was explained to occur through interactions with some Dominican clinicians and poor community members. Humiliation and feelings of worthlessness were connected to perceived mistreatment by Dominicans.

In our exploratory analysis of depression, anxiety, and functional impairment, we found that self-reports of mistreatment by Dominicans associated with a 6.6-point increase in BDI score. Ever having been interrogated or deported associated with a 5.2point increase in BDI score, while knowing someone who had been interrogated or deported was associated with a 3.4-point increase in BAI score. Considering approximately 30% of our sample reported perceptions of mistreatment by Dominicans and one- quarter knew someone who was interrogated or deported, these exposures represent a substantial burden on the mental health of Haitian migrants. Perceived discrimination is associated not only with higher depressive symptoms but decreased ability to complete daily tasks, a particularly detrimental effect for migrants who are typically far removed from their family and natal community and who are relied upon for financial remittances.

"Othering" notions of difference originally promulgated under anti-haitianismo resurfaced in the clinical setting. Dominican clinicians employed essentialist as well as contextual approaches in framing the ailments of migrants. First, some complaints were reduced to biological or behavioral differences. Haitians were sometimes characterized as preferring to live in crowded conditions or as having cultural or social customs predisposing them to disease. In some instances, Dominican clinicians assigned a different physiology altogether to Haitian patients, contending that their collective suffering as a poor and marginalized group has, over time, habituated them to pain and suffering, a perspective that reduces the social to the biological (Fassin, 2001). While this "clinical gaze" (Foucault, 1975) seemed to prevent some clinicians from scrutinizing broader determinants of ill-health, other care providers cited the precarious conditions in which migrants live. Both of these approaches – one essentialist, the other contextual – were rooted in a "biopolitics of otherness" (Fassin, 2011, p. 214).

Attributing feelings of worthlessness, humiliation, and powerlessness to interactions with Dominicans reflects low public regard and high internalized stigma. Haitian participants connected feelings of worthlessness to their own perception of how Dominicans consider Haitians as a whole. As a collective body, many Haitians perceive themselves to lack vale, a perception reinforced through structural practices such as unpredictable round-ups and deportations, paying lower wages, passing over them in clinical settings, or blaming them for the cholera epidemic. In this way, discrimination influences how migrants perceive themselves, their deservingness, and their own place in the racial-moral hierarchy of Dominican society. Future research should explore how internalized stigma and humiliation within this population relate to macro-level ideologies, practices, and institutional policies that construct and perpetuate hierarchies of deservingness (Viruell-Fuentes, Miranda, & Abdulrahim, 2012).

As well, these experiences were illustrative of "humiliation" rather than "discrimination." Imilyasyon, an emotionally charged and locally salient word among migrants, contrasts with the more legalistic concept of discriminación. Different meanings of negative social experiences can be reflected in the linguistic constructs used by majority and minority groups (Beck, Mijeski, & Stark, 2011). In the Dominican Republic, discriminación may convey a more abstract concept, one more closely associated with the criticism of international human rights organizations and foreign diplomats, whose critiques are sometimes broadcast on the front pages of national newspapers (Noticias Aliadas, 2011). In this study, Dominican participants seemed to know what discrimination was but felt strongly that it no longer operates to the degree that it once did. For Haitians, humiliation rather than discrimination appeared to more accurately encompass the personal experience of living and working in the Dominican Republic. Humiliation seems to more closely mirror the experience of stigmatized groups – those who are first differentiated from the dominant group, labeled, and stereotyped consequently suffer status loss and discrimination and have limited access to economic, social, or political power (Link & Phelan, 2001). Tracking the language of those who bear the brunt of structural violence can help "expose assumptions and political practices that hold structural violence in place" (Briggs, 2005, p. 283).

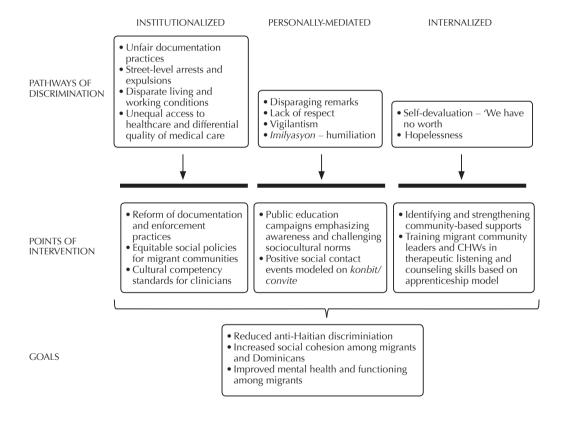


Figure 4. Conceptual outline of anti-Haitian discriminatory pathways and points of intervention.

To reduce negative effects of perceived discrimination and humiliation, interventions must break the institutional, personally mediated, and internalized pathways through which discrimination causes harm (Jones, 2000; Figure 4). First, to dismantle anti-Haitian institutional policies, major steps are needed toward reforming unfair documentation practices, which systematically deny valid work permits and perpetuate street-level arrests and deportations. Equitable health and social policies must address longstanding service gaps in marginalized communities, particularly in rural areas where disparities are greatest. In the health sector, cultural competency standards should be integral to clinical training and practice, with attention to the unique health needs and expectations of Haitian migrants. Finally, nationwide public education campaigns can challenge anti- Haitian norms by articulating the contribution Haitian migrants have long made to Dominican society, contextualizing their health within broader social determinants, and emphasizing the two countries' shared values.

To reduce personally mediated and internalized discrimination, community interventions can build on shared cultural practices among Haitians and Dominicans. The identical social structures represented by the *convite / konbit* form of collaboration among farmers is an example of how the two countries share certain customs and values (Domínguez, Castillo, & Tejeda, 1978; Métraux, 1951). The shared linguistic root of convite / konbit and its spirit of solidarity and cooperation point to how both groups have much in common. The *convite / konbit* can thus provide a model for community-level interventions that bring Haitians and Dominicans together, with the aim of identifying common goals and fostering community empowerment. Such "positive contact events" can be successful at reducing prejudicial beliefs (Pettigrew & Tropp, 2006). Grounding such events in a shared historical heritage can help foster their acceptance by the community.

Additionally, strengthening existing forms of community support in migrant communities and following principles of the apprenticeship model to train community health workers (CHWs) and lay providers can help reduce harmful effects of discrimination and stigma (Murray et al., 2011). Based on findings in Haiti (Wagenaar et al., 2013; Khoury et al., 2012), community-based support in Haitian migrant communities likely includes nonbiomedical care providers, such as Christian pastors and traditional healers, including Vodou priests and herbalists. Support networks in migrant communities are underexplored and deserve more inquiry. Dominican CHWs can help educate fellow Dominican community members about the harmful effects of discrimination, correct unfounded fears and misinformation, and promote social events to facilitate trust and integration. Haitian migrant community leaders can be trained in basic therapeutic listening and counseling skills in order to help fellow migrants with feelings of low self-worth and humiliation. Essentially, this model encourages social cohesion and mobilization by incorporating existing resources and empowering community members with new knowledge and skills.

#### LIMITATIONS

While this study sheds new light on a poorly understood population, there are several important limitations. First, while native-speaking Spanish and Kreyòl RAs collected all data, analysis was conducted in English. Important nuances and subtleties communicated in the original languages may have been lost. Our survey results are limited by the small sample size and limited inference to the six purposively enrolled communities. Cross-sectional surveys cannot distinguish multifactorial pathways. The current quantitative analyses are intended to be hypothesis generating, and larger studies are required for hypothesis testing of the relationship between discrimination, humiliation, and mental health among Haitians in the Dominican Republic.

# **CONCLUSION**

This analysis helps advance an understanding of the mental health of "peripheral migrants" in developing countries, particularly in contexts where the historical, social, and cultural identities of sending and receiving populations are deeply intertwined. In the Dominican Republic, Haitian migrants have long constituted an important part of the country's economic and social fabric, yet remain marginalized from legal, health, and social spheres. That vulnerability becomes evident when assessing their mental health, which is associated with perceptions of humiliation and discrimination.

#### **ACKNOWLEDGMENTS**

The authors wish to express their sincere gratitude to the research assistants who collected data for this study, namely Mere Dieuliphene, Willy Altindor, Jean Peter Osirias, and Jhefri Augustin Reyes Reinoso. We thank Dhaysi Batista Berroa, Rossemary Ausuncion Hierro Burgos, and Ivette Esperanza Hierro Burgos for their time in transcribing Spanish audio files. Bethany Battig, Jean Verneus, and Brian Gross translated Spanish and Kreyòl documents into English. We thank Brianna Sky Keefe-Oates and Dhaysi Batista Berroa for assistance in translating the abstract to Spanish. Without the support of Sr. Rafael Alvarez Castillo, Dr Ambrosio Rosario, and Dr Luis

Adolfo Dominguez Garcia, this study would not have been possible. We thank the two anonymous reviewers who provided helpful feedback on earlier versions of this manuscript.

# A BUEN HAMBRE NO HAY PAN DURO

WITH GREAT HUNGER NO BREAD IS TOO HARD TO EAT



# Social stressors, social support, and mental health<sup>3</sup>

#### ABSTRACT

This mixed-method study explored the social world of Haitian migrants, examining forms of social support and social stress, as well as their relationship to mental health. Among six Haitian migrant communities in the Cibao Valley of the Dominican Republic, a community-based survey (n = 127) was conducted to assess migration experiences, current stressors, mental health, and functioning. In addition, to explore perceptions and experiences of migration, social interactions, and mental health, the study drew upon in-depth interviews and free-listing activities among Haitian migrants, as well as cognitive interviews with select survey participants. Depressive, anxiety, and mental distress survey scores were associated with 1) negative social interactions (including interrogation or deportation, perceived mistreatment by Dominicans, and overcrowding) and 2) lack of social support, including migrating alone. Mental distress scores were higher among women, and being married was associated with higher anxiety scores, potentially reflecting unmet social expectations. In qualitative data, participants emphasized a lack of social support, often referred to as tèt ansanm (literally meaning "heads together" in Haitian Creole or Kreyòl and roughly defined as solidarity or reciprocal social collaboration). The authors of the study propose that the practice of tèt ansanm – also termed konbit, and, in the Dominican Republic, convite could be used as a means of facilitating positive-contact events among Haitians and Dominicans. These interactions could help counteract social stress and build social capital in settings similar to those of the study.

<sup>3</sup> Originally published as: Kaiser, B., Keys, H., Foster, J., and Kohrt, B. 2015. "Social stressors, social support, and mental health among Haitian migrants in the Dominican Republic." Pan-American Journal of Public Health 38(2): 157-162. The text has been lightly edited.

#### BACKGROUND

For migrant populations, life in a host community can entail multiple psychosocial stressors, including adjustment to a new culture, changes in identity, and institutional and interpersonal discrimination (Bhugra & Becker, 2005). Post-migration social support can be an important contributor to mental health (Porter & Haslam, 2005). Strengthening social capital has thus become a focus of public health and policy goals. Social capital refers to social cohesion, support, and/or participation within a group (bonding) and with the broader social structure (bridging). Social capital has been considered an important buffer against social stress, defined as stress that arises from negative interpersonal relationships (Almedom, 2005). These factors collectively represent the "social world," a term used in this report to describe both positive and negative aspects of the social environment.

Migration in the Americas is an important process that drives much economic activity. There are nearly 60 million international migrants in the Western Hemisphere (IOM, 2020). While most Latin American countries are net emigration centers, there is increasing "south-to-south" movement among Latin American states (IOM, 2020). A case in point is the Caribbean island shared by Haiti and the Dominican Republic. There, migration has profoundly shaped the development of both countries. Haitian migrants are overwhelmingly undocumented and often live in communities without basic services. A legacy of anti-Haitian discrimination (anti-haitianismo) has contributed to their status as a nearly invisible population. For example, in response to the cholera outbreak, Dominican authorities undertook a campaign of forced expulsions of Haitian migrants (Amnesty International, 2011), while more recent legislation effectively stripped entire generations of Haitian-descended Dominicans of their right to citizenship (Archibold, 2013). Unsurprisingly, mental health needs of Haitian migrants remain largely unexplored and underserved (see previous chapter).

#### THE SOCIAL WORLD OF HAITIAN MIGRANTS

To address this knowledge and service gap, a field study was completed in the Cibao Valley from March-April 2011 (see previous chapter). Using ethnographic and epidemiologic methods, this study found a positive association between perceived discrimination and symptoms of mental illness. Haitian migrants often described harmful social interactions with Dominicans and fellow migrants using the term *imilyasyon* (humiliation). At the same time, they expressed the desire for increased social cooperation with their Dominican neighbors. Across multiple forms of data collection, themes of social capital and social stress arose – findings that demand greater scrutiny.

This report draws upon data from the field study to explore the impact of the social world on mental health of Haitian migrants in the Dominican Republic. Of particular interest are the context and content of social interactions and how they may serve as either sources of support or stress. The report concludes that there is a need to explore potential avenues to promote social capital to enhance mental health. The goal of the report is to shed more light on the mental health of this population with the practical application of informing mental health interventions and policies in the region (Kohn et al., 2005).

#### STUDY OVERVIEW

The original field project was supported by a research partnership among Emory University (Atlanta, Georgia, United States); Universidad Autonoma de Santo Domingo (San Francisco de Macorís, Dominican Republic); and Hospital San Vicente de Paúl (San Francisco de Macorís) to conduct a mixed-methods study of mental health and migration experiences. Six predominantly migrant communities were identified through in-country discussions with research partners and community members. The communities were located throughout Duarte Province, which has a total population of 310,000. One community was in the urban core of a large city, and the remaining five were in rural settings. Rural communities in Duarte Province tend to be more mixed, with Haitian migrants, including Haitian-descended persons, living alongside Dominicans. This contrasts with communities found in other parts of the country known as bateyes - communities historically composed of Haitian agricultural workers and their families. Traditionally, bateyes were constructed at the behest of large Dominican ingenios (sugar companies) (Martínez, 1999).

Quantitative data were collected through a community-based, cross-sectional survey that assessed mental health using culturally adapted instruments - the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI) - plus two locally developed instruments: the Kreyòl Distress Idioms (KDI) scale and the Kreyòl Function Assessment (KFA) (Kaiser et al., 2013). The adapted BDI and BAI underwent a rigorous process of cross-cultural adaptation in Haiti to ensure that the adapted instruments achieved semantic, technical, content, criterion, and conceptual equivalence. The KDI drew on ethnographically identified idioms of distress, locally salient ways of experiencing and expressing cognitive, emotional, and somatic suffering. The KFA was developed based on a free-listing activity among a convenience sample of Haitian migrants (21 men and 23 women). This activity asked participants to identify the necessary tasks for caring for one's self, family, and community. The most commonly cited tasks were used to develop separate male and female function assessments, which ask participants to report difficulty completing each task (see previous chapter).

A household-level census in each of the six communities facilitated random sampling, which used probability of selection proportional to size of the community for the cross-sectional survey (n = 127). Multivariable linear regression models were constructed using backward selection of significant ( $\alpha$  < 0.05) predictors for the BDI, BAI, KDI, and KFA scores, accounting for clustering effects at the community level.

Qualitative data used for this report included audio-recorded in-depth interviews with Haitian migrants (n = 21), free-list data collected during development of the KFA, and cognitive interviews. Table 1 provides an overview of study participant characteristics (with additional details provided in the previous chapter). In-depth interviews drew on a purposive sample of Haitian migrants and focused on migration experiences, perceptions and experiences of discrimination, clinical experiences, treatment-seeking behavior, and causes and symptoms of mental distress. Interviews were transcribed verbatim into Kreyòl (Haitian Creole) by Haitian research assistants and translated into English by bilingual speakers. Transcripts were read closely for instances of social interactions.

The study was approved by the Emory University Institutional Review Board and the Ethics Committee of Hospital San Vicente de Paúl. All participants gave verbal informed consent. No identifying information was recorded with quantitative data, and audio transcripts were de-identified. Three multilingual (Kreyòl–Spanish–French), Haitian-born, locally hired research assistants collected data from the Haitian participants. The second author (HK), an American proficient in Kreyòl, French, and Spanish, coordinated the study.

**TABLE 1:** Characteristics of migrant Haitians participating in in-depth interviews and survey, Dominican Republic, March-April 2011.

Characteristic	Number (%)			
In-depth interview (n=21)				
Sex: female	6 (28.6)			
Age (years) 20-29 30-39 40-49 Unknown	11 (52.4) 6 (28.6) 2 (9.5) 2 (9.5)			
Occupation Rice farm laborer Market vendor Construction worker Other/unknown	9 (42.9) 5 (23.8) 2 (9.5) 5 (23.8)			
Survey (n=127)				
Sex: female	53 (41.7)			
Mean age (standard deviation): 33.4 (8.9)				
Married	23 (18.4)			
Mean household size (range) 4.42 (1–16)				
Migrated alone	46 (36.8)			
First time in Dominican Republic at time of survey	26 (20.8)			
Knew someone in Dominican Republic before migrating	67 (54.0)			
Had job arranged in advance	16 (12.8)			
Engage in periodic trips to Haiti	100 (78.7)			
Sends remittances back to Haiti	100 (79.4)			
Report that 'Dominicans mistreat Haitians in my community'	36 (28.8)			
Past experience of interrogation or deportation-self	13 (10.4)			
Past experience of interrogation or deportation – knowing another	31 (25.0)			
Mental health outcomes	Mean score (95% confidence interval)			
Adapted Beck Depression Inventory Adapted Beck Anxiety Inventory Adapted Kreyòl Distress Idioms Adapted Kreyòl Function Assessment	27.1 (25.2, 29.0) 16.2 (14.7, 17.7) 14.5 (13.1, 15.9) 18.5 (17.4, 19.5)			

# TÈT ANSANM ("HEADS TOGETHER"): PERCEPTIONS OF SOCIAL SUPPORT IN MIGRANT COMMUNITIES

Results of the free-list activity that informed the function assessment provided insight into migrants' perceived responsibility toward the community. Responses about caring for one's community were largely focused on social interactions and building solidarity, such as participating in tèt ansanm (literally meaning "heads together" in Kreyòl and roughly defined as reciprocal social collaboration); living in peace; and having meetings. Ways to support the physical community, such as cleaning and hygiene, were secondary. Interestingly, in a previous study in Haiti, activities in support of the physical community, such as planting trees, cleaning, and repairing the road, were more common among participants' responses (Kaiser et al., 2013).

The concept of tèt ansanm (also termed konbit, and, in the Dominican Republic, convite) arose frequently not only in the free-lists but also in survey responses and interviews. Tet ansanm can be used to refer to solidarity as well as a form of collaborative action in which community members assemble to support a neighbor in completing a task requiring many laborers (Vega, 2007 [1981]). Rather than expecting payment, participants expect reciprocation when they need equivalent support. As tèt ansanm is considered central to communal life for Haitians (Métraux, 1951), many migrants bemoan its absence in the Dominican Republic. Interview participants pointed to both the transient nature of migration and a general lack of support structure (ankadreman) to explain migrants' lack of ability to realize tèt ansanm. Furthermore, when survey participants indicated that they have difficulty carrying out a task included in the function assessment and were asked to provide reasons, responses often reflected similar themes. Although most reasons for functional difficulty referenced economic problems (65.9%), almost all others were social: mistreatment by Dominicans (16.7%), lack of solidarity (9.5%), and not being in one's own country (4.8%). Thus, nearly 30% of reasons for functional difficulty were related to impaired social relationships. Many responses specifically referenced a need for tèt ansanm. Thus, this key Haitian form of social support appears to be lacking for this migrant population, and its absence is used to communicate a broader lack of solidarity and social support.

# SOCIAL SUPPORT, SOCIAL STRESS, AND MENTAL HEALTH **OUTCOMES**

A lack of social support was associated with worse mental health outcomes in the survey findings (Table 2). Migrating to the Dominican Republic alone was associated with higher depression, anxiety, and mental distress scores. Interestingly, being married was associated with a higher level of anxiety symptoms, and number of people living in the household was associated with increased experience of mental distress. The positive association between anxiety and marriage could be explained by worry for a spouse's safety or the stress of trying to meet family obligations amid difficult conditions. These associations suggest that social stress – such as that brought about by overcrowding and failure to meet role expectations – might play a stronger role in mental health than social support potentially provided by co-habitants.

Past interrogation or deportation, or knowing another migrant who had had either of those two experiences, was also associated with higher anxiety symptomology. Immigration authorities were said to make arbitrary arrests, leaving some Haitian participants feeling like "little toys." Similarly, perceptions that Dominicans mistreat Haitians were positively associated with depressive symptoms and functional impairment. Finally, Haitian migrant women reported more mental distress and functional impairment than men (see previous chapter), suggesting important gender implications in potential social support interventions for this population, outlined in more detail below.

**TABLE 2**: Results of multivariable linear regression models for Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), Kreyòl Distress Idioms (KDI), and Kreyòl Function Assessment (KFA) total scores among Haitian migrants, Dominican Republic, March-April 2011<sup>a,b</sup>

Variable	<b>BDI</b> (n=123)		<b>BAI</b> (n=122)		<b>KDI</b> (n=120)		<b>KFA</b> (n=124)	
	aß (95% Cl <sup>c</sup> )	P	aß (95% CI)	P	aß (95% CI)	P	aß (95% CI)	Р
Came to the Dominican Republic alone	5.2 (1.5, 8.9)	0.01	3.5 (0.4, 6.6)	0.03	3.7 (0.7, 6.7)	0.02	-	-
Reports that Dominicans mistreat Haitians	7.6 (3.8, 11.3)	0.001	_ d	-	-	-	2.7 (0.2, 5.2)	0.03
Interrogated or deported (self or acquaintance)	-	-	3.5 (0.4, 6.5)	0.03	-	-	-	-
Married	-	-	3.8 (0.1, 7.6)	0.04	3.6 (0.03, 7.2)	0.05	-	-
Female	-	-	-	-	3.0 (0.3, 5.7)	0.03	2.1 (-0.03, 4.2)	0.05
Number of people in household	-	-	-	-	0.4 (0.03, 0.9)	0.04	-	-
Community	Fe =10.8	0.001	F=6.7	0.001	F=5.5	0.001	F=3.3	0.01

a Model fit ( $r^2$ ): BDI = 0.38; BAI = 0.32; KDI = 0.35; KFA: = 0.18.

b Variables considered for inclusion were: "age," "sex," "marital status," "education," "length of time in DR," "migrated alone," "knew someone in the DR prior to migrating," "engages in periodic round-trips between Haiti and the DR," "number of household members," "feels that Dominicans mistreat Haitians," "ever been interrogated or deported or knew someone who had been interrogated or deported," and "community of residence." The following item was added to the regression model for the KFA: "If reason cited for function impairment is anti-haitianism."

c CI: confidence interval.

d Not applicable.

e F-test for significant differences in outcome scores across levels of the categorical variable "community of residence.

## Social expectations and social stress

Further evidence that social stress is particularly salient within this migrant population was obtained from qualitative data collected in tandem with survey data. Among the 52 participants indicating particularly severe depressive symptoms (as indicated by scores of 2 or 3 for any of the items listed in Table 3), cognitive interviewing was used to explore reasons for those experiences. While many responses focused on economic hardship (50.0%), a notable proportion of responses (23.1%) attributed depressive symptoms to social interactions or social stress (Table 3). For example, many responses focused on family responsibilities, particularly failure to meet obligations to children. Another common thread was that many depressive symptoms arise due to negative social interactions, generally involving mistreatment by Dominicans, though sometimes including other Haitians. Finally, a lack of support structure or help in the community was reported to leave some feeling a sense of failure or fear. These data suggest that social stress and failure to meet social expectations represent an important mental health burden among Haitian migrants in this study.

In-depth interviews provided a more nuanced understanding of the ways that social expectations contribute to mental distress among migrants. Although communication with family members in Haiti was thought to provide some social support, for many Haitian migrants, familial and other social relationships represented a central cause of distress. Participants spoke of the high expectations held by their family and friends who remain in Haiti, including that migrants will earn sufficient money to support the family through remittances. Sending remittances was commonly practiced, albeit often with difficulty: "Every month, I send money, even if it's not much. I help them. We all help our families. Even those of us that don't make much money, we help our families" (Male rice farm laborer). Nevertheless, many Haitian migrants indicated a profound sense of guilt or failure to live up to expectations, whether due to lack of money to support their family in Haiti, lack of ability to feed or educate their children, or being otherwise unable to fulfill their roles. Participants also reported feeling ashamed for their friends to see how they live.

In addition to the burden of trying to meet social expectations, attempts to maintain familial relationships often exacerbated stressors inherent to the migrant experience. Haitian migrants were able to maintain communication through phone calls, but attempts to visit family members placed undocumented Haitians at risk of deportation: "You know we're outside immigration [law]. We don't have papers; we're really not legal. Our heads get loaded (tèt chaje) [we worry]" (Street vendor).

Lack of documentation and fear of deportation – daily stressors that worsen mental health – also disrupt migrants' support systems and strain coping mechanisms. Ultimately, failure to meet social expectations, encounters with the immigration system, and attempts to maintain family relationships only compounded migrants' own feelings of misery (lamizè) due to living apart from their family and support system.

**TABLE 3:** Reasons for endorsement of items from the Beck Depression Inventory: the role of social interactions and social stressors in selected responses from cognitive interviews with Haitian migrants, Dominican Republic, March-April 2011.

Item	Sample responses
Failure	At 37 years of age I can't do anything for my children. That makes me not have hope. (Male, 37 years old) Because we don't have a support structure, someone to help us. (Male, 36 years old)
Guilt/regret	I see myself with too many children; I can't give them a good education; I can't raise my kids well. (Female, 31 years old)
Self-dislike	Lots of times after you see how [Dominicans] treat us, we [feel we] shouldn't have come here. (Female, unknown age) Because I'm not useful for my wife. (Male, 40 years old) The misery I experience; the Dominicans say whatever they want. They don't respect us. (Female, 43 years old) There's no help for me facing the problems that come my way. (Female, 31 years old)
Thoughts of suicide	Because I can't see how I can help my children. (Female, 32 years old)
Worthlessness	Because if my parents have nothing I can't help them; for me when I look at myself I'm worth nothing. (Female, 39 years old) Because the way I was living, now I come to see that I'm worthless before other people. I feel like I've become "worse" in the eyes of Haitians here. (Male, unknown age)
Crying	Dominicans humiliate me; they treat me like garbage. (Female, unknown age)
Fear of bad things happening	I don't have people here with me; if bad things happen I don't have help.  Dominicans don't really respect Haitians, they do with us as they want.

### STRENGTHENING SOCIAL CAPITAL FOR HAITIAN MIGRANTS

This study suggests multiple ways in which the social world of Haitian migrants in the Dominican Republic fails to provide a buffer against mental distress and in fact exacerbates mental ill-health. On one hand, migrants pointed to a general lack of support and particularly the absence of tèt ansanm, an important form of solidarity in Haiti. In addition, the presence of others – including housemates and spouses – seemed to be largely a source of distress in the community-based survey (i.e., social burden rather than social support). Based on this study's qualitative data, this association could be explained through the stress of failing to meet social expectations, which extends to

family in Haiti. Finally, life for Haitian migrants is one disproportionately marked by social stress via negative interactions with both Dominicans and fellow migrants.

To counteract social stress and build social capital in this setting, interventions should seek to bond migrants within their social group and bridge them to the larger social matrix of Dominican society. In migrant communities, Haitian "culture brokers" - long-term residents with connections in the area and Spanish-language proficiency – could support newly arrived migrants and educate local Dominican clinicians on important cross-cultural aspects of treating Haitian patients. Local community health workers could be trained to provide mental health services according to a model piloted in Haiti that includes recognition of common mental disorders and basic therapeutic and counseling skills (Kaiser and McLean, 2015). Recognizing that the activities of tèt ansanm are traditionally gender-separated in Haiti, interventions should actively involve both genders to ensure that migrant women, who appear to bear a greater mental illness burden, fully benefit.

A key way forward is through positive-contact events modeled on the *convite* / konbit. In the Dominican Republic, the convite developed among rural farmers to share tasks, while in Haiti, an identical structure is the konbit, synonymous to tèt ansanm. The common etymological root of this cooperative system reflects the two countries' shared customs and values. Positive-contact events, such as workshops, community meetings, and leisure activities, will likely have greater acceptance by local communities if they are based on this shared history. Furthermore, it may be worthwhile to consider the *convite / konbit* as appropriate venues for microfinance or health insurance collectives among friends and family. Finally, this strategy would certainly gain greater traction if regional and national governmental and nongovernmental organizations, with budgetary and political capacity, assume a central role in developing and promoting such interventions.

#### LIMITATIONS

This study had some limitations. First, the quantitative analysis was limited by the 1) small sample size, 2) purposely selected communities, and 3) cross-sectional survey design, which prevented drawing conclusions regarding causality. Second, the qualitative data analysis was conducted in English, potentially losing sight of nuance. Third, female gender was not associated with higher BDI scores in this population, despite a gendered risk with the same Kreyòl BDI among a population in Haiti's Central Plateau (Wagenaar et al., 2012). This may reflect regional differences in the cultural and linguistic applicability of Kreyòl-adapted items of the BDI (Wagenaar et al., 2012).

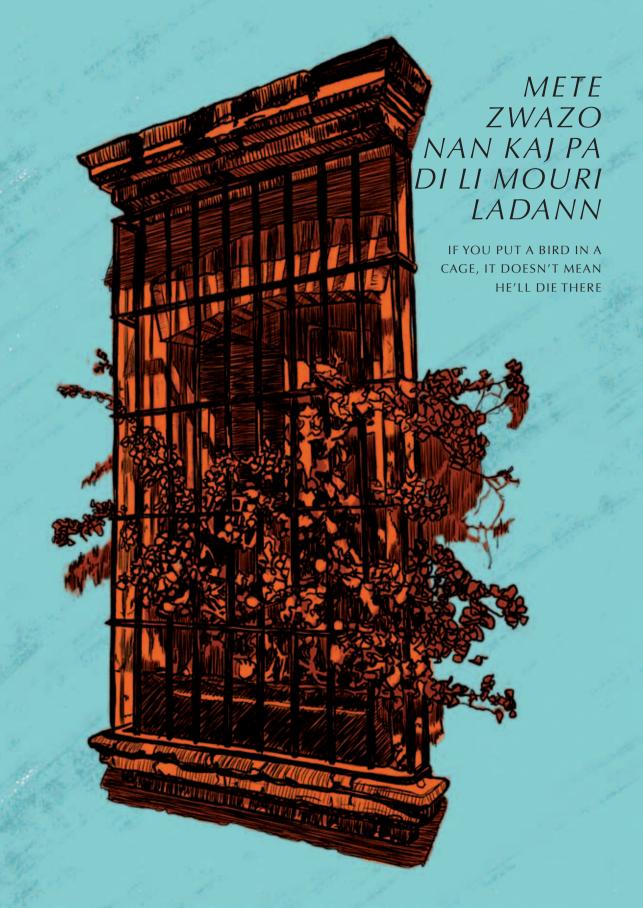
In contrast, the locally developed KDI tool appeared to function well in this Haitian population. Future studies should assess engagement in and perceptions of tèt ansanm in a more rigorous way, such as exploring it as a potentially culturally salient measure of collective efficacy or social capital.

#### CONCLUSIONS

This study explored whether the social world of Haitian migrants in the Dominican Republic represents a source of support or stress. Findings suggest that social stressors and failure to meet social expectations represent causes of mental distress. In addition, tèt ansanm, a key form of social support and solidarity in Haiti, was markedly lacking within this migrant population. We propose that interventions derived from a shared convite / konbit model of social interaction could provide a key means of improving both Haitian-Dominican relations and mental health outcomes by strengthening bonding and bridging social capital.

#### ACKNOWLEDGMENTS

The authors thank the research assistants who collected data for this study, namely Mere Dieuliphene, Willy Altindor, Jean Peter Osirias, and Jhefri Augustin Reyes Reinoso. They also thank Dhaysi Batista Berroa, Rossemary Ausuncion Hierro Burgos, and Ivette Esperanza Hierro Burgos for their time in transcribing Spanish audio files. Bethany Battig, Jean Verneus, and Brian Gross translated Spanish and Kreyòl documents into English. Without the support of Rosa Ypania Burgos Minaya, Rafael Alvarez Castillo, Ambrosio Rosario, and Luis Adolfo Dominguez Garcia, this study would not have been possible.



CHAPTER THREE

# Life "under the wire:" pathways of discrimination and addressing mental health<sup>4</sup>

Despite suffering humiliation, we are obligated to look for life here because there is no life in Haiti.

Jhon, Haitian migrant in the Dominican Republic

M'ap reflechi ak dlo a [I am thinking with tears]. Dominicans humiliate you. 'You're from another country,' they shout. Their words strike you and fill your eyes with water.

Sylvie, Haitian migrant in the Dominican Republic

### **INTRODUCTION: SYLVIE AND HUMILIATION**

Sylvie had left Haiti a decade ago, when she was 18 and pregnant with her first child. Her boyfriend had been beating her, and her mother decided that the best thing for her was to move to the neighboring Dominican Republic. Her mother said that, at least over there, she might find *sekerite* – security – and more job prospects. She crossed the border *anba fil*, or "under the wire," a Haitian Kreyòl phrase for crossing without authorized documents. Eventually she found her way to a large city in the Cibao Valley. Living with extended relatives in a barrio of mostly Haitian migrants and poor Dominicans, she found a life for herself selling clothes in the market.

Sylvie was one of several participants in a mixed-methods research project investigating the mental health of Haitian migrants in the Dominican Republic (see Chapter One). When we first met, Sylvie, like many other Haitian women in the country, was selling clothes in a large, urban street market. The market was a cacophony of noise, smells, and sights. Street vendors were selling giant heaps of plantains and coconuts, slaughtering chickens, and yelling out their prices to passers-by. Pick-up trucks bearing enormous speakers were blasting bachata and meringue music. Motorcycles zipped around pedestrians. In the market, Haitian women sit on plastic buckets on the sidewalks selling clothes while Haitian men tote cell phone chargers

<sup>4</sup> Originally published as: Keys, H. 2015. Life "under the wire:" perceived discrimination and mental health of Haitian migrants in the Dominican Republic. In *Global Mental Health: Anthropological Perspectives*. Kohrt, B. and Mendenhall, E., (eds.). Left Coast Press, Walnut Creek, CA. The text has been lightly edited.

and CDs for sale. Nearby construction sites are the other major economic opportunity for migrant Haitian men in this region of the Dominican Republic.

In the market, Sylvie described the positive gains she had made since leaving Haiti, but then she delved into the social difficulties of migrant Haitians. Dominicans sometimes "humiliate you because you're Haitian," she explained. Following the recent spread of cholera across the border, humiliation – or in Haitian Kreyòl, imilyasyon – had become particularly intense. Now, Dominicans "won't buy clothes from us because they think cholera is in the clothes we sell." Cholera, it seemed, had thrust an otherwise invisible population into the public eye, where they guickly became associated with, and blamed for, the dreaded disease. Our fieldwork revealed that imilyasyon entails belittlement, powerlessness, and inferiority in light of acute and chronic stressors, such as stigma due to epidemic cholera or the everyday struggles amid long-standing discrimination (see Chapter One). Overall, imilyasyon is an intensely personal experience situated within large-scale, structural obstacles and a complex sociocultural and historical legacy.

# BACKGROUND: HAITIAN MIGRATION TO THE DOMINICAN REPUBLIC AND ANTI-HAITIANISMO

Sylvie's accounts must be contextualized within the sociocultural history of Haitian migration to the Dominican Republic, a history that has involved dynamic (re)conceptualizations of racial, cultural, and national identities.

Originally recruited to work on Dominican sugar plantations in the early 20th century, Haitian migrants now work in many other sectors, especially construction, rice production, and informal services such as Sylvie's sidewalk clothes sales (Ministerio de Trabajo, 2011). Most migrate on the periphery of development, moving between poor, typically rural sending communities in Haiti and marginally improved receiving communities in the Dominican Republic (Martinez, 1995). At present, there is no official estimate of the Haitian and Haitian-descended population in the Dominican Republic, but it is thought to be between 500,000 and 1.5 million people (Canales et al., 2009), the vast majority undocumented (Ferguson, 2006).

Anti-Haitian discrimination (Spanish: anti-haitianismo) plays a major role in their marginalized status. The roots of anti-Haitianism go back to European colonialism, when wealthy Spanish elites sought to exploit poor black and mulatto classes (Sagas, 2000). The Trujillo dictatorship in the Dominican Republic (1930–1961) officially promulgated anti-Haitianism as a means to consolidate a Dominican identity (Derby, 1994), culminating in the massacre of thousands of Haitians and Dominico-Haitians along the border in 1937 (Turits, 2002). Anti-Haitianism construes Haitians as superstitious Vodou believers, more African and less civilized than their Dominican counterparts, and bent on conquest (Tavernier, 2008). In this way, anti-Haitianism constructs a Dominican identity vis-à-vis Haiti (Howard, 2007), differentiating the Dominican citizen from the migrant non- citizen, an "othering" process (Barth, 1969) that attributes greater moral worth to Dominicans (Bartlett, Jayaram, & Bonhomme 2011). However, race remains a complex construct for Dominicans, as most share some degree of African descent (Sagas & Inoa, 2003). Nonetheless, while anti-Haitianism is no longer an officially sanctioned institutional practice, its effects remain pervasive: routinely denied authorized status and citizenship, access to education and health care, and workplace safety and employment opportunities (United Nations, 2008), Haitian migrants and their descendants live amid widespread material and social deprivation.

# "WE DON'T HAVE PAPERS": INSTITUTIONAL-LEVEL DISCRIMINATION AND DOWNSTREAM EFFECTS

Ou met chita – "please sit, sit," said Sylvie as we conversed in Kreyòl. She placed a plastic chair in front of me. I joined her on the sidewalk along one of the central thoroughfares in the market. As a nursing and public health student, I had come to the Dominican Republic after conducting research in Haiti's Central Plateau. In Haiti, we had explored how rural Haitians conceptualize, experience, and seek care for common mental disorders, such as depression and anxiety. Our research efforts focused on recognizing everyday language that communicates mental distress (Keys et al., 2012), characterizing the relationship between Vodou explanatory models of mental illness and treatment-seeking (Khoury et al., 2012), and culturally adapting mental illness screening instruments for use among Haitians (Kaiser et al., 2013). Prior to this experience in Haiti, I had participated in a brief service project in the neighboring Dominican Republic, where my university's School of Nursing had long partnered with a Dominican university and public hospital. After our project in Haiti, I felt a strong pull to understand the mental health of Haitian migrants, a largely neglected population in anthropological, health, and human rights literature. A year after our project in Haiti, I returned to the Dominican Republic and met Sylvie during my first week there.



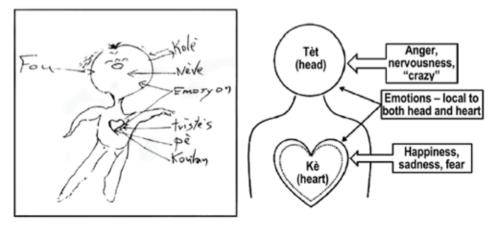
Figure 1. Haitian rice laborers at rest under trees. Photo by Hunter Keys, 2011.

Sitting in the market together, our conversation began with introductions and a discussion of Sylvie's work, which quickly led to the challenges of living without legal documentation from the Dominican government. "We don't have papers, so we sell clothing, because there's nothing else for us to do," she explained. Women, she said, work in the market. Haitian men work construction jobs in cities or as laborers on rice farms in rural areas (Figure 1). "Even if you have a certain level of education, [the Dominicans] don't allow you to work. . . . If you try to go to an office, they say no." I found that Haitian participants placed a high value on being documented. "If you respect yourself," continued Sylvie, "you will do anything to earn your work permit." The problem, she said, was that the work permit, or cédula, was simply unaffordable. Sylvie's voice started to rise, and she went on: "Listen, I'm not trying to go to Miami or New York. But, they make us pay the same amount as if we're going to the USA [over \$200 USD]. It's impossible for us." Sylvie concluded that this was an intentional arrangement to keep them in low-paying jobs: "It's a way for them not to give the job to you, asking about the cédula." Sylvie's sentiments were echoed by a group of Haitian men working on a nearby rice farm, who remarked on the constraints faced by those living without documents and the perpetual nature of poverty: "Where can you put a day's work for 400 gourdes [approximately \$10 USD]? You can't send your kids to school. They all have to bend down right there in the dirt. They do the same thing that the father is doing; once the child is grown, that's what the child will end up doing too."

Still, for those who can afford documents, a better life is not always guaranteed. Later in our conversation, Sylvie described the arbitrary harassment that Haitians experience at the hands of immigration officials: "If [immigration officials] come for you, you must show them your passport. Sometimes they will treat a Haitian like a little toy, and they will make you spend what you have to get it back. . . . They will take your passport and visa from you and sell it to a Haitian that looks like you, and it's the same immigration person that will give you problems for not having your passport later." The analogy of being treated "like a toy" was echoed by other interviewed migrants. Conversations with Sylvie and others were suffused with feelings of belittlement and powerlessness, stemming from their limited standard of living and everyday dealings with immigration authorities, street-level agents charged with carrying out the "dirty work" of unfair institutional norms (Fassin, 2011, p. 218).

# "THEY HUMILIATE US": IMILYASYON, THE LANGUAGE OF SUFFERING AND COMMON MENTAL DISORDERS

In a later conversation, Sylvie recited a list of ailments that afflict migrants: "Haitians may have accidents, headaches, body pain, [or] problems with pregnancy." From earlier work in Haiti, I was familiar with some common expressions that Haitians use when they express their suffering. Idioms of distress centered on the head, heart, or stomach. We found that these idioms can convey mental distress, particularly idioms pertaining to the head and heart (Figure 2; see Keys et al., 2012). For example, *tèt pati* (Kreyòl) literally means "a head that has left." *Tèt cho* (Kreyòl) is literally "a hot head." These idioms are sometimes used in stressful situations that affect concentration, problem-solving, memory, or otherwise normal behavior and functioning.



**Figure 2.** Conceptual and emotional map of the self made by focus group participants, Central Plateau, Haiti, summer 2010. Image from Keys et al., 2012.

Idioms of distress have long been recognized as an important window into local worlds, allowing outsiders to ascertain how people in other cultural settings experience, communicate, and assign meaning to their mental and physical health (Guarnaccia, Lewis-Fernandez, & Marano, 2003; Hinton & Lewis-Fernandez, 2010; Kohrt & Hruschka, 2010; Mendenhall et al., 2010; Nichter, 1981, 2010). Ethnographic and epidemiologic methods are useful for determining how idioms overlap or diverge from standard psychiatric categories, such as depression and anxiety. For example, in the Haitian context, head and heart-based Kreyòl idioms of distress, such as kè bat fo (racing heart), kè fè mal (heart hurts), and tèt fè mal (headache), seem to correspond to symptoms that suggest autonomic arousal arising from anxiety. The idiom reflechi twòp (thinking too much) conveys intense rumination and sadness (Kaiser et al., 2014) and associates strongly with depression and, to a lesser degree, anxiety symptoms.

I probed the issue of headaches further with Sylvie, asking about causes of head pain. She explained that working in the sun can cause headaches, in which case pain medicine helps. Then, she said, "If someone has done something to you, you can be reflecting, and wondering what else is going to befall you. Like if mean people are going to come do bad things to you, it can make you reflect a lot and give you a headache." In Haiti, causes of "reflecting or thinking too much" (Kreyòl: reflechi twòp) include food and financial insecurity, trauma, and failing to realize one's goals. Here, Sylvie described "thinking too much" in the context of her interpersonal relationships with Dominicans: "[The Dominicans] may call us bad names, say 'cursed Haitian.' These words can make you reflect. . . . After a series of humiliations, this reflection can make your head hurt." When asked what relief can be found for those who think too much, she said, "They just stay at home, they don't even eat, they are just reflecting. They will stay in private, just bathe and then get back into bed and lie down. There will be people who think that their time to die has come."

In this example, Sylvie's description of "thinking too much" includes important core symptoms of depression such as social isolation and suicidal ideation. As an undocumented migrant in the street market, Sylvie comes into close contact with Dominican immigration officials as well as everyday Dominicans who frequent the market. She and many other Haitian migrants report emotions and sensations associated with depression, which they attribute to daily insults, name-calling, belittlement from Dominicans, and fear of "mean people who do bad things to you," i.e., Dominican employers and government workers. In our cross-sectional survey of Haitian migrants in the area, the mean score on the Kreyòl version of the Beck Depression Inventory score was 27.11, which is in the range for clinical depression and is 30% higher than the average score among rural Haitians across the border in their home country (Wagenaar et al., 2012). While cross-sectional studies like these cannot establish causal pathways, they shed light on potential risk factors for those

who may become migrants and on the psychological effects of harsh social conditions, including negative interactions with Dominicans, not found in Haiti. Thinking and reflecting too much over "a series of humiliations" exemplifies how the language of suffering is infused with meaning and communicates important aspects of psychological distress that might otherwise go undetected.

Notably, humiliation also appears connected to socioeconomic class. Another participant, an older Haitian man working as a rice farm laborer, said that humiliation was not something limited to interactions with Dominican employers and government workers, but rather it was largely experienced at the hands of poor Dominicans: "The big men [landowners], we help them in their work. The Dominicans who don't have opportunities, who don't have money like the big men, they don't want to see us around." In a separate discussion, one Haitian woman recalled how poor Dominicans threaten and steal from Haitians. She explained: a poor Dominican may "know a Haitian working in a wealthy area, [so] when payroll day arrives, they know you got your money, [so] they come at night with a gun to rob you, even if they are your friend." Many Haitian participants felt resigned to accept humiliation as inevitable, communicating feelings of disempowerment in their daily lives:

Even if the Dominicans embarrass us, you must humble yourself before them [Kreyòl: *mete'w pti devan yo –* "to make yourself small before them"], because you are not in your country when they are humiliating you. . . . You have to be calm and accept humiliation from their hands. (Haitian man, Dominican Republic, 2012)

As these examples show, a locally meaningful term like *imilyasyon* can embody the broader social imbalances between economic classes (Rechtman, 2006), including disenfranchised Dominicans, who may feel empowered by an anti-Haitian ideology (Martinez, 2003). Furthermore, contrasting metaphors of feeling like "little toys" while the "big men" wield authority and power illustrate the social inequality and disempowerment borne by these individuals. For Sylvie, there is unfairness to it all, because "If you as a Haitian weren't humiliated, you would stay at home, comfortable like a Dominican. They don't have *tèt pati* (a head that has left, i.e., forgetfulness and worry), they don't have *tèt cho* (a hot head, i.e., unusual/psychotic behavior), they don't have anyone giving them problems." Contextualized within the social and class struggle from which it originates, humiliation (*imilyasyon*) can be thought of as a "label of distress" among those who suffer at the hands of others and are shut out from social and economic gains (Kohrt et al., 2004).

Institutional and personally mediated, anti-Haitian discrimination generates psychosocial stress for many Haitian migrants. Important idioms such as "thinking too much" and the locally meaningful experience of humiliation can reveal how local

constructs can communicate the stress of common mental health disorders, such as depression and anxiety, while pointing to larger social inequalities between groups. For those concerned with addressing mental health disparities in low- and middleincome countries, examining the language of suffering used by marginalized groups facilitates recognition of clusters of symptoms associated with those disorders. This in turn can open up pathways for treatment and advocacy, implications that we consider below.

# "WE HAVE NO WORTH": SELF-DEVALUATION AND INTERNALIZED RACISM

A recurrent finding in interviews with Sylvie was the concept of vale, meaning worth or value in Haitian Kreyòl. Vale can refer to both the material worth of money and the feeling of self-worth held by an individual. In their use of vale, migrants connected these concrete and symbolic meanings. For example, one Haitian woman connected material poverty to feelings of worthlessness, saving bluntly, "In life, when you have nothing, you're worth nothing. You're poor." The poverty that many Haitian migrants experience in the Dominican Republic appeared to carry its own significance: "It's because I'm not in my country that I feel like I am worth nothing," said one community member. Feelings of worthlessness are another core symptom of depression. In our survey, 69% (n = 88) of participants endorsed feelings of worthlessness on the adapted Kreyòl Beck Depression Inventory, indicating how pervasive this experience is for many migrants. What is particularly interesting is that feelings of worthlessness were attributed not just to poverty itself but also to the experience of living in poverty in the Dominican Republic as a second-class group. Sylvie said, "If a Dominican does something bad to you, it is no different than doing something bad to a dog. Because you're a Haitian, to him you are just like a dog, and you don't have any vale (value). It's like you're more animal than person." One Haitian man went further to say that in the Dominican Republic, not only do Haitians hold less value than street dogs, they are "faceless" (Kreyòl: san visaj) in the eyes of their Dominican neighbors.

Finally, in multiple retellings, when a Haitian inflicts some transgression against a Dominican, the Haitian community as a whole must expect retaliation. Sylvie explained, "If a Haitian does something bad to a Dominican, we will all pay for the other Haitian that has done bad things." Such reprisals against Haitians have been well cataloged (Paulino, 2006). Participants in our study recalled stories in which Haitians were murdered in retribution for some supposed wrongdoing. One group of Haitian rice farmers recounted a chilling story of a Dominican who suspected a Haitian had stolen his cow. In turn, a handful of Haitians were murdered in revenge, individuals who presumably had nothing to do with the incident.

At the end of story, the cow was discovered to have simply wandered off – it had never been stolen. The story concludes with the cow simply meandering back to its corral. This narrative, regardless of its veracity, reveals the general state of fear and uncertainty within the migrant community. Stories of anti-Haitian violence exemplify what David Howard (2007, p. 726), a scholar of Caribbean development, describes as a "fear induced . . . pre-emptive attempt to defend a racialized space or boundary." Routine violence, whether actual or implied, further contributes to perceived worthlessness, and ultimately impedes the economic and personal security desperately sought after by Sylvie and her fellow migrants.

# ANTI-HAITIANISM AS A SOCIAL DETERMINANT OF MENTAL HEALTH

Poverty and social discrimination in combination reinforce each other and together are a major threat to mental health. Discrimination is widely recognized as a social determinant of health because it systematically disadvantages certain groups (Williams & Mohammed, 2009). There is ample evidence of the negative effect discrimination has on both mental and physical health (for a good review article on this subject, see Pascoe & Smart Richman, 2009). As Sylvie's narrative and other examples demonstrate, anti-Haitianism operates through institutional, personally mediated, and internalized pathways (Jones, 2000). In the Dominican Republic, institutional practices discriminate against Haitians by obstructing their access to authorized documents, in turn limiting access to education, health care, political rights, and other "common goods" (Leventhal, 2013). In addition, discrimination can be personally mediated by one individual against another. Sylvie and others described hurtful social interactions between themselves and Dominicans, including arbitrary street-level harassment, name-calling, and belittling. Finally, discrimination can be internalized. Here, an individual accepts the devaluing attitudes and beliefs held by the dominant group, generating feelings of self-doubt, dislike, or contempt for oneself or one's group (Ahmed, Mohammed, & Williams, 2007). Confronted by routine, devaluing street-level interactions as well as seemingly insurmountable structural obstacles, Sylvie and others like her expressed personal feelings of worthlessness and the notion that, as a collective body, Haitians pa gen vale – have no worth.

### MEETING MENTAL HEALTH NEEDS OF HAITIAN MIGRANTS

The sociocultural context of Haitian migrants contributes to the increased need for physical and mental health services, and the context simultaneously predicts a system in which care will also be delivered in a discriminatory and woefully inadequate

manner. This manifests as multiple obstacles encountered by Haitian migrants as they try to access health care. First, there are financial hurdles in accessing and paying for care. Second, due to economic constraints or fear of being apprehended by authorities, migrants may delay care until their condition is unbearable. Third, migrants feel belittled in the eyes of Dominican clinicians, who are said to favor those with legal status and insurance, which leads sick Haitians to forgo care. Fourth, in Haiti, mental health needs are often tended to by traditional healers or spiritual figures in the community rather than by biomedical providers, because of the poor care and discriminatory experiences within the biomedical care system (Wagenaar et al., 2013). Thus, for Sylvie and other Haitian migrants in the Dominican Republic, special considerations must be taken to meet their mental health needs. Our work in Haiti found that many rural Haitians prefer community-based supports for mental health concerns (Wagenaar et al., 2013), a preference possibly maintained by migrants in the Dominican Republic.

Dominican health care workers in emergency rooms and rural health clinics are likely the only individuals that migrants may encounter who could address mental health in a biomedical context. There are severe shortages of trained psychiatrists and psychologists for Dominican patients, and mental health specialty services are nonexistent for migrant Haitians. Ideally, the background and life experiences of many Haitian patients deserve special attention by Dominican clinicians, particularly those who work in settings where migrants seek care, such as emergency rooms and primary care clinics. As a form of task-sharing in mental health services, emergency and primary care clinicians potentially could develop therapeutic relationships with Haitian patients by incorporating brief, migration-related items into the history-taking, which grants a global sense of the individual's life story and reveals potential sources of psychosocial stress. These items include asking about their life circumstances in Haiti, what compelled an individual to leave Haiti, if he or she came alone or with others, and how long ago. The clinician can also inquire about post-migration issues such as expectation-reality discrepancy, support networks, and daily functioning. For example, a therapeutic relationship between a Domini- can provider and Sylvie might inform the provider of her past abusive relationship and economic insecurity in Haiti, potential trauma or exploitation faced during migration, and experience of hurtful interactions in the street market. This information helps formulate a picture of the patient's "local world" (Kleinman & Benson, 2006), or how that person views his or her life and environment, based on the understanding that Haitian migrants face unique stressors prior to, during, and after migration. Though training Dominican clinicians to develop a more psychosocial perspective of Haitian migrant patients is not going to transform the structural violence experienced by migrants, the process of Dominican clinician engagement might facilitate broader social attention to the needs of migrants.

Of course, linguistic differences between Dominican clinicians and Haitian patients pose a challenge. Although using trained medical interpreters is ideal, this is often not possible. Hospital and clinical staff could instead recruit bilingual "culture brokers" from migrant communities. These could be Haitians who have already lived for some time in the country, speak fluent Spanish, and are familiar with issues faced by migrants. Most importantly, they should be interested in serving not only as interpreters but also as advocates. Inquiring into the everyday lives of migrants gets at the heart of acknowledgment - "the first ethical task" in the face of someone's suffering (Kleinman & Benson, 2006, p. 1675). Culturally sensitive approaches toward Haitian patients can help the clinician understand illness explanations, patterns of coping and seeking help, emotional expression and communication, and relationships with care providers (Berkman & Glass, 2000). As we have seen, complaints of head, heart, or stomach pain can be used by Haitians to communicate psychosocial distress (Keys et al., 2012). In addition to taking psychosocially focused migration histories, Dominican clinicians can investigate medically unexplained symptoms such as vague pain, fatigue, and gastrointestinal complaints with an inquiry into possible links with impaired daily functioning, migration-related stressors, and strained interpersonal relationships (Kirmayer et al., 2011). Doing so allows clinicians to assess adaptation to the host society and provides an opportunity to promote mental health and well-being.

#### COMMUNITY-LEVEL INTERVENTIONS

As Sylvie's account illustrated, anti-Haitian discrimination occurs at an inter- personal level among community members. In addition, poor social integration and lack of social support within communities increase risk for common mental health disorders like depression and anxiety (Berkman & Glass, 2000). With the extremely low numbers of formally trained mental health specialists available in the Dominican Republic, and given that Haitians are unlikely to seek mental health care from general practitioners and health care workers, community-level interventions are imperative in order to reach this population. A practical step to address mental health at the community level is through increasing positive social contact between Haitians and Dominicans.

First, this approach enhances the "social capital" of a community. Social capital refers to cohesiveness and trust among community members, leads to positive social engagement, fosters a sense of control over life circumstances, and consequently has strong effects on health (Berkman and Glass 2000; Marmot, 2006). Stigma and prevailing attitudes toward Haitians impede mutual trust and social cohesion. One way of reducing these barriers is through increased positive social contact, such as through

community meetings, workshops, leisure activities, and other events shown to reduce prejudicial attitudes (Pettigrew & Tropp, 2006; Walker et al., 2005).

In this context, community gatherings may gain more acceptance if they are based on forms of social organization that have culture-specific meaning and historical precedence. In the Dominican Republic, the convite (Spanish) is a form of cooperation among farmers who band together to accomplish tasks (Domínguez, Castillo, & Tejeda, 1978). In Haiti, an identical structure is the *konbit* (Kreyòl) (Métraux, 1951). The similar purpose and etymological root of this social structure reveal how customs and values of the two countries overlap. Through collaborative activities modeled on the convite / konbit, Haitian migrants and their Dominican neighbors may discover that they share similar obstacles and common goals. For example, in Sylvie's community, both Haitian and Dominican market vendors could organize a cooperative convite / konbit to engage with one another outside their routine occupational roles. Key community leaders could collaborate with local public health authorities and community health workers already "on the ground" to develop cooperative convite / konbit activities that focus on shared values and customs between Haitians and Dominicans, while educating community members about the harmful effects of anti-Haitian discrimination.

While the cooperative *convite / konbit* approach is basic in its outline, it emphasizes social cohesion among Haitian and Dominican community members. Anti-Haitian discrimination thrives where social cohesion is weak, yet it is through social networks that the stigmatized and the dominant population interact. For example, Sylvie lives in a dense urban enclave of fellow migrants and poor Dominicans. Her job in the street market brings her into a web of relationships with Dominican passers-by, immigration authorities, and other Haitian migrants. In rural areas, Haitian migrants interact with Dominican agricultural employers – the gran neg, or "big men" for whom they work – and poor Dominican neighbors, who themselves may feel threatened by Haitians for displacing them from jobs. It is in this context, within the lived worlds of both Haitians and Dominicans, that the stigma of being an undocumented Haitian is defined and perpetuated. Understanding the social and cultural processes that create stigma within these local worlds should be the starting point for reducing stigma (Kleinman & Hall-Clifford, 2009). Positive contact events modeled on the *convite / konbit* build on this premise by opening the way for constructive relationships.

## **INSTITUTIONAL-LEVEL STRATEGIES**

Anti-Haitian discrimination remains embedded in such institutional practices as access to health care, education, and citizenship as well as upward mobility in the job market. Ultimately, addressing social determinants of mental health becomes as much a "political project as a health project" (Mittelmark, 2003, p. 10). For Sylvie, this means creating social and political conditions that foster a sense of control and self-determination in her life. Thus, reform of unfair social conditions must involve community members, civil society, and policy makers. To accomplish positive change, two fundamental steps are (1) raising public awareness of social determinants of health and (2) taking legislative and policy action.

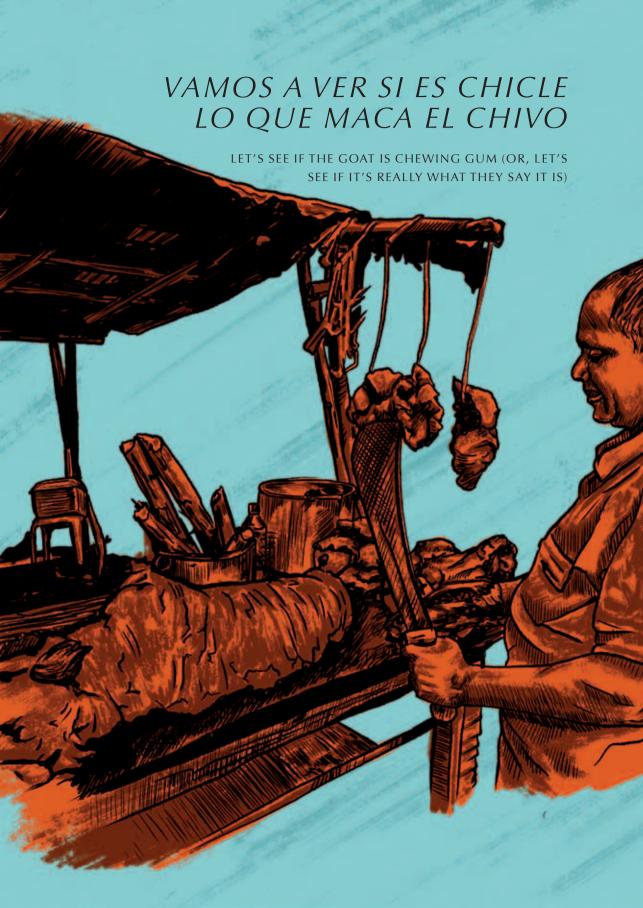
First, drawing on local community members' own understandings and vocabularies of social determinants of mental health can help to galvanize action (Briggs & Nichter, 2009). Across diverse contexts, themes of dignity, opportunity, empowerment, and security re articulated in similar ways (Narayan et al., 2000). These themes could form the basis of nationwide communication strategies that emphasize the two countries' shared history and cultures, counter the idea that individual decisions and behavior alone lead to mental illness, explain the central role of social determinants in producing chronic mental disorders in marginalized groups like Haitian migrants, and discuss the negative impact of mental illness on well-being (Niederdeppe et al., 2008).

Public health messaging should link health inequalities and human rights together so that they assume a more prominent place in the public domain. For example, in the Dominican Republic, a rights-based approach could connect discrimination and xenophobia with consequent impacts on mental health and well-being. There must be concomitant legal and civil society involvement, chiefly in the areas of documentation, labor rights, and health benefits. For Sylvie, being undocumented, lacking employment rights, and being unable to access, afford, or receive quality health care all affect her mental health. Legislative health policy reform can address these systemic, institutional-level problems, through such initiatives as a bilateral immigration policy and strengthened mental health services.

There is already an avenue to strengthen existing mental health services through reform of health policy. While the Dominican Republic has no explicit, national-level mental health policy, Law No. 12-06, passed in 2006, updated standards for mental health services and stipulated the individual right to receive mental health care (WHO/PAHO, 2008). Drawing on evidence that shows how mental health interventions are associated with improved economic outcomes in resource-poor settings (Lund et al., 2011) and on human rights principles that the country articulated in its Constitution (Dominican Republic, 2010), strong arguments can be made to increase support of mental health systems nationwide, which would carry population-level benefits for both Haitian migrants and Dominicans.

Ultimately, positive change at the societal level hinges on empowerment, or the ability to chart one's own course, have control over life circumstances, and be an active partner in the change process (Wallerstein & Duran, 2006; WHO, 2005a). For

Haitian migrants in the Dominican Republic, positive change encompasses the ability to participate more fully in Dominican society through access to education, employment, safe physical and social environments, health care, legal rights, and social support. For Sylvie, empowerment may entail a heightened sense of self-determination and control in her life course and a feeling of being capable of making decisions in her life. Attaining these fundamental aspects of well-being can be accomplished through individual and community-level empowerment supported by broad-based legislative reform to reduce mental health disparities.



# Case studies in mental health: language, measurement, and structural violence<sup>5</sup>

## INTRODUCTION

Here, my colleague Bonnie Kaiser and I draw on applied research from Haiti and the Dominican Republic to analyze three core concepts in global mental health: the issue of language and communication in mental health research and service delivery; the challenge of measuring mental illness in cross-cultural settings; and finally, the need to recognize and address structural violence as the strongest driver of global mental health disparities.

We begin the chapter with a discussion of language and global mental health communication. Drawing on our field research in both settings, we describe how awareness of certain idioms of distress can be useful in recognizing, communicating, and ultimately treating mental illness in non-Western contexts. We then discuss the benefits and limitations of universalist and particularistic (or relativist) approaches to measurement of mental illness, as well as methodological challenges. We argue for adopting a hybrid approach that utilizes both adaptation of standard psychiatric screening tools, as well as development of local scales based on idioms of distress. Such an approach avoids the pitfalls that arise from assumptions of universality, while facilitating clinical and public health communication. We conclude the chapter by situating mental health disparities within the broader matrix of structural violence. Structural violence theory, originally articulated by Johan Galtung and later developed in medical anthropology by Paul Farmer, provides a critical lens to better understand mental illness in these settings because it traces mental illness back to its root causes: unjust institutionalized processes that produce and perpetuate disadvantage.

Our case study examples come from a series of interdisciplinary team graduate student projects conducted in Haiti (2010, 2011) and the Dominican Republic (2011, 2012). Beginning several months before the January 12, 2010 earthquake, our American university had partnered with Project Medishare, a local Haitian NGO, to

<sup>5</sup> Originally published as: Keys, H., and Kaiser, B. 2017. "Language, measurement, and structural violence: Global mental health case studies from Haiti and the Dominican Republic." In The Palgrave Handbook of Global Mental Health: Socio-cultural Perspectives. White, R., Jain, S., Orr, D., and Read, U. (eds). Palgrave Macmilan UK, London. The text has been lightly edited.

plan exploratory research to understand how mental illness is experienced, communicated, and treated in Haiti's Central Plateau. This NGO was largely supported by Haitian national staff, ranging from community health workers to Haitian doctors and nurses who were obligated to complete a year of social service. Emory University had partnered with this NGO to provide funding and support short-term clinical services by visiting American students and professionals. In previous visits, student teams had noted that mental health needs seemed largely unaddressed or unexplored. The aftermath of the earthquake made this concern all the more pressing.

In the neighboring Dominican Republic, Emory University School of Nursing had partnered with a public, tertiary-care hospital in the Cibao Valley. There, the School of Nursing and Dominican partners conducted short-term mobile clinics in marginalized communities throughout the hospital's catchment area. During one of these visits, a student team noted that little was known regarding the population of Haitian migrants who used the public hospital or their communities. The research discussed in this chapter derives from these established partnerships between this American university and local NGOs and healthcare centers. The research questions themselves regarding mental illness were developed in collaboration with these various research partners, and our findings draw on qualitative and quantitative data collected in both settings.

First, we should recall that the field of "global health" emerged out of academic and policy circles in Western, industrialized countries. The health and disadvantage faced by people in poorer, non-Western settings became a subject of inquiry, advocacy, and "intervention." While this is a simplistic rendering, it points to the relationship between those who come from the industrialized "global North" and arrive in settings of extreme poverty and hardship in the "global South."

When researchers from more privileged backgrounds arrive in settings where "participants" are far less privileged, there are clearly many ethical challenges (King et al., 2014). In this chapter, we try to forefront both these challenges and our attempts to overcome them. For example, in Haiti, everyone speaks Kreyòl, a language that combines French words with syntax of West African languages. French has long been the language of power in Haiti and remains the language of business and government, vet is spoken fluently by only 10% of the population. Though our research team included fluent French speakers, our training in Krevòl and close collaboration with translators was essential to communicate with both Haitian professionals and community members. Furthermore, there were issues surrounding appropriate language specifically to explain the purpose of our research and the nature of the research questions. In Haiti, there is no universally understood term for the domain of health known as "mental health." Thus, even broaching the subject presents challenges in describing exactly what we as a research team were investigating.

Secondly, mental illness can be a highly stigmatizing form of suffering in many places, Haiti and the Dominican Republic included. Were we to inadvertently cast ourselves as "the outsiders wanting to learn about 'crazy people' (fou)," we could have unintentionally stigmatized community members we sought to interview or learn from. Furthermore, there was great potential for problems or misunderstandings to arise from power differentials between us as outsiders, the local professionals we worked alongside, and patients and community members. The history of both countries has long been marked by outside political influence, often exploitive; there is also a long history of intervention and humanitarian assistance, especially in Haiti. We had to remain sensitive to the ways in which our presence, attention, and involvement with some community members did or did not convey a sense of privilege not afforded to others. We had to clearly articulate what our purpose was, as well as what risks and benefit our research posed to community members. To do so, we worked closely with local partners and research assistants to conduct the research in a sensitive way. We had translators and cultural brokers in all interviews, and rather than conducting focus group discussions ourselves, we trained a local community healthcare coordinator to do so.

### LANGUAGE AND IDIOMS OF DISTRESS

A central challenge in addressing global mental health disparities is achieving successful communication between biomedical psychiatric categories and the constructs of mental distress employed by local populations. *Idioms of distress* are powerful communicative tools that convey forms of suffering embedded in particular ways of conceptualizing the world (Nichter, 2010). Their use not only demonstrates how some groups of people communicate distress but also the ways in which they ascribe meaning to their illness experience. For example, (Yarris, 2014) describes how in Nicaragua pensando mucho (thinking too much) and dolor de cerebro (brain ache) are manifestations of the suffering that grandmother-caregivers feel in the absence of their migrant daughters. Beyond reflecting straightforward symptoms, these idioms indicate the ambivalence experienced by grandmothers, who rely on daughters' remittances yet feel that they

are inadequate to make up for their lack of ability to achieve the moral and cultural ideals exemplified by having their family together. Additionally, research demonstrates how idioms of distress reflect particular ways of making sense of the self, personhood, and one's place in the broader world (Hinton et al., 2010; Kohrt & Hruschka, 2010). In recognizing the broader socio-cultural and meaning systems that are both reflected and embedded within idioms of distress, it becomes clear why they should not be considered reducible to psychiatry categories but considered in their own right.

From our perspective as Western, non-Haitian researchers interested in mental health, how do we even begin identifying these idioms? A first step consists of participant observation, combined with a sensitivity to issues of language. Our field experience in Haiti included much time in mobile clinics, where we collaborated with Haitian medical providers to diagnose and treat common medical problems among community members. Interestingly, we found that patients often expressed their complaints in reference to parts of the body, particularly the head (tèt) and heart (kè); (Keys et al., 2012). One of the most common complaints of patients was "my heart hurts" (kè m fè mal), typically diagnosed as acid reflux and treated with antacid medication. In addition to participant observation in these clinics, we also conducted semistructured interviews with clinicians and community members, eliciting expressions and explanations of such phrases that appeared pertinent to mental illness. In these discussions, we found that "my heart hurts" could signify complex emotional states, including grief and sadness. An earthquake survivor even used this expression when she recounted her story of profound loss. Thus, we found that "head" and "heart" complaints took on both physical and mental dimensions.

Why is it that – despite conveying multiple, complex meanings – these idioms were interpreted by Western-trained, Haitian biomedical providers as simply reflux disease, foregoing exploration of the complaint and providing symptom-relieving treatment? Multiple issues are at play in this dynamic. First, we should ask how rural Haitians regard a mobile clinic as a source for psychosocial care. In many of our interviews with clinicians and community members, it appeared that Haitians simultaneously draw on multiple sources of care for psychosocial complaints, such as religious and spiritual figures and other community-based structures (Khoury et al., 2012). Additionally, these idioms are inherently ambiguous. Thus, "kè m fè mal" as used in the mobile clinic may not, for this patient, explicitly reference feelings of sadness; the idiom may mean different things and be interpreted differently depending on context. Second, clinicians often told us that minimal training, coupled with the severe lack of treatment options – whether pharmaceuticals or referral to social workers or psychologists with another organization – left them with little choice but to forego exploration of these idioms. Many clinicians acknowledged that "kè m fè mal" can in fact represent sadness, but the conditions of such an austere clinical setting prevented them from determining if that was the case. With limited time to see many patients and lacking the ability to intervene in psychosocial needs, why even attempt diagnosis? Finally, one could argue that such an emphasis on biomedical explanations on the part of Haitian clinicians in fact reflects how biomedicine in Haiti – first introduced through the French plantation aristocracy and later North American influences – continues to supplant local frameworks of disease, which include Vodou explanatory models (Lecomte & Raphaël, 2010).

In the Dominican Republic, we found that idioms may also communicate broader experiences of injustice. In the Dominican Republic, Haitian migrants are a largely disadvantaged population owing to both overt and hidden anti-Haitian policies and practices. As a result, many Haitian migrants report experiencing *imilyasyon* (humiliation). When prompted to explain what humiliation means to them, and what exactly causes it, many migrants reference the harmful, interpersonal interactions they have with Dominicans (see Chapter One). In the workplace, many describe feeling humiliated when they are underpaid or assigned to menial tasks; in the general community, they may be victim to name-calling and harassment by immigration authorities. At the same time, a Haitian may feel humiliated by a fellow migrant, one who may have gained more material and social success in the Dominican Republic, or one who teams up with Dominicans to exploit other migrants. We will explore these issues of mental distress, social justice, and structural violence in more detail below.

Idioms of distress can thus provide a window onto the local world of those suffering from mental illness and provide a means to address mental health disparities in a culturally sensitive way (Kaiser et al., 2014). For example, there are practical benefits of identifying and incorporating idioms of distress into everyday clinical practice. A clinician in Haiti may explore in greater depth patients' complaints of head or heart pain and thereby potentially uncover broader psychosocial distress experienced by the service-user. Institutional changes can also facilitate such clinical communication. For example, Zanmi Lasante/Partners in Health, an NGO with a strong presence in this region of Haiti, has begun providing mental health mobile clinics in the region where we conducted our research (Fils-Aimé et al., 2018). This care-giving format enables longer interactions than a typical mobile clinic, as well as evaluation by mental health specialists, both of which facilitate exploration of potential psychosocial needs. In addition to mobile clinics, Zanmi Lasante provides hospital-based mental healthcare and trains community mental health workers, all of which extends the provision of specifically mental healthcare and relieves the problems cited by clinicians as limiting their ability or motivation to explore idioms of distress in greater depth (Raviola et al., 2012, 2013). In fact, clinical and community-based mental health providers specifically incorporate idioms of distress like *kalkile twòp* (thinking too much) into their communication, alongside psychiatric terms like depression and anxiety, such as through the use of the locally validated Zanmi Lasante Depression Symptom Inventory (Rasmussen et al., 2015).

Beyond their use in clinical settings, idioms of distress could be folded into public awareness and education campaigns that tie into the broader push for policy reform. In the Dominican Republic, public health advocates could link the experience of humiliation felt by migrants to issues of racism, stigma, and discrimination. More fundamentally, recognizing the importance of idioms of distress imparts legitimacy to what the patient feels: no longer is "heart pain" simply reflux disease; it may instead communicate sadness and grief resulting from either trauma or structural factors, including poverty and discrimination. Allowing the patient to share his or her own understanding of heart pain, or humiliation, empowers those who have long been powerless, a point that we will tie into our later discussion of structural violence and mental illness. Their complaints are given recognition in the context in which they are used, where social inequality, gender-based violence, and poverty are daily struggles.

#### MEASUREMENT

Challenges regarding mental health communication extend into the realm of measurement. Although it might seem that instruments aiming to assess mental illnesses are relatively apolitical and unproblematic, they in fact reflect the power structures that underlie diagnostic systems. For example, diagnostic and measurement tools privilege categorizations and symptom clusters developed within Western psychiatry (Kirmayer, 2012), and we should recall that in its early days, Western psychiatry explicitly pathologized non-white, non-Western cultures and ethnic groups (Littlewood et al., 2000). Furthermore, uncritical cross-cultural application of these instruments reflects certain assumptions, such as the universality of mental illness and completeness of psychiatric symptom lists (Kleinman, 1977). In contrast, much research has demonstrated variability in experience and manifestation of mental illness, and scholars argue that global mental health research must move away from such strictly Western diagnostic systems (Summerfield, 2008). Ultimately we must ask, to what extent can the instruments developed in Western settings be brought to bear on the detection and treatment of mental illness cross-culturally? Rather than adopting a strictly biomedical approach or completely disregarding the large evidence base of biomedical psychiatry, what balance can we strike between these two extremes?

Approaching cross-cultural measurement in global mental health via translating standard tools can be thought of as a universalist approach. This contrasts with particularistic (or relativist) approaches, in which instruments are locally developed with the aim of capturing particularly local ways of experiencing and expressing mental illness (Weaver & Kaiser, 2014). A universalist approach has the benefit of producing quantitative data regarding an internationally-recognized set of diagnostic categories, which are assumed to be comparable across settings. Being able to draw on such data can be powerful to support arguments regarding relative burden and proposed response, including funding allocations. At the same time, this approach has been criticized as a form of biomedical imperialism, privileging psychiatric categories and ignoring local ways of experiencing and communicating distress (Summerfield, 2008). Importantly, such approaches run the risk of failing to measure what they intend to measure, which undermines any attempts at cross-cultural comparison. For example, Kohrt and Hruschka (2010) argue that instruments attempting to assess Post-traumatic Stress Disorder (PTSD) might in fact be getting at any number of things, including forms of stigma and suffering not at all related to trauma. Additionally, they note that word-for-word translation of some Western instruments has resulted in unintended, harmful effects among survey participants, who may be asked to respond to survey questions and select answer choices based on stigmatizing vocabulary.

In contrast, a particularistic approach has the benefit of ethnographic validity; in other words, we can be confident that what we are measuring is what we think we are measuring. Such approaches rely on local systems of communication, ways of understanding the world, and particular ways of experiencing and expressing mental distress (Weaver & Kaiser, 2014). At the same time, by privileging the local to such an extent, it becomes difficult to achieve useful cross-cultural comparison, which is important in driving policy decisions and donor goals. Thus, while the particularistic approach has certain advantages, there must also be "re-translation," so to speak, of acquired data and research findings for monitoring and evaluation purposes and for audiences unfamiliar with the use of such methods.

Below, we describe several approaches to instrument development that have been used in Haiti that range from universalist to particularistic. We describe the varying strategies adopted to adapt or develop instruments and address the strengths and limitations of each. In particular, we highlight the methodological and epistemological shortcomings that remain with each approach – what can be considered the "trade-offs" of selecting one method over another. We hope that these examples can guide decisions regarding measurement that effectively balance ethnographic validity with policy and intervention aims.

# 1. Adapting depression and anxiety measures

Our first example comes from our work in Haiti's Central Plateau, described earlier. As part of our exploratory qualitative work, we sought to develop measurement tools for common mental disorders, such as depression and anxiety. Recognizing the need to balance universalist and particularistic aims, we used a combination of adaptation of existing screening tools and development of local instruments to assess mental distress (the latter will be described below). We selected the Beck Depression Inventory II and Beck Anxiety Inventory due to their longstanding acceptance and use in Western clinical settings (Beck et al., 1996; Beck & Steer, 1990).

We adopted the approach to cross-cultural instrument adaptation outlined by van Ommeren et al. (1999). The adaptation process begins with two rounds of translations by individuals: first, a lay bilingual individual translates all items, commenting on comprehensibility, acceptability, relevance, and completeness. Next, a bilingual professional – in our case, a Haitian doctor – adjusts any translations and likewise provides relevant comments according to the four categories above. The final step entails a series of focus group discussions with community members. For each item, we explored what might cause this experience, in order to understand whether it is conceptually equivalent locally. We then elicited alternate ways of discussing the same phenomenon that might be better understood locally. Finally, we asked whether each item was comprehensible, acceptable, and relevant.

Based on focus group discussions, we identified several problematic components of initial translations, which – without the insight gained from focus group discussions – might have led us to measure something other than intended (Kaiser et al., 2013). For example, the Beck Depression Inventory (BDI) item regarding loss of interest was initially translated directly, *pèdi enterese*. However, during focus group discussions, participants interpreted this item as referencing contexts in which one should not engage with others. Their understanding of "loss of interest," as literally translated from English, seemed to relate more to social interactions and their appropriateness, rather than a more individually-focused sensation that may reflect a core symptom of depression. Instead, we adjusted the item to *m pa sou sa* (literally, "I'm not on it"), which better reflects the intent of the original English item.

Despite these adjustments to develop screening tools that were comprehensible, acceptable, relevant, and complete in comparison to the original tools, there remain shortcomings with the adapted versions. First, the BDI in particular is difficult to administer verbally, as items consist of multiple sentences among which participant must choose the most applicable to their experience. In administering the BDI in surveys, we found the tool to be cumbersome for participants. Additionally, despite efforts to ensure that items map onto local experiences, we nevertheless took as our starting point biomedical psychiatric categories. We thus recognized that we likely missed relevant experiences of mental distress.

## 2. Developing a local measure of idioms of distress

In response to this shortcoming, we simultaneously developed an instrument based on local idioms of distress, the Kreyòl Distress Idioms (KDI; Kaiser et al.,

2015) screening tool, to be used in conjunction with the BDI and BAI. The aim of this tool was to assemble a collection of key expressions locally understood to communicate mental distress. First, drawing on our research team's interviews, focus group discussions, and participant observation, we identified 43 potentially meaningful idioms of distress to be considered for inclusion in a screening tool (Keys et al., 2012). Using interviews and a focus group discussion, we further explored these idioms, seeking to understand how they are understood and used in the communication of distress. We reduced the item set by removing idioms that used stigmatizing language or were redundant, poorly understood, or not specific to mental distress (Kaiser et al., 2013). After pilot-testing the KDI, we removed 4 more items that seemed to reference severe mental illness or used potentially stigmatizing language. The final tool was a 13-item instrument assessing mental distress.

There are several challenges inherent in this form of instrument development. First, the iterative approach used to develop it was very time-intensive, particularly compared to direct translation of screening tools. It is also possible that we tended to include those items that most stood out to us as unique to this setting, running the risk of privileging the "exotic" rather than the most important or useful means of communicating and assessing distress. Using this methodology, we should recognize how our own values can "creep" into the ways in which we analyze and interpret data, taking care to use safeguards such as inter-rater reliability, in which multiple co-investigators read the same texts and compare their interpretations. Even more important are efforts to work closely with local collaborators to ensure that interpretations are accurate and research foci are appropriate. Our interviews and focus group discussion that further explored potential idioms of distress we had identified were focused specifically on avoiding the risk of privileging the exotic.

Furthermore, by transforming idioms of distress – which communicate with a vast array of goals – into a tool for the identification of mental distress, we risked pathologizing normal reactions to circumstances of trauma, injustice, and structural violence. It is important to be aware of and try to minimize such problems in developing local screening tools. For example, our interviews and focus group discussion focused specifically on idioms of distress aimed to identify those considered locally to be most relevant to mental distress.

## 3. Developing a hybrid tool

A final approach to measurement likewise combines the goals of ethnographic validity and cross-cultural comparison. Here we describe the process used in the development and validation of a local screening tool for depression, the Zanmi Lasante Depression Symptom Inventory (ZLDSI; Rasmussen et al., 2015). This tool was the result of a collaborative effort among Partners in Health – an American healthcare NGO – their local Haitian partner Zanmi Lasante, and research collaborators. It involved a series of steps, beginning with key informant interviews and pile sorts, during which participants categorized and described a range of potentially relevant items, in order to provide insight into their meaning and interrelatedness. The instrument developed based on these qualitative data included both rigorously reviewed items referencing depression symptomology, as well as three idioms of distress from the KDI. Development was followed by a clinical validation process by mental health care providers, as well as iterative refinement of the tool based on its application in multiple hospitals and communities.

This approach yielded the only clinically validated tool among those discussed here, which also required the most extensive process of development and refinement. Comparison to clinical diagnosis is valuable for achieving construct validity, allowing more rigorous comparison to biomedical categories, and allowing for estimation of depression prevalence. At the same time, this approach necessarily privileges biomedical psychiatry diagnostic categories and requires the availability of professionals trained in it, which is often a shortcoming in global mental health research (Bolton et al., 2002). In this case, the validation process involved all Haitian mental health professionals, largely familiar with the idioms of distress and conceptual categories adopted by their patients. Thus, this tool represents a hybrid approach that allows for cross-cultural comparison and prevalence estimation, while avoiding hegemonic displacement of local forms of meaning-making.

#### Strengths and limitations of measurement tools

As indicated above, each of these approaches entails trade-offs. The rigorous adaptation process we employed with the BDI and BAI can effectively balance the goals of cross-cultural comparison and ethnographic validity, especially when used in tandem with a locally developed tool like the KDI. At the same time, the adaptation process is time-consuming, and ultimately the tools rely on categories of biomedical psychiatry. Development of a purely local screening tool best achieves the goal of ethnographic validity, ensuring that mental distress is assessed based on the concepts, categories, and means of communication that are meaningful and preferred. At the same time, this process is even more time-consuming, relies on in-depth qualitative research, and is less interpretable cross-culturally, including in communications with policy-makers and donors. The ZLDSI balances the goals of cross-cultural comparison with ethnographic validity and is the only tool that is clinically validated. At the same time, qualitative data collection and clinical validation are time consuming and require the availability of trained specialists. Finally, because clinical validation is in comparison to biomedical psychiatric constructs, categories developed in the West are necessarily privileged. This privileging of universalist over particularist approaches and of Western-derived psychiatric constructs over local categories, as well as potentially pathologizing normal responses to trauma and hardship all carry important implications for global mental health research and practice.

#### STRUCTURAL VIOLENCE AND MENTAL ILLNESS

One of the greatest lessons we have drawn from our experiences in Haiti and the Dominican Republic is that mental health disparities occur within broader systems of structural violence. Mental health research and service provision in low- and middleincome countries cannot stop at clinical treatment; there must be a concomitant effort to dismantle the institutional and structural arrangements that lead to suffering in the first place. To address this topic, we will present work in the Dominican Republic, where we investigated mental health of Haitian migrant workers (see Chapter One). Experience of Haitian migrants in the Dominican Republic illustrate how social, political, and historical spheres come together to perpetuate subjugation and suffering, mental illness being just one example.

Structural violence refers to broadly operating social, economic, and political forces that structure risk for death and disease (Galtung, 1969). As a theoretical construct, structural violence explores why certain groups suffer more disease or disadvantage than others. Suffering takes myriad forms: from "event-based" assaults such as torture or rape to more engrained, institutionalized forms of suffering such as racism and poverty (Farmer, 1996). Structural violence acknowledges that suffering is diverse and is disproportionately spread across the human population. In the face of such complexity, however, structural violence traces this disproportionate burden of suffering back to the unjust institutional processes that create and perpetuate it. Indeed, those institutional-level processes can range from the economic arrangements that benefit some people over others, to social and political forces that confer greater power and standing to some groups, even to ways in which disadvantage itself is explained or talked about: how do our socioeconomic privilege and historical trajectory influence how we understand and explain other people's suffering?

Haitian migrants in the Dominican Republic, as well as Dominicans of Haitian descent, are familiar with disadvantage. To this day, the Dominican Republic, a country that originated from a Spanish colony, celebrates its independence from Haiti (won in 1844) rather than Spain (self-imposed annexation ended in 1865). This is a telling fact because it reveals how the Dominican Republic contrasts its national identity with that of Haiti's, instead more readily embracing the identity of its Spanish founders. The distinction goes beyond nationality, however. Race and racism are deeply implicated in the two countries' shared history as well and are embedded in the present-day experience of Haitian migrants.

When we consider how racism becomes institutionalized, the story of anti--haitianismo (anti-Haitianism) in the Dominican Republic provides a clear example. Dominican independence brought with it differentiation of one group from another: of one population defining itself in opposition to Haiti and its negative tropes. This gave rise to attitudes that Haitians are "more African," have a different language, culture, and spirituality that is un-Christian and superstitious, and that they are determined to invade and conquer the entire island (Paulino, 2006; Sagas, 2000). In its most egregious form, anti-Haitianism was official state practice during the Trujillo dictatorship (1930-1961), culminating in the massacre of thousands of Haitians along the border region in 1937. The genocide has never been formally acknowledged as such by the Dominican government.

Anti-Haitian ideology differentiates Dominicans from Haitians on cultural and moral grounds and helps consolidate power over the Haitian and Haitian-descended minority in Dominican society. It is not only a discourse that moralizes against Haiti and Haitians but a political and economic structure that supports and justifies the exploitation of those minorities. The economic benefit of migrant workers from Haiti is well understood. In the early 20th century, Haitian migrant workers were recruited en masse for work on sugar plantations, housed in batey communities, and employed as manual labor for a thriving economic sector in the country's early history (Martinez, 1999). Over time, Haitian migrant workers, seeking to escape poverty, political turmoil, and structural violence in their home country, have sought opportunities in other industries as well, including construction, rice and cacao agriculture, and tourism (Ministerio de Trabajo, 2011). Today, there are an estimated 500,000 to 1.5 million Haitians and Haitian descendants in the Dominican Republic, the vast majority undocumented, many of whom have lived in the country for two or more generations (Canales et al., 2009).

One of the most apparent ways in which anti-Haitianism operates as structural violence is through widespread denial of authorized documents to Haitian migrants and their descendants, the periodic stripping of citizenship and legal rights of Dominicans of Haitian descent, and round-ups and forced expulsions of Haitians or "Haitian-looking" persons. The laws surrounding documentation of migrant workers in the Dominican Republic, and their interpretation and enforcement, appear deliberately obfuscated in order to create an underclass of exploitable workers.

In many of our conversations with Haitian migrants, they describe the profound insecurity that comes from not having documents, of having them arbitrarily confiscated, and the fear and uncertainty that accompanies such a life (see Chapter One). For example, one Haitian street market vendor recounted how immigration authorities

may demand proof of documentation, which is then sold to another Haitian migrant. In other accounts, research participants expressed their frustration at the impossibility of completing all required steps, and paying all necessary fees, to acquire documents legally. Lack of documents constrains upward mobility in the job market, leaving most in menial, low-paying jobs, as well as engendering fear of apprehension should they leave their communities, even for medical care (Leventhal, 2013). They are unable to organize or petition for their human rights easily, and as such live in communities that lack basic services such as water and sanitation and workplace or living standards (Simmons, 2010). In short, a policy and practice of "non-documentation" further pushes this population to the fringes of society. Keeping an entire population undocumented thus represents a form of institutionalized anti-Haitianism.

To examine how mental illness relates to these forms of structural violence. we need only examine the stories and explanations provided by Haitian migrants themselves. Imilyasyon is something felt by an individual, often one in a very lowpaying, unskilled job. More than likely, this individual does not have authorized documents. Consequently, this individual lives in an isolated community with other migrants, probably without basic infrastructure or access to healthcare. Interactions with Dominicans may involve daily insults such as name-calling or overt discrimination in markets, the workplace, or healthcare settings. All of this occurs alongside fear of apprehension and expulsion by Dominican authorities. Furthermore, in the face of such difficulty, this individual may feel a sense of failure to meet expectations of family back in Haiti, who are perhaps relying on this individual for remittances. In short, life is precarious.

Structural violence sits at the intersection of economic and social forces that simultaneously disparage and exploit the Haitian minority; it is the racist, nationalistic discourse that blames Haitian migrants and their descendants for their problems. Our research findings point to ways in which Dominican society arranges itself to create disadvantage among Haitians and their descendants. One obvious impact of that arrangement is the effect on mental health, including increased depression and anxiety symptoms, feelings of worthlessness and humiliation, uncertainty, and the perception that such hardships in life are unavoidable. Structural violence not only "structures" the conditions in which many migrants live; it also shapes how an individual perceives those conditions, to the point that suffering itself is assumed to be inevitable.

# Meeting the challenge of global mental health disparities

Acknowledging the role that structural violence plays in driving global mental health disparities is a first step towards reducing them (Ecks & Sax, 2005; Williams & Mohammed, 2013; Patel, 2015). Mental health of Haitian migrants in the Dominican Republic can be traced back to conditions set in place from unfair institutional prac-

tices, such as denying them authorized documentation, which in turn pushes migrants into lower socioeconomic positions and deprives them with a sense of control over one's life. Linked to this policy of unfair documentation is a history of anti-Haitianism, inherited from the legacy of slavery and Eurocentrism that privileged lighter skinned individuals with greater social status. Structural violence not only includes these broadly operating economic and political forces but also the everyday ways in which people conceptualize and explain health disparities. For some Dominican participants, the poor living conditions of many migrants, and their risk of waterborne diseases like cholera, were due in some degree to intrinsic character flaws found only among Haitians (explored in detail in the next chapter). In conversations with Haitian participants, however, we heard them link their suffering to lack of infrastructure and access to healthcare in their communities, as well as the hurtful interpersonal relations with Dominicans. In the end, many migrants felt powerless to change their circumstances, further compounding feelings of worthlessness and humiliation.

In the Dominican Republic, mental health of Haitian migrants is intricately bound to historical processes of differentiation, and especially anti-Haitian racism. Countering the institutional and interpersonal dynamics of anti-Haitianism requires a committed effort on multiple fronts. At the institutional level, there must be comprehensive reform of current documentation policies, so that migrants and their descendants can be brought into the larger fold of Dominican society. Equitable social and health policies should address longstanding service gaps in marginalized communities that include both migrants and poor Dominicans. Public awareness campaigns could also be implemented to challenge anti-Haitian discourse, inform the public of its harmful effect on mental health and well-being, and emphasize the two countries' shared customs and values. Such efforts would not be without challenges. Our field study was exploratory in nature, and as such we did not have the time or data analysis completed to begin articulating these forms of intervention. At a minimum, our field project generated cross-cultural dialogue and awareness among both groups of each other's perspectives on these complicated issues. Our research was reflexive throughout the entirety of the project. As a team we met to discuss findings as they emerged, and in so doing we engaged in self-criticism and reflection, culminating in several presentations at the local public hospital and university. Furthermore, we shared our perspective on anti-Haitian racism and the recent cholera outbreak in a joint letter published in Spanish (Keys et al., 2014). These discussions with audience members and as a team revealed how short-term field projects like ours could at least foster much-needed conversation, in both professional venues like peer-reviewed journals and public health fora, and in the communities where data collection occurs.

This "community-level" experience that we shared as a research team can even be framed as a form of positive contact. "Positive contact events" could assemble both Haitians and Dominicans; such gatherings have been shown in other settings to

be effective at reducing prejudicial beliefs held by the dominant group (Pettigrew & Tropp, 2006). In this way, global health research, particularly when it is communitybased, participatory research (Foster et al., 2010a, 2010b), could serve as an intervention in itself. Positive contact events might gain better traction in these communities if they are modeled on the konbit / convite form of social collaboration. In Haiti, the konbit is a collective gathering of neighbors who join together to accomplish shared tasks; in the Dominican Republic a similar structure is the convite. As evident in the shared etymological root of konbit / convite, Haitians and Dominicans may find that they share common cultural practices and values, and as such may find a productive and comfortable space to articulate ways of reaching greater social cohesion. This model of social collaboration may be particularly helpful in this setting, where social interactions between Haitians and Dominicans, and among Haitians themselves, appear to be a source largely of stress rather than support (see Chapter Two). Such collaborations can hopefully provide a foundation for future intervention, research, and advocacy.

# CONCLUSION

We have provided these case studies to illustrate three core areas of global mental health: the issue of language and cross-cultural communication, challenges in crosscultural measurement of mental illness, and the fundamental role that structural violence plays in driving mental illness. In our work and that of NGOs like Zanmi Lasante, we have witnessed the successful care provision that is facilitated by merging psychiatric and local conceptualizations of mental illness. In particular, we advocate for incorporating idioms of distress into clinical communication and using a hybrid universalist/particularist approach to measurement. We recognize too that ultimately, closing the mental health gap in low-resource settings becomes as much a political project as a health project (Mittelmark, 2003). One way to engage in this political project and help steer global mental health towards a more equitable future is to develop effective cross-cultural communication and measurement techniques and work towards dismantling the underlying economic, political, and social structures that perpetuate mental health disparities.

# OU PA LAVE MEN OU POU SIYE A TE

YOU DON'T WASH YOUR HANDS TO DRY THEM IN THE DIRT



# Cholera and anti-Haitian stigma<sup>6</sup>

#### ABSTRACT

As cholera spread from Haiti to the Dominican Republic, Haitian migrants, a largely undocumented and stigmatized population in Dominican society, became a focus of public health concern. Concurrent to the epidemic, the Dominican legislature enacted new documentation requirements. This paper presents findings from an ethnographic study of anti-Haitian stigma in the Dominican Republic from June-August, 2012. Eight focus group discussions (FGDs) were held with Haitian and Dominican community members. Five in-depth interviews were held with key informants in the migration policy sector. Theoretical frameworks of stigma's moral experience guided analysis of how cholera was perceived, ways in which blame was assigned and felt, and the relationship between documentation and healthcare access. In FGDs, both Haitians and Dominicans expressed fear of cholera and underscored the importance of public health messages to prevent the epidemic's spread. However, health messages also figured into experiences of stigma and rationales for blame. For Dominicans, failure to follow public health advice justified blame of Haitians and seemed to confirm anti-Haitian sentiments. Haitians communicated a sense of powerlessness to follow public health messages given structural constraints like lack of safe water and sanitation, difficulty accessing healthcare, and lack of documentation. In effect, by making documentation more difficult to obtain, the migration policy undermined cholera programs and contributed to ongoing processes of moral disqualification. Efforts to eliminate cholera from the island should consider how policy and stigma can undermine public health campaigns and further jeopardize the everyday "being-in-theworld" of vulnerable groups.

<sup>6</sup> Originally published as: Keys, H., Kaiser, B., Foster, J., Freeman, M., Stephenson, R., Lund, A., and Kohrt, B. 2017. "Cholera control and anti-Haitian stigma in the Dominican Republic: from migration policy to lived experience." Anthropology and Medicine 26(2): 123-141. The text has been lightly edited.

### INTRODUCTION

### Cholera on Hispaniola

Cholera is an intestinal infection caused by the bacterium Vibrio cholerae that can lead to profuse diarrhea, dehydration, and death. Since it thrives where basic sanitation and access to healthcare are limited or non-existent, cholera has been called "the disease par excellence of social inequality" (Briggs, 2001, p. 676), arousing fear, uncertainty, and blame (Briggs & Mantini-Briggs, 2003; Nations & Monte, 1996). In short, cholera is imbued with moral signification, and its epidemiological profile – striking society's poorest - can likewise play into stigmatizing beliefs about the poor and socially marginalized – that they are ignorant, dirty, and dangerous (Douglas, 2001[1966]).

In October 2010, a United Nations peacekeeping force negligently introduced cholera to Haiti (Piarroux et al., 2011; Transnational Development Clinic, 2013). Haiti shares the Caribbean island of Hispaniola with the Dominican Republic. Cholera spread to the Dominican Republic within one month of its introduction to Haiti (Tappero & Tauxe, 2011). In short time, the cross-border movement of Haitian migrants became implicated in the disease's spread. An official publication released by the Ministry of Health remarked on the vulnerability to cholera faced by migrant communities: "The appearance of the epidemic was imminent given existing social conditions that favored outbreaks: zones of extreme poverty [and] a constant migration flux on the island" (Salas Castro, 2012, p. 118, authors' trans). Haitian migrants not only became implicated in the epidemic but designated as a specific target population for intervention. What remains under-explored from this time period, however, is how vulnerability to the epidemic became structured, felt, and understood from the viewpoints of both migrants and Dominicans.

This paper explores the interplay among stigma, infectious disease, and migration, with emphasis on how constructions of "illegality" at the policy level impinge on the everyday "being-in-the-world" of an undocumented, stigmatized population (Willen, 2007b, p. 10; Willen, Mulligan, & Castaneda, 2011). First, an ethnographic study uncovers stigma's moral experience. The discussion then moves from a "local world" to consideration of Regulation 631-11 (hereafter, "the 2011 Regulation"), a national-level migration policy passed during the epidemic seeking to "regularize" migrants through additional documentation requirements. Comparing ethnographic findings alongside the 2011 Regulation sheds more analytical light onto the ways in which stigma's power operates across community and policy domains to not only jeopardize health but reinforce moral paradigms of deservingness and "othering."

# Haitian migrants in the Dominican Republic and anti-haitianismo

Migration on Hispaniola is exemplary of stigma processes rooted in the valuation of certain traits and the institutional practices of deciding who deserves entry into the body politic. In the Dominican Republic, social exclusion of Haitians largely derives from a devaluing of the Haitian "Other" along lines of race, culture, and nationality, elements that have shaped identity since the island's site as a colonial frontier (Paulino, 2006). The slave revolution (1791-1804) that gave birth to Haiti inspired fear in the Spanish colony to the east; the revolution in effect "transformed the Negro from slave to bloodthirsty menace" (San Miguel, 2005, p. 45). This caricature would seem out-of-place in a setting of racial and cultural mestizaje (mixing) (Andújar, 2015), yet it simply reflected the dominant strain of thought among those in power at the time: that African-descended persons were a hindrance, if not threat, to progress (Trouillot, 1995). The period from 1822 to 1844 remains indelible in Dominican historical memory. While the Haitian army sought to unify the island as a single, emancipated nation (Martinez, 2003), their presence in the east generated enough anti-Haitian sentiment to spark revolution and independence from Haiti, rather than the colonial metropole, Spain. Raising the specter of a potential "Haitian invasion" or else characterizing the presence of Haitians as an invasión pacífica (peaceful invasion) became a recurring means of manipulation by the country's elite (Paulino, 2006).

Nationality and *raza* (Spanish, "race") gradually coalesced as pillars of hegemonic power. Raza was equivalent to culture, nationhood, and ethnicity – always linked to a white, Catholic, Spain (San Miguel, 2005). *Anti-haitianismo* construed the "black, pagan, and African" Haitian as an existential threat to Dominican *raza* (Paulino 2002, p. 110). Of course, denying the "African component" is not a Dominican exception but rather a pervasive feature in parts of the world where people were racially stratified and subordinated (Hoetink, 2000). The privilege of the Dominican elite depended on othering "the people below" (Baumann, 2004, p. 42). Meanwhile, "the people below" were busy crafting shared cultural values, beliefs, and traditions that dispelled the idea of "fatal conflict" (Martinez, 2003). The dictator Trujillo (1930-1961) – alarmed by this blurring of cultural and social boundaries by the intermingling of both peoples (Derby, 1994) – took up *anti-haitianismo* with murderous effect, launching a genocide against Haitian and Haitian-descended people in 1937. Overt violence still occurs today, whether through extrajudicial deportations or at the hands of mobs (Brodzinsky, 2015; Paulino, 2006).

The economic development of the Dominican Republic has depended heavily on Haitian migrants (Martinez ,1999), yet they and their descendants are rou-

tinely denied authorized status (United Nations, 2008). For example, in 2013, the Dominican Constitutional Court rendered thousands of mostly Haitian-descended persons stateless by reversing the longstanding policy of *jus soli* (birthright) citizenship among those born in the country to undocumented (mostly Haitian or Haitian-descended) parents (IACHR, 2015). The astonishing retroactive decree – applying to all persons born after 1929 – affected generations and sparked a mass movement of undocumented persons across the border into Haiti (Ahmed, 2015). Two fronts of marginality open up when a legal system withholds or confiscates documents from an entire group of people: the material, palpably experienced by the undocumented in menial, physically arduous jobs, unhealthy living conditions, and disqualification from resources such as healthcare (Simmons, 2010); and the moral, where value systems normalize suffering and "undeservingness" (Willen, 2015). In sum, the "migrant space" is a nexus where the "biopolitics of Otherness" (Fassin, 2001) conspire with forms of conjugated oppression (Holmes, 2006) to exploit the minority and help pattern health inequalities (Hatzenbuehler et al., 2014).

#### STIGMA'S MORAL EXPERIENCE

Nothing is more punitive than to give a disease meaning – that meaning being invariably a moralistic one (Sontag, 1990, p. 58).

Disease, like any other negative attribute, acquires moral significance that carries social and material consequences. The unfolding of moral labeling occurs in both the interpersonal and broader, structural worlds in which people live. In both domains, stigma entails a moral experience that relates to how people assign meaning and value to "what matters most" in life (such as status, relationships, a job, health, or religious experience) (Yang et al., 2014). As a conceptual device, local worlds refers to realms of human experience, such as neighborhoods, work places, or social networks, where dominant and minority groups interact and where moral standing is sought or lost (Kleinman & Hall-Clifford, 2009). For stigmatizers, stigma can serve as a pragmatic defense in the face of perceived threats; for the stigmatized, it erodes a sense of control in life, discredits social status, and threatens what really matters (Meyer, Schwartz, & Frost, 2008; Yang et al., 2007).

At the collective level, stigma's structural determinants are rooted in moral economies, currents of values, norms, and sentiments that circulate in a given society to govern and integrate broad spheres of social and political life (IMPRS, 2020). Hierarchies of power emerge when societies value certain physical differences over others, such as race and sex, or social categories, such as ethnicity, class, occupation, and citizenship status. This translates into forms of biopolitics, where bodily differ-

ences justify "othering" people from the figurative body politic (Fassin, 2001), and conjugated oppression, where social categories like ethnicity and citizenship status synergistically compound an individual's vulnerability beyond that of either category alone (Bourgois, 1988; Holmes, 2006).

The valuing of some differences over others provides substance to discriminatory policies that determine who in society is deserving of attention or care (Willen, 2015). For example, policies that block undocumented or "illegal" im/migrants from health-care intuitively "make sense" because of prevailing value systems in those societies (Willen, Mulligan, & Castaneda 2011, p. 332). To contribute to a scholarly agenda that attends to how "illegality" is both constructed and experienced, this paper considers stigma from both ethnographic and policy perspectives, drawing on lived experience in a local, cultural world as well as an analysis of immigration policy and its discourse.

# METHODS, STUDY SITE, AND INSTITUTIONAL STRUCTURES

"Everything goes in there, dirty diapers, everything" said the Dominican woman in disgust, referring to the canal that snaked through her community, a rural village in the Dominican Republic's Duarte Province (Dominican woman, La Caya, D02). "You can catch [cholera] almost immediately." The rural village where the woman lived was home to a mix of Haitian migrant and Dominican families living roughly an hour's drive from the provincial capital, San Francisco de Macorís. In this quiet community, all inhabitants were in some way connected to the local production of rice, planted in vibrant, green fields that stretched out from the dirt road connecting their village to the national highway. Canals draining the fields coursed behind little houses and shacks, where some latrines fed directly into the slow-moving, dark water (Figure 1). Out in the fields, men could be seen hunched over in rows, engaged in *travay mikwòb* – loosely translated from Kreyòl as "dirty work" (Figure 2). They were mostly Haitian, and the dirty work involved weeding out rice fields by hand. In Duarte Province, migrants tend to work in agriculture or as construction laborers and market vendors in urban areas. For them, it is all mostly dirty work.

These ethnographic findings come from a field study conducted from June-August 2012 in and around San Francisco de Macorís, the provincial capital of Duarte Province. At the time of the study, 252 cumulative cases and 6 deaths were reported in the province (PAHO, 2015). A longstanding research partnership between Emory University, the regional campus of Universidad Autónoma de Santo Domingo, and the regional public hospital had fostered strong relationships among various key figures in the area, including Haitian and Dominican research assistants (RAs), professional contacts at the regional public health office and hospital, and community gatekeepers



**Figure 1.** Canal in La Caya (pseudonym), Duarte Province, Dominican Republic. Photo by Hunter Keys, 2012

in surrounding communities. The ethics committees of each institution approved the study.

Most activities were focused in two communities: Esperanza (pseudonym), a small barrio within the urban core of San Francisco de Macorís, and La Caya (pseudonym), a rural village outside the city. In addition to their urban-rural differences – a dichotomy known to reflect disparities in access to safe water and sanitation services throughout the country (Ministerio de Salud Publica, 2013) – these communities were selected because previous fieldwork had revealed high levels of perceived discrimination among migrants, that they were home to both Haitian migrants and Dominicans living in close proximity to each other, and because strong relationships had developed between the research team and community gatekeepers (see Chapter One). In short, the two communities offered a unique site to investigate the way interactions between migrants and Dominicans play out against the backdrop of the material space in which they live (Neely and Samura, 2011) – where polluted canals snake by shacks and municipal services are in short supply.

Like settings in many other parts of the globe, (e.g., Holmes, 2006; Mason, 2012; Willen, 2007a-b), accessing and affording healthcare in the Dominican Republic is strongly dependent on documentation status. Two laws, the General Health Law and the Social Security Law, adopted in 2001, helped establish the current Dominican



**Figure 2.** Haitian men at work in rice field, Duarte Province, Dominican Republic. Photo by Hunter Keys, 2012.

National Health System, which falls under the purview of the Dominican Ministry of Health (Leventhal, 2013). In theory, the General Health Law created a universal health coverage system to fulfill the right to health – articulated in Article 61 of the country's Constitution. The Social Security Law encompasses the financing regimes for health insurance plans, consisting of contributive and subsidized mechanisms. Crucially, obtaining coverage requires a cédula, the government-issued identification card issued by the Junta Central Electoral (Central Elections Board).

For the uninsured, healthcare largely occurs in publicly subsidized hospitals and clinics. San Francisco de Macorís is home to a large referral hospital, the Hospital San Vicente de Paúl. Smaller public health clinics are found in poor barrios and rural communities. For those without insurance, care in these structures is paid out-of-pocket. Thus, documentation status directly affects one's ability to access and afford healthcare.

#### DATA AND ANALYSIS

Field methods consisted of key informant interviews and focus group discussions (FGDs). Newspaper articles and official policy documents released during the period

of the study were included for analysis. In each community (Esperanza and La Caya), four FGDs were conducted with 5-7 participants each, stratified by nationality (Haitian or Dominican) and gender. Ages ranged from 18 to 73 years (Table 1). FGDs were audio-recorded and moderated by native-speaking RAs not from the study communities. Audio-recorded interviews with policy figures were held in San Francisco de Macorís and Santo Domingo (Table 2). These individuals included a top official at the country office of the International Organization for Migration (IOM); an advocate at Centro Bono, a national-level non-profit devoted to human rights of Haitians and Haitian-descended persons; and various Dominican legal experts, including a judge at an office of the Junta Central Electoral.

All audio files were transcribed verbatim in the original language (Kreyòl or Spanish) and translated into English. MaxQDA software was used for data management (VERBI, 1989-2010). Thematic analysis of transcripts considered emic and etic themes pertaining to stigma, cholera, and healthcare access, with emphasis given to idioms of distress and other locally meaningful ways of communicating psychological and social stress. The cross-section of ages and professional backgrounds among participants as well as inclusion of both urban-rural communities and Haitian-Dominican nationalities facilitated triangulation of findings.

**TABLE 1**: Characteristics of Haitian and Dominican focus group discussions participants

Nationality	Location‡	Gender	Focus Group ID	Age Range	Total participants
Haitian	Rural	М	H01	18-37	6
Haitian	Rural	F	H02	25-33	5
Haitian	Urban	М	H03	25-34	6
Haitian	Urban	F	H04	18-25	6
Dominican	Rural	М	D01	23-73	7
Dominican	Rural	F	D02	+	6
Dominican	Urban	М	D03	21-48	5
Dominican	Urban	F	D04	40-54	6

t = missing information

<sup>‡ =</sup> The rural location is represented in the text with the pseudonym *La Caya*, and the urban location is *Esperanza*.

**TABLE 2**: Characteristics of interview participants

Interview ID	Occupational Title	Location	Gender	Age range
LP01	Manager at large agricultural plantation	[interview conducted over phone]	М	40s
LP02	Top official at country mission office for International Organization for Migration (IOM)	Santo Domingo	М	40s
LP03	Judge at Central Elections Board (agency that issues authorized documents)	Duarte Province	М	50-60s
LP04	Volunteer for national-level advocacy group for Haitians and Haitian-descended per- sons in Dominican Republic	Santo Domingo	М	20-30s
LP05	Judge	Duarte Province	М	50-60s

Exploring how members of these communities perceived the cholera epidemic, and at a deeper level, how cholera may have figured into stigma and blame, posed certain methodological challenges. FGD participants were recruited during a concurrent epidemiological survey of cholera risks among migrants and Dominicans in the area (Lund et al., 2015). Through survey questions that captured demographics, knowledge of cholera, and perceptions and experiences of imilyasyon, (Kreyòl, "humiliation"; discussed in detail below), the team identified participants who appeared to have insight into how cholera had affected Haitian-Dominican relationships in their communities. The historical and social legacy of intermarriage and shared cultural customs complicates clear distinctions between "Dominican" and "Haitian." For this reason, we allowed focus groups participants to self-report their nationality as either Haitian or Dominican. For FGDs, cholera was the point of departure: what exactly is cholera? How does one fall ill from it? How can one prevent it? Beyond drawing out characterizations of the disease, the study pursued a deeper exploration of cholera's social ramifications: how did cholera get here? Who is responsible for it, and what should be done about it?

# THE VIEW FROM BELOW: "WE ARE OBLIGATED TO SUFFER"

In all focus group discussions, canals were said to clearly pose a health risk. Participants expressed fear of the epidemic; one Haitian man said that "no one can escape it" (Esperanza, H03) while a Dominican woman in the same community

exclaimed that "no one wants it to come!" (D04). All cited contaminated drinking water and poor sanitation, sharing common points on prevention, including hygiene and water treatment. At times, participants recited nearly verbatim the language in Ministry of Health flyers, printed in both Spanish and Kreyòl versions that displayed a smiling cartoon character next to the headline, "What is cholera?" (Figure 3).

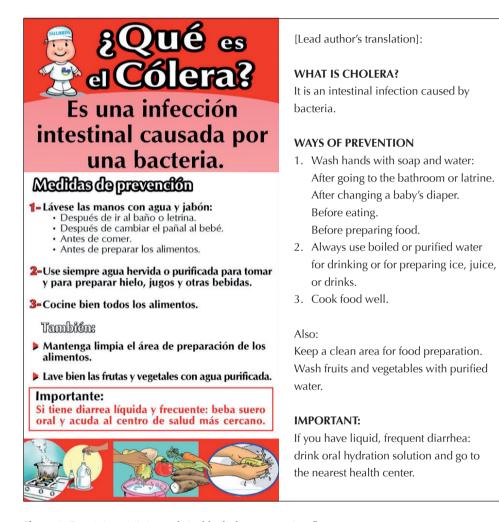


Figure 3: Dominican Ministry of Health cholera prevention flyer

Notably, all instructions on the flyer corresponded to individual actions. The flyer's emphasis on individual-level behaviors – such as hand washing or seeking care when ill – mirrored the perception among some participants that responsibility largely lay with the individual (Table 3).

**TABLE 3**: Preventative behaviors recounted by FGD participants

Behavior	Sample responses
Hand washing	We take care of ourselves. We boil water [and] a large amount of people chlorinate it, and if they go to the bathroom, when they leave [finish], they wash their hands. (Dominican man, La Caya, D01)
	Before eating, one must wash his hands. After using the bathroom, one must wash his hands with soap. (Haitian man, Esperanza, H03)
Food preparation	But I see some folks who take all the precautions. They wash their hands; they wash fruits before they eat them. Their foods are well cooked. (Haitian man, Esperanza, H03)
	When you go to cook, cook with clean water. (Dominican man, Esperanza, D03)
Treat water	You take a little water, and put some Clorox in it [] because you need to eliminate microbes. (Haitian woman, La Caya, H02)
	If you have potable water in the house, you use it, you personally keep yourself clean, you clean the house, the kitchen utensils, the food, this avoids contamination. (Dominican man, La Caya, D01)
Seek medical care	The person who has the symptoms should run to the doctor. (Dominican woman, La Caya, D02)
	When you're at the health center, they say how to protect yourself, and they give you information so you don't forget. (Haitian woman, La Caya, H02)

For some Dominican participants, an emphasis on individual behavior seemed to be adopted and applied more broadly – beyond the context of cholera itself and onto the traits and behavior of Haitians themselves:

Moderator: What else are the differences in this problem, the problem of cholera in Haiti and here in the Dominican Republic?

Dominican Participant 1: Well, over there people die of cholera more than here, I think.

Moderator: Why?

Dominican Participant 2: Over there, they live underneath trash. They do their necessities; they do everything, and that's why they get sick. And besides, they don't have hygiene. (Dominican men, Esperanza, D03)

The last statement in this exchange is noteworthy. While both Haitians and Dominicans agreed that "more people die of cholera" in Haiti, Dominicans contended that cholera arose out of how Haitians live – that is, what they do – as the main reason for cholera's toll. Haitians were often categorized as dirtier, incapable of taking care of themselves. One Dominican man went so far as to explain how he considered

loaning a toilet to his Haitian neighbors, but thought otherwise when he realized that he "couldn't loan a toilet to all the Haitians" (La Caya, D01).

For Haitian participants, none of these characterizations was really new. In a setting where anti-Haitianism went back not just decades but centuries, cholera seemed to produce no major shifts in attitudes. Indeed, if anything, it appeared to reinforce them:

When cholera was just affecting Haiti but hadn't yet come to the Dominican Republic, the Dominicans were always humiliating the Haitians, [but] after it finished ravaging Haiti, it came to the Dominican Republic, and they said this illness came along with the Haitians. (Haitian woman, Esperanza, H04)

*Imilyasyon* (humiliation), a key idiom for this population (see Chapter One), was often a verb in the active voice, as in Dominicans "humiliate us" (*yo imilye nou*). Humiliation was thus something done to someone – here, Dominicans doing something offensive to Haitians.

Nearly all accounts of humiliation centered on name-calling, belittling, and conveying the attitude that Haitians were without value (Kreyòl, pa gen vale) in the eyes of Dominicans. This occurred through the concrete experience of having one's paperwork confiscated by authorities, who then re-sell it to another individual bearing some likeness to the original bearer, or having few options but travay mikwòb. At the same time, humiliation filtered into day-to-day social interactions. In some anecdotes, Haitians at border check-points who appeared too thin or to have lost weight were presumed to have had cholera and were denied official entry. In the community, Dominican market goers were said to sometimes pass over clothes that Haitian vendors were selling, for fear that the clothes were contaminated with cholera (see Chapter One). In healthcare centers, Dominican clinicians were said to ignore undocumented Haitians "even though you are sick and should be taken care of urgently" and sooner care for a Dominican patient because "he is already in his country" (Haitian man, La Caya, H01). The psychological distress that this generated was enough for some migrants "to just stay home, they don't even eat, they are just reflecting [...] There are people who think that their time to die has come" (Haitian woman, 2011).

On top of it all, there was little they seemed capable of doing in the face of it:

Even if the Dominicans embarrass us, you must humble yourself before them [mete'w piti devan yo – lit. "make yourself small before them"], because you are not in your country when they are humiliating you [...] You have to be calm and accept humiliation from their hands. (Haitian man, La Caya, H01)

Humiliation is not only something done to you, but something you can do next to nothing about.

This sense of resignation was expressed in another idiom, *oblije*, or feeling obligated to endure suffering and hardship. The phrase was used in explaining original motivations to come to the Dominican Republic, as in "We're obligated to be here. If our country offered us opportunity, we would not leave" (Haitian man, Esperanza, H03). Once in the Dominican Republic, feeling *oblije* extended into daily stressors, including widely acknowledged cholera risks. Contrary to assertions by some Dominicans, who figured Haitians preferred using canal water, one Haitian man explained, "The canal water is not good for us, [but] we are *oblije* to use it because there is no other water. Only the Dominicans have tap water in their homes" (Haitian man, La Caya, H01). Haitian participants described having little choice but to practice open defecation. In another anecdote, Haitians were targeted by vigilante mobs for defecating in plastic bags and throwing them on the roofs of their houses (Official at IOM, LP02).

In fact, among Dominican participants, only one individual remarked on how the epidemic had been introduced to Haiti by the UN peacekeeping force (Dominican man, La Caya, D01), and there was no discussion of the profound disparity in water and sanitation infrastructure between the two countries. Instead, it was more common to hear how Haitians live in such crowded conditions that "everything they do goes towards the canal" (Dominican man, La Caya, D01); that they "don't take any precautions" (Dominican woman, La Caya, D02); or that they even "have a much lower culture" (Dominican man, La Caya, D01). The unifying thread was that Haitian individuals were themselves responsible for bringing cholera to the Dominican Republic.

In contrast, Haitian participants referenced specific structural hardships behind the epidemic, linking cholera to lack of access to safe water, distance and difficulty in reaching health centers, hazards found in the workplace, and feeling ignored by public health campaigns. "This is like a river whose source is unknown to us," said one Haitian man (Esperanza, H03), while another in the same community remarked, "Authorities could at least hold meetings with us in order to let us know how to act with regard to cholera. Unfortunately, we do not have this" (Esperanza, H03). There was a common refrain of feeling powerless to change such circumstances.

In sum, explanations for cholera's prevention or spread mapped onto different moral registers, which were in turn linked to longstanding ways in which Haitians and Dominicans understood themselves and each other. For Haitians, idioms like *imilyasyon* and *oblije* communicated an internalized sense of powerlessness and recognition of one's lower stratum in Dominican society (Holmes, 2011). Race and nationality had long contributed to an embodied experience of undeservingness (Willen, 2012a), but the added burden of being turned away at border checkpoints or in markets for inhabiting potentially cholera-infected bodies further crystallized this recognition.

Even the disease, "like a river whose source is unknown" (Haitian man, Esperanza, H03), seemed to have an agency unto itself. Among Dominicans, epidemic disease and its association with Haitian migrants were conflated as new forms of stigma power (Markel, 1997); that more Haitians were dying from cholera only reinforced the preexisting stereotype that Haitians were, as a whole, morally inferior – dirtier, ignorant, incapable of taking care of themselves; cholera had shored up their moral disqualification as a collective group (Briggs & Mantini-Briggs, 2003).

#### THE VIEW FROM THE TOP: EXCLUSION AS STATE PRACTICE

Every person [toda persona] has the right to health.

- Article 61, Constitution of the Dominican Republic, 2010

The right to health is a person's fundamental right and as such, should be a universal entitlement for all human beings. There are state policies for migration control, but I do not believe one has anything to do with the other, and therefore, they should not be linked to health policies.

- Dominican judge, Duarte Province, 2012

In early January 2011, one year after the earthquake that struck Port-au-Prince and several months into the growing cholera epidemic, nearly 1,000 Haitian migrants were forcibly removed from the Dominican Republic and "returned" to Haiti (Amnesty International, 2011). A few months later, the Dominican Director of Migration, José Ricardo Taveras, cited an estimate of 500,000 Haitians in the country, telling local reporters that "nobody can resist an invasion of that nature" (Archibold, 2011). His quote is striking not just for its allusion to "an invasion" (and the historical memory of 19th century Haitian-Dominican relations) but for the statistic it employs. In an important paper co-authored by a prominent Dominican sociologist, the same figure is referenced to illustrate the sinister use of population estimates of the Haitian and Haitian-descended population in the Dominican Republic (Corten et al., 1995). The New York Times article went on to explain how, with the advent of cholera in the country, the hospitality extended to Haitians in the aftermath of the earthquake was running thin.

Mr. Taveras responded to the Times in a commentary published in the Dominican newspaper *Listín Diario*. In it, he took issue with the characterization of recent Dominican immigration policy as connected to the cholera epidemic: "Cholera was not brought to Hispaniola by Haitians, it was brought to us by soldiers dispatched by the UN. Haiti and the Dominican Republic are victims of unfortunate chance" (Ricardo Taveras Blanco, 2011). Palpably frustrated at the international criticism of his country for the deportations, he continued:

Who is guiltier for the difficult life of our neighbors? The indifference of certain countries, who so dramatically portray themselves and claim solidarity that translates into nothing more than soldiers who cannot even safeguard Haiti from organized crime, human trafficking, and civil insecurity in general? Or us, accused of a passing solidarity but who act in the exact opposite of the indifference of those who so frequently chastise us, those who are in fact the true bearers of responsibility for confronting this drama? (Ricardo Taveras Blanco, 2011)

They were applying the law, he explained. How audacious, he contended, that the same countries that regularly deport many more undocumented immigrants from their borders would insinuate that the Dominican Republic is racist.

In the realm of Dominican political power, there is always push-back against international criticism regarding treatment of the Haitian and Haitian-descended minority (e.g., Noticias Aliadas, 2011). Here, however, it seemed that Mr. Taveras sought to differentiate immigration policy from the concurrent public health crisis. One might infer from Mr. Taveras that a policy of forced deportations, present in Dominican society well before cholera, was an affirmation of national sovereignty and sprang from the need to enforce existing laws – at a time that just happened to co-occur during the epidemic. Indeed, a common motif used by policymakers to explain immigration policy, and with it the practice of round-ups and expulsions, is "regularization."

Amidst the throes of an epidemic that gripped the country, the national government managed to make important changes to the country's immigration policy. On October 19, 2011, almost one year to the day that cholera was confirmed in neighboring Haiti, President Leonel Fernández signed into law Regulation 631-11, which sought to "guarantee the effectiveness and adequate implementation" of the General Migration Law by adding 15 new requirements for foreign workers to gain authorized status (Congreso Nacional 2011, Art 1, authors' trans). The requirements entailed a host of new hurdles, including obtaining a valid visa, a notarized birth certificate, a medical examination, and criminal background check. A long list of other documents, translated into Spanish, were also declared necessary to present in person at the General Migration Department in Santo Domingo, to be filed by four different migration agencies and the national police (Congreso Nacional, 2011). Previous to the 2011 Regulation, some of these requirements were already in effect (such as a valid visa); the dilemma arose in compliance with the new rules, which, explained Mr. Taveras, were aimed at "eliminating the chaos generated by the current illegal status of the labor market that encourages foreign labor" (Abiu Lopez, 2012).

What effect did adding these requirements really have? In short, the new legislation only added another barrier to gaining authorized status, already out-of-reach for most. The most obvious constraint in the daily lives of most migrants was cost. Some described earning between 3-5 USD/day, while a visa for authorized work in

the country was approximately 200 USD. The additional paperwork required beyond the visa entailed further costs and bureaucratic hassles. Based on this field study and others previous to it (see Chapter One; Simmons, 2010), it is nearly impossible to imagine the typical migrant crisscrossing the island to assemble notarized documents, have them translated into Spanish, and appear in person at multiple migration-related offices. To complicate matters, in Haiti, infrastructural shortcomings frequently prevent the civil registry from issuing documents that would prove an individual's identity. Meanwhile, in Santo Domingo, an official at the IOM described the Haitian consulate as woefully under-resourced to meet the needs of the estimated hundreds of thousands of Haitian migrants and Haitian-descended Dominicans, the latter sometimes seeking documentation on behalf of their parents or grandparents who had originally emigrated from Haiti.

The requirements were also contentious among Dominican employers: "Those regulations have been designed to reduce [the] foreign-working force. That is, the migration regulations are so complete and the costs are so high that a company won't be able to afford the luxury of having a foreign worker" (Employer of migrants, LP01). The onus, then, fell not only on migrants to navigate the various bureaucracies to acquire necessary documents (and pay their associated costs), but on their employers as well, tasked with filing a letter of solicitation to hire each foreign worker, register them with migration authorities, and ensure repatriation at contract's end. That same interviewed employer conceded that the true intent of the Regulation was to drastically reduce the number of Haitian migrant workers in the country through its costly administrative fees and procedures. After the legislation passed and employers faced losing a sizable part of their workforce, the office of Mr. Taveras was apparently inundated with phone calls from Dominican employers, who explained how they personally knew some of their Haitian employees for years and that "they deserved more respect" than being forced to return to Haiti (Official at IOM, LP02).

The position taken by Mr. Taveras and the Dominican government regarding the legality of Haitian migrants relates to "an enduring manifestation of traditional modernity – the ostensibly rational bureaucratic state regime" (Willen 2007a, p. 2). At a national level, the state's various bureaucracies can subjectify individual – that is, what passes for rational state practice is in fact a subjective rendering of a specific group of people, a rendering that in turn legitimizes their marginalization (Fassin, 2011). Borrowing from de Sausurre, Baumann's (2004) contrast of language (*langue*) and daily language use (*parole*) can be helpful here: the language of official policies and discourse can reflect the assumption that state policies and their enforcement are rational and, by extension, moral. "Irregular" migrants are subjects of regularization; the "chaos of the labor market" necessitates intervention. In turn, everyday language of Dominicans employs a similar mode of delimiting and categorizing the Haitian "Other:" as lacking self-care, possessing a "lower culture," and in turn posing a threat.

This interplay between *langue* and *parole* is mutually reinforcing, to such effect that excluding a group of people from the healthcare system "intuitively 'makes sense'" (Willen, Mulligan, & Castaneda, 2011, p. 332), allowing for a convenient escape from reconciling how the Dominican Republic can enshrine the universal right to health in Article 61 of its Constitution yet still work to disqualify undocumented persons from accessing healthcare (Leventhal, 2013). Even the judge overseeing the provincial office of the Junta Central Electoral, the governing body tasked with issuing *cédulas*, conceded that, "If you do not have documents in the first place, it is difficult to access the health system" (Dominican judge, LP03).

On one hand, the right to health is understood as a fundamental human right regardless of citizenship; on the other, under a rubric of "regularization," the government outlined a series of near-impossible steps to undertake in order to become documented and in turn access healthcare, a policy that fit into a longer pattern of devaluing the undocumented Haitian "Other."

## **DISCUSSION**

In this study of cholera, stigma, and policy among Haitian migrants in the Dominican Republic, juridical and everyday discourses about cholera contributed to material and psychosocial harm. Study participants understood the cholera epidemic in different ways. Most Dominicans embedded their explanations within the realm of individual responsibility, connecting cholera to supposed character flaws among Haitians as a collective group. In contrast, Haitians recalled the everyday assaults of structural violence, in particular *travay mikwòb* (dirty work), lack of access to safe water and sanitation, and harmful interpersonal interactions with Dominicans, encapsulated in the idiom *imilyasyon*. Another idiom, *oblije* (obligated to suffer), communicated resignation to life's hardships. This difference in explaining cholera – whether through innate character flaws or structural hardships and stigma – points to ways in which host and migrant groups perceive disease, the structures and behaviors that either mitigate or exacerbate its spread, and how an epidemic contributes to othering processes.

Stigma became enacted on the policy front as well. One year into the epidemic, the Dominican legislature modified the documentation process, effectively pushing migrants further anba fil – "under the wire," a Kreyòl colloquialism for living undocumented – and disqualifying them from health insurance. In light of forced deportations of migrants during the epidemic, tensions arose between advocacy groups that condemned the deportations and the Dominican state. Dominican policymakers denied that the deportations had any relationship to the epidemic, arguing that migration policy and enforcement had no bearing on the constitutionally-mandated right to health.

Yet our ethnographic findings show how the 2011 Regulation aligned with and helped reinforce prevailing forms of anti-Haitian stigma and political routines of separating "Dominican insiders from Haitian outsiders" (Derby, 1994, p. 502). As the epidemic spread, the Regulation hardened the line between the authorized and the unauthorized. Rather than considering social and environmental inequalities in migrant communities as grounds to expand access to social services, a "biopolitics of Otherness" (Fassin, 2001) effectively worked to create a stratum of "biological non-citizens" (Mason, 2012) whose perceived disease risk to others warranted further social exclusion. Those unable to join the pool of the authorized could be more readily blamed for their position in Dominican society. This aligned neatly with tropes of assigning complex problems rooted in structural violence to individual responsibility, feeding the current that delineates the deserving from the underserving (Willen, 2012a).

In the end, there was striking resemblance between the logics that circulated on-the-ground and those within the chambers of Dominican political power. Cholera reinforced preexisting anti-Haitian beliefs; character flaws supposedly intrinsic to Haitian migrants were to blame for the epidemic's spread. At the national level, new documentation requirements left migrants to blame for their failure to comply; those unable to do so could be subject to forced expulsions. This line of reasoning acted as currency in a moral economy that legitimized their already low stratum in Dominican society (Willen, 2015).

# Key recommendations

In the time since this study's fieldwork, makeshift camps just across the border accommodate over two thousand Haitians and undocumented persons fleeing the Dominican Republic for fear of forced deportations or worse. An outbreak of cholera in those camps has already claimed the lives of nearly two dozen people (Ahmed, 2015). In the face of such circumstances, what is the contribution of ethnographic and policy analyses such as those offered here?

Rather than perpetuating the difference between the undocumented (mostly Haitians and their descendants) and documented ("legitimate" citizens), a starting point to address and help dismantle anti-Haitian stigma and expand norms of deservingness to include migrants would be a policy based on the shared interests between the two countries. Foremost is the argument that migrant laborers from Haiti are indispensable to the economic development of both countries (Ministerio de Trabajo, 2011). Acknowledging the role that they continue to play in the country's economy – and via remittances, Haiti's own – figures into the political debate that often frames Haiti's domestic turmoil as a threat to Dominican security. It follows that facilitating a realistic pathway for authorized migration would bring with it greater chance for economic and political stability on both sides of the island.

The cholera epidemic has resoundingly shown that the health of both countries' populations relies on bilateral cooperation to improve living standards, not only for undocumented persons but the poor in general. Reducing stigma and addressing unfair migration policies is a public health issue for both countries. The Call to Action Plan for a Cholera-Free Hispaniola, supported by major global health actors in concert with the Ministries of Health in both countries, underscores the role of community mobilization in eliminating cholera from the island (PAHO/UNICEF/CDC, 2012). This study's findings could be applied in community-level efforts outlined in the country's cholera elimination plan (Ministerio de Salud Publica, 2013). Health messages could not only emphasize individual-level behaviors but also cholera's structural determinants such as poverty, documentation and healthcare, and stigma's harmful effects (Nations & Monte, 1996). Developing messaging strategies at sites "closer" to material and social inequalities (eg., community clinics, public hospitals, neighborhood associations) could provide a more democratic means to shape those messages and their content (Briggs & Nichter, 2009). One way to engage at the community level is to improve collaboration between Haitian migrants and Dominicans. Positive contact events (Pettigrew & Tropp, 2006) could be modeled on culturally relevant forms of social organization, such the *convite / konbit* (see Chapter Two).

Most applicable in this setting is a documentation policy that takes into account circular migration and that collaborates with Dominican employers to help migrants qualify for health insurance during their stay in the country. Such policies would help ensure personal security among migrants and the chance to create a more sustainable livelihood. Of course, given the Constitutional Court's ruling in 2013, the status of thousands of Dominican-born, Haitian-descended persons demands special consideration of the unique circumstances faced by that population (IACHR, 2015).

Reforming the documentation system, strengthening healthcare financing, and curbing anti-Haitian stigma at state and local levels cannot be left to the Dominican government alone. There is already a network of advocacy groups and non-governmental organizations (NGOs) that may be receptive to principles outlined here (Wooding & Moseley-Williams, 2004). Similarly, multilateral agencies bear considerable responsibility in supporting the Dominican government's efforts to resolve these challenges, extend the universal health coverage ideal to migrants within its territory, and respond to the crisis on the border.

# **CONCLUSION**

Cholera's appearance in the Dominican Republic thrust the population of undocumented Haitian migrants into a harsh spotlight. For a bacterium that conjures filth and "invasion," cholera became loaded with meaning and fit into moralistic, anti-Haitian

tropes. In communities, Haitians were blamed for the epidemic and felt powerless to change their circumstances. A national-level migration policy further consolidated stigma's power. Moral sentiments, values, and norms circulate between the poles of intersubjective experience and institutional policies. Capturing the social and material consequences of these moral economies makes ethnography especially relevant. The evidence that emerges from this approach may more effectively challenge claims for exceptions to the right to health.

#### **ACKNOWLEDGEMENTS**

The authors thank Ms. Rosa Ypania Burgos, Mr. Rafael Alvarez Castillo, Dr. Luis Adolfo Dominguez, and Dr. Ambrosio Roasrio for the institutional support they provided on behalf of the Universidad Autónoma de Santo Domingo, the Ministerio de Salud Publica, and the Hospital Regional San Vicente de Paúl. We thank Liza Vertinsky, Emory School of Law, for her input and guidance on legal analysis. Sarah Willen and Sam Martínez provided helpful comments on earlier versions of this manuscript, as did an anonymous reviewer. We thank the research assistants who collected data for this study, including Dhaysi Batista Berroa, Jhefri Augustin Reyes Reinoso, Mere Dieuliphene, Anniset Jean Charles, Benson Cherichel, Yanahaira Rivera, Asela Tejada, and Lidia Joaquin. The Emory Global Health Institute and the American Association of Occupational Health Nurses provided funding to support this project. The study was approved by the institutional and ethical review boards of Emory University and the Hospital Regional San Vicente de Paúl, San Francisco de Macorís. The lead author is supported by the Netherlands Organization for Scientific Research.



#### CHAPTER SIX

# Social exclusion, disease elimination, and the right to health<sup>7</sup>

#### **ABSTRACT**

Hispaniola, the Caribbean island shared by Haiti and Dominican Republic (DR), accounts for 90% of lymphatic filariasis (LF) in the Americas. Both countries have committed to LF elimination by 2020. In the DR, LF occurs mainly in bateyes, or company towns that historically hosted migrant laborers from Haiti. A legacy of anti-Haitian discrimination as well as the 2013 Sentencia, which stripped generations of Haitian-descended Dominicans of their citizenship, ensure that this population remains legally, economically and socially marginalized. Despite this context, the country's LF elimination program (PELF) has worked in bateves to eliminate LF through health education and annual drug treatment to interrupt parasite transmission. Based on interviews with batey residents and observations of PELF activities from February-April, 2016, this study describes local understandings of social exclusion alongside the PELF community-based approach. The Sentencia reinforced a common perception shared by batey residents: that their lives were unimportant, even unrecognized, in Dominican society. At the same time, through its work, the government-run PELF has partially counteracted some of the effects of social exclusion. These findings suggest that neglected tropical disease (NTD) programs can not only improve the health of marginalized populations, but also create a platform for confronting human rights violations.

<sup>7</sup> Originally published as: Keys, H., Gonzales, M., Beau De Rochars, M., Blount, S. and Noland, G. 2018. Building trust through lymphatic filariasis elimination: a platform to address social exclusion and the right to health in the Dominican Republic. *Health and Human Rights Journal* 20(1): 41-52. The text has been lightly edited.

#### INTRODUCTION

In the Western hemisphere, the story of lymphatic filariasis (LF) – or rather, the story of people who live with LF – begins with an ignoble chapter in human history (Fassin, 2009). Along with untold millions of enslaved Africans, the Atlantic slave trade brought the disease from Africa to the Caribbean island of Hispaniola (Vincent et al., 1987). The first 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 (Dubois, 2012). Haiti arose out of this colonial furnace as the first free black republic in the world. The Haitian Revolution (1791–1804) was so radical that, at the time, "not even the most extreme political left 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 (Trouillot, 1995, p. 82). 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 (WHO, 2015). LF is endemic in 72 countries, with 856 million people at risk for infection and 40 million currently suffering from the disfiguring and disabling complications of lymphedema or hydrocele (WHO, 2017a). The 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 suffering for those already affected.

At present, Hispaniola accounts for 90% of LF in the Americas (WHO, 2013). Haiti, the poorest country in the hemisphere, bears a higher disease burden than the DR (Oscar et al., 2014). 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 (see Chapter Seven). LF is rare outside of *bateyes*, meaning that they have been the predominant foci of LF transmission, likely due to the regular influx of Haitian migrants that may inadvertently import

infection from Haiti, combined with impoverished environmental and sanitary conditions that favor breeding of the *Culex* mosquito vector (IACHR, 2015; Noland, Blount, & Gonzales, 2015).

The DR is distinct among Caribbean nations because it was there that large-scale sugar plantations expanded *after* the abolition of slavery (Hoetink, 2000). Through the early 20<sup>th</sup> century, Haitian migrants were crucial to the growth of sugar production yet also were cast as a threat to Dominican society. The dictator Rafael Trujillo (1930–1961) manipulated colonial-era sentiments of race both to exploit the migrant workforce and to consolidate power over a bicultural and largely harmonious world made by Dominican and Haitian peasants (Turits, 2002). It is unclear to what extent *anti-haitianismo* (anti-Haitianism) exists as popular ideology in the DR today. More likely, it continues to be a useful tool for the Dominican elites to justify their economic power (Baud, 1996). Indeed, the ideology has generally served those wielding greatest power throughout the history of the DR: early colonial rulers; the intelligentsia of the newly formed republic; North American corporate enterprises and the American military; and certain contemporary Dominican political parties and policymakers (Mayes, 2014; San Miguel, 2005).

In addition to migrants from Haiti, *bateyes* are also home to Dominican-born persons of Haitian descent, who comprised an estimated 25.5% of the total *batey* population in 2016 (see Chapter Seven). Like migrants, they too contend with a history of discrimination in the country. The 2013 Constitutional *Sentencia*, or "the Sentence," which stripped citizenship from an estimated 200,000 people of mostly Haitian descent, further reinforced their marginalized status (IACHR, 2015). This decision reinterpreted the principle of birthright citizenship – in effect since 1929 – by arguing that children born to those in an irregular migratory situation were "foreigners in transit" and not entitled to Dominican citizenship. Revoking citizenship has left them unable to perform basic civil functions such as registering children at birth, getting health insurance, enrolling in school and university, participating in the formal economy, presenting legal claims in courts, or traveling within the country without risk of expulsion (IACHR, 2015).

These downstream effects 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) (IACHR, 2015). Furthermore, the country has ratified multiple international frameworks pertaining to discrimination, including the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). Just five 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 (CERD, 2012).

The far-reaching consequences of statelessness on human rights should be quoted in full. The 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 territory of which they are nationals or the right to enter in said territory, the prohibition of collective expulsions, among others (IACHR, 2015, p. 13-14).

In short, social exclusion in the DR creates exceptions to what the country would otherwise claim as universal rights.

There is, however, some alignment between policy and practice from the stand-point of the right to health. The Dominican Constitution declares that *toda persona* – every person – has the right to "integral health" and calls for the state to "procure means for the prevention and treatment of all sick- nesses, ensuring access to quality medication and giving medical and hospital assistance for free to those who need it" (Dominican Republic, 2010, Art. 61, para. 1). The Dominican Ministry of Health has operationalized this lofty goal in part by establishing government-funded primary care centers in or near *bateyes*. Each is staffed by a doctor, nurse, supervisor, and several community health promoters (Baker et al., 2007).

In 1998, the Dominican Ministry of Health established the *Programa de Eliminación de la Filariasis Linfática* (PELF). Baseline mapping revealed LF infections among the *bateyes* in the southwest and east of the country, along with a small focus in an impoverished neighborhood of Santo Domingo (*La Ciénaga*). Due to funding limitations, PELF began interventions only in the most endemic region (southwest) in 2002, but gradually scaled up to each of the three foci. The main intervention is annual house-to-house MDA of albendazole (donated by GlaxoSmithKline) and diethylcarbamazine (donated by Eisai since 2013) in target communities.

Initially, PELF was a vertical program in which strategy, evaluation, and interventions were centrally directed. However, the program rapidly recognized the importance of community engagement to achieve sufficient MDA coverage – at least 65% of the total population in endemic areas (WHO, 2011). Beginning in 2003, interventions were folded into the local health care system (Baker et al., 2007). By mobilizing local primary care staff, neighborhood associations, and community volunteers, MDA campaigns have avoided a separate operational structure, helped to generate

trust and job satisfaction, and improved MDA coverage (Baker et al., 2007; PELF, personal communication, 2016). Average population coverage has been 80.7% across all MDA campaigns. To date, LF antigen prevalence in all formerly endemic areas of the country has been reduced to less than 2% – the level at which MDA is no longer needed (WHO, 2011).

These accomplishments are especially noteworthy because the chronology of PELF and its MDA activities correspond to a period over which the Dominican political and judicial system took a more aggressive stance towards the migrant and Haitian-descended population (IACHR, 2015). 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 certificates to those born to parents without Dominican residency; in 2011, a regulation added more requirements, many of which were nearly impossible to fulfill, to acquire legal status; and in 2013, the Constitutional Court issued the *Sentencia* (IACHR, 2015). These 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" (IACHR, 2015, p. 128).

How, then, to account for the successful public health campaign to eliminate LF in *bateyes* amid a context of social and legal exclusion? This paper responds to this question from two angles: by exploring social exclusion in *bateyes* and by describing the community-directed approach of the PELF program. Here, *social exclusion* focuses on subjective experience, or how people perceive certain relations, events, or circumstances that signal their rejection or not mattering in a local world. The analysis of PELF gives attention to community engagement processes between PELF and the *bateyes*. Examining social exclusion alongside the approach taken by PELF reveals contrasting perspectives in how people see themselves in relation to institutions and each other, and informs human rights discussions in which the capability to live a dignified life is a primary benchmark.

#### METHODS AND ANALYSIS

Data for this study are based on interviews and observations collected in February–April 2016, when PELF and The Carter Center, a health and human rights non-governmental organization (NGO) based in Atlanta, USA, undertook a survey of malaria and LF prevalence in extant *bateyes* nationwide (southwest, east, and north regions of the country) (Keys et al., 2019). Additional data come from a follow-up interview completed in March 2018.

During the 2016 survey, the lead author interviewed 27 batey residents across three geographic regions to collect personal narratives of general life, hardships, and

support systems in bateyes. These individuals were enrolled during surveying activities based on their personal and/or professional background and insight into daily life and local history of their batey. Interview participants were Haitian- or Dominicanborn, ranged in age from early 20s to early 70s, and spoke in either Spanish or Kreyòl. Three were heads of their juntas de vecinos (neighborhood associations); two were community health volunteers in the bateyes where they were born. One woman was a school teacher in a batey. One man was the co-founder of a small advocacy group supporting the rights of Haitian migrants in the region. The rest were agricultural laborers, market vendors, or unemployed. Interview participants were selected through established networks with PELF colleagues, snowball referral from other informants, or relationships from previous fieldwork (see Chapters One and Five). An interview guide was initially developed around core themes such as migration, livelihoods, coping and support, health and disease, care-seeking, and the 2013 Sentencia. Perceptions and reported experiences with PELF were not explicitly solicited; rather, interviews with batey residents sought to capture their personal narratives and to provide space to articulate daily life and social exclusion from their points of view. The structure of interviews was adapted over time in response to findings.

The lead author also accompanied PELF colleagues during the 2016 survey to observe their day-to-day responsibilities, which included making initial contact with *juntas de vecinos*, supervising survey teams, and ensuring adequate follow-up treatment for survey participants who tested positive for malaria or LF. Over three months, the lead author accompanied PELF colleagues in both formal and informal settings, including community meetings in *bateyes*, regional public health offices, and "street-level" interactions with *batey* residents.

Based on established rapport developed during these accompanying activities, a follow-up interview was done in March 2018 with two individuals at PELF. Since 2002, both individuals have worked as *facilitadores* (facilitators) for MDA campaigns, tasked with fostering links between the elimination program and the *bateyes*. The purpose of this interview was to seek feedback on emerging themes from the 2016 interviews and gain additional insight into community engagement for LF elimination.

After providing oral informed consent, interview participants spoke with the lead author for approximately 1–1.5 hours, typically at their residence or work place. Interviews with *batey* residents were audio-recorded and then transcribed verbatim in the original language into Word documents. Field notes and observations were also typed as Word documents. All documents were then uploaded into MAXQDA software for qualitative analysis. To protect confidentiality of participants, all names appearing are pseudonyms. Ethical approvals for both the survey and in-depth interviews were provided by ethical review committees in the DR (CONABIOS), the University of Amsterdam, and Emory University.

An initial reading of all documents was done to develop and apply a coding

scheme. *A priori* codes ranged from economy and labor; documentation; health care; feelings of unimportance; support/coping; and community engagement/mobilization. *In vivo* codes sought to link recurrent explanations, incidents, and other phenomena as emphasized by participants, often in their own wording or idioms. Examples of these codes include *afectado* (or "affected" by the *Sentencia*); *chache lavi / buscar la vida*, or "to look for life" in reference to migration or finding work; *pa gen vale / no vale nada*, or worthless; *moun politik / gobierno* to refer to public authorities, the government, and local politicians; and *tèt ansanm* ("heads together") to refer to social support among the Kreyòl-speaking population.

Following code assignment, text segments were retrieved based on shared codes and re-categorized under two contrasting themes: 1) *batey* residents share feelings of unimportance, especially since the 2013 *Sentencia*; 2) despite their social exclusion, PELF has been successful in reducing LF through mutual respect and interpersonal relationships.

## **FINDINGS**

"Dead but alive": Social exclusion in DR bateyes

The *Sentencia* re-classified Victor Fernandez, a man in his late 60s who served on the local neighborhood association, as a foreigner in the land of his birth. His parents had come from Haiti in the 1940s and were issued identity cards by an *ingenio* (sugar company) in cahoots with the government. Although he possessed a state-issued birth certificate and *cédula* (state-issued identity card), Victor was no longer considered a Dominican citizen due to supposed problems with his parents' documents – which had been issued by Dominican authorities in the first place.

Sitting in a plastic chair on his patio, Victor grew animated, and asked rhetorically:

The first Spanish who were born here, what blood did they have? They didn't grow out of the earth like a plant. They came from somewhere else. We all did. We have the same rights, we are Dominican, but the laws say we aren't.

He attributed the *Sentencia* to, "people *a nivel de arriba* [at the top] [...] a few powerful economic sectors" that sow division, which then trickles into daily life. For example, Victor had once been stopped on a bus and asked for his passport. In his telling, this was prompted by his darker skin, as lighter-skinned individuals were not asked to show theirs. "I only show my passport when I travel outside my country," he responded firmly.

"Erasing history," notes Paul Farmer, "is perhaps the most common explanatory sleight- of-hand relied upon by architects of structural violence" (Farmer, 2004, p. 308). Victor's account forcefully pushes back against this erasure. He recalls that social exclusion on Hispaniola goes back a long way, from Spanish *conquistadores*, to the growth of Dominican sugar plantations that ensnared Haitian cane cutters like his parents, to the present day, in which his own life has been upended. This long reach of history figures into Victor's interpretation of himself in 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" (Fassin, 2011). 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 official 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 office that his permit would last five years, only to discover that it was valid for only one. This bitter experience, along with not having enough time to comply with recent changes in documentation requirements, left 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. This is what the government has done to us in the last 10 years. They've eliminated all sources of work by closing the *ingenios*. Agriculture has been completely abandoned. That's why we're in the state that we're in.

Juan Carlos, an older man who had migrated from Haiti at age 12 and later became an advocate for migrants, shared an anecdote illustrating how *bateyes* could be manipulated for political ends. During the election campaign leading up to Joaquín Balaguer's second administration (1986–1996) – one that breathed new life into Trujillo's (1931–1960) *anti-haitianismo* (anti-Haitianism) – the government saw an opening to round up votes among the undocumented *batey* residents:

At the time, everyone was given a *cédula* to go vote for Balaguer. Later, we were told that the *cédula* was fake, that it was only given to us to vote in their favor. We didn't know anything, but we voted, [because] that was their plan.

The 2013 Sentencia reinforced this pattern: taking away documents from Dominican-born persons of Haitian descent leaves them, as Juan Carlos said, muerto con vida – "dead but alive." In his words, "These kids without documents, they can't advance in life, they can't go to school and find a good job." His perspective was shared by two female community health volunteers, each in different regions of the country. One said, "If the child can't study, they have to work hard, in the fields cutting wood to make charcoal," while the other remarked, "If you don't have documents, how can you care for your family?" Others linked unauthorized status to restricted mobility, expressly using the verb to walk. One woman said that documents were essential for those in bateyes, "so that they can walk," while others would say that without documents, "you cannot walk far" due to risk of apprehension.

For those seeking to recover documents in the fallout of the *Sentencia*, interactions with local bureaucrats also generated sentiments of unimportance. One woman, a Dominican-born school teacher affected by the *Sentencia*, described the scene at the local registry office: "All they say are little words" (*palabritas*). "Without an important person (*alguien grande*) – they won't make a case of me" (*no me van a hacer caso*), or in other words, they ignore me. Positioning herself in relation to "a big person," one who can move the levers of clientelism, implied that she saw herself as powerless. Similar phrasing has been found among the Kreyòl-speaking population: Haitian migrants have referred to themselves as *ti malere*, or "little miserable ones," toiling at the behest of *gwo nèg*, or "big men," connoting smallness and disempowerment (see Chapter One).

This sense of powerlessness derived not only from recent government decisions such as the *Sentencia* or bureaucratic obstacles, but also from government *inaction* – from lack of concern for material hardships in *bateyes* or lack of follow-through by those promising to improve life and livelihoods. Like Antonio Guzman, who remarked on the humiliation felt by those left unemployed in the *batey* after closure of the local *ingenio*, Esther Beauvil, a Haitian-born woman living in the southwest region, also communicated the perceived slight from government inattention.

In 1998, she and her family lost their home in the southwest region to Hurricane Georges. Living in a small *batey*, they moved further inland to another *batey*. Years earlier, Esther had migrated from Haiti and married a Dominican-born man. In the time since they relocated, she worked as a cleaning lady in the homes of wealthier people in the capital, because in the *batey*, *bagay yo di* – "things are hard." (Figure 1)

At the time of the interview, the country was in the throes of an election. It was not uncommon to see pickup trucks carrying giant speakers blasting announcements to vote for some candidate. Sitting in the shade of a small, scraggly tree, Esther looked around her in disgust. She said people here eat only what grows from their *conucos*, or subsistence gardens. There was no water source, no decent roads, and no schools. She said:



Figure 1. Scene from batey, Dominican Republic, 2016. Photo by Hunter Keys.

It's like the government doesn't even know there are people here. Only when there are elections will you see cars roll in with people to talk to us, and after, you'll never see them again. We'll vote for them, but they don't deserve it, because they don't remember us. The government doesn't sit down with us (*Leta pa chità avek nou*).

In sum, for *batey* residents, the relations and circumstances that signaled their rejection ranged from the empty promises of politicians, lack of improved livelihoods, or gestures and "little words" at local bureaucratic offices. The social cues of exclusion extended onto the street. Some participants cited instances of being called names, based on some physical trait such as hair texture or skin tone, for presumably being Haitian. Drawing on the Kreyòl idiom *pa gen vale*, or worthless, an older man, who had come to the DR decades before, said simply, "When they say you have no worth, it means you are not a person." At stake was both a sense of self- worth and a sense of belonging to the broader social body: of being a full-fledged *moun* (Kreyòl, person) or *reconocido* (Spanish, recognized) in Dominican society. In short, these accounts reflect the "desire to be recognized as socially ratified persons" (Willen, 2012, p. 819).

"Public, because it's for everyone": The 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 after 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.

A light came on and a shirtless man unlocked the door and opened it a crack. He peered at the strangers on his doorstep, sheathed machete in hand. *Somos de salud pública* – "we are from public health," said Yulisa. A few expressions in Kreyòl seemed to defuse any tension, and the man opened the door to welcome the PELF team inside.

Yulisa is in her 50s and has worked for PELF since 2002. She also assists a local non-profit that advocates for the rights of those left stateless after the *Sentencia*. In her words, the court decision "was an abuse." She does not claim any Haitian descent, and explains, "I may not have the same culture [as those in the *bateyes*]. I cannot judge how people live." Quite familiar with the poverty of *bateyes*, she went on. "I'm only there to give assistance or advice about health. If I see that you do not even have a table or chair, I won't ask for a table and chair to do my job when I visit your home."

Simple steps like these were, for Yulisa, *por la confianza* – to maintain trust. Others working for PELF remarked on the importance of maintaining trust with community members. One *promotora* (health promoter) described how some in her *batey* were cautious to approach another promoter in the area because she was known to gossip about her patients. To do the job right, she explained, "You have to know how to keep their trust."

Yulisa completed several steps before going to Gertrude's home. At PELF's central headquarters, she reviewed the positive sample that had been collected weeks earlier. She then contacted the local health promoter in the area, and explained to the promoter that she would need to give advanced notice to Gertrude that another team would arrive for more testing.

Inside Gertrude's home, a bare light bulb dangled overhead, casting a faint glow. *Ou met chità, chità* – "please, sit," said her husband, offering their only piece of furniture aside from their bed: a little stool that barely rose more than a foot off the ground. True to her word, Yulisa declined the stool, preferring that Gertrude sit there for the blood draw. On the mattress were two infants sleeping quietly under a mosquito net, their soft breathing almost synchronized. The inside air was hot and stuffy. The high-pitched buzz of mosquitoes greeted the visitors, prompting Gertrude's husband to take shelter under the mosquito net. With more frequency, Gertrude kept slapping at her legs, exclaiming with a little laugh, *Anpil moustik!* – "so many mosquitoes!" Yulisa drew the blood carefully, placed a drop onto a glass slide for later analysis, and packed up their materials. They told Gertrude they would return to provide treatment if her sample was positive (which it was, so they did). The team exchanged farewells.

Aside from following up with patients for treatment, facilitators like Yulisa are tasked with fostering relationships with *bateyes* to carry out MDA campaigns. Typically, their main point of contact in *bateyes* is at *juntas de vecinos* (neighborhood associations). The relevance of the *juntas* to daily life cannot be understated; as one association president explained:

The community must be *empapada* [literally, "soaked," or here, infused] with the junta and the junta with the community. [...] What we look for is a way for the community to feel more united, that we all need each other.

Similarly, a traditional way in which rural Haitians band together to share tasks is called *tèt ansanm* (Kreyòl for "heads together"). In the DR, Haitian 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 (see Chapter Two). 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 (Stolk et al., 2003). 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 (Baker et al., 2007). 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."

"We are not nationalists," Yulisa says. "We always say it's a problem for the whole island, not just [Haiti]. [...] After all, mosquitoes don't have passports!" Wilson adds, though, that because of migration, "so long as there are cases in Haiti, there will be cases" in the DR.

#### DISCUSSION

While this study was not designed to capture perspectives of residents towards PELF, the findings point to widespread feelings of unimportance that contrast with the elimination program's approach of non-discriminatory access to testing and treatment. The program's success in achieving high MDA participation rates and reducing LF despite this context of social and legal exclusion suggests ways to narrow the gap between human rights obligations and the present reality of violations resulting from the *Sentencia*.

Fundamentally, these findings reflect opposing viewpoints over how people should be recognized 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 (Martínez & Wooding, 2017). This "modernizing" shift in tactics, of course, follows a historical trajectory. In the early 20<sup>th</sup> 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 (Baud, 1992; Fletcher and Miller,

2004). From a historical perspective, the *Sentencia* was but the latest strategy to enlarge the proletarian sub-class (Martínez & Wooding, 2017).

For participants in this study, the *Sentencia* affected not only daily life but also their internalized sense of who they were as people, as *yon moun* (Kreyòl, a person) or *una persona reconocida* (Spanish, a recognized person). This assault on dignity was evident in the comment that it was as though, "the government doesn't even know there are people here"; in the humiliation felt by those without jobs; in the description of those rendered stateless as "dead but alive"; and in the experience of a Dominican-born man singled out to show his passport on a bus. Social exclusion in the DR continues to shape how people see themselves in relation to the government and each other.

Counter-current to this dynamic, PELF, through its operational goal of mass drug administration, qualifies all residents in areas of LF transmission as deserving of attention, regardless of documentation or immigrant status. This approach helps to counteract a major consequence of being undocumented: exclusion from health insurance schemes offered by employers or the government (Amnesty International, 2015). Indeed, as previous field studies have found, persons without identity documents are forced to pay out of pocket or receive less specialized care, even in the public system (see Chapter One; Leventhal, 2013). In their work, Yulisa and others explained that the disease was not isolated to Haiti, nor one brought by Haitians, but one, "for the whole island" to resolve. This global perspective makes everyone responsible for LF. For the PELF team, the causative agent of LF went beyond the parasite, whose edematous effects on the body were depicted on informational posters carried door to door. Rather, LF was cause and consequence of poverty, migration, and disenfranchisement – distal forces, they admitted, that lay beyond the scope of their work.

Operationally, PELF recognized the need to collaborate with *bateyes*. Mobilizing communities entailed acknowledging local authority held by neighborhood associations, support systems that seemed to carry more respect among *batey* residents than the municipal or national government, whose candidates for office were said to make fleeting appearances motivated only by votes. Gaining trust was essential for approaching a population harboring deep skepticism of outsiders, particularly government agencies. Finally, trust and respect could be conveyed in simple interactions between PELF and those they try to reach – such as an unassuming attitude inside a home without a chair. Small gestures indeed, they nonetheless reflect an approach that recasts *batey* residents as participants in their own health, a rebuttal of the, "state politics of abandonment" that diminish their place in society (de la Cadena, 2015, p. xix).

By rejecting a discriminatory approach, PELF acknowledges the right of all *batey* residents to one specific aspect of the right to health – protection from, and treatment for, LF. This process presupposes that the lives of *batey* residents are worth reach-

ing, regardless of whether political or legal circles have declared them illegitimate. Recognition of *batey* residents by PELF contrasts starkly with the *loss* of recognition accumulated over years of discrimination, structural violence, and the recent *Sentencia*. In a way, PELF has found itself in the space between the powerful and the weak, between a political and judicial system that considers *batey* residents as nothing more than cheap laborers, and the residents themselves, whose claims for recognition *as people* are at stake.

A picture of perceived social exclusion in *bateyes* is evident. Yet observations and interviews, as well as epidemiological evidence of reduced LF transmission, reveal features of PELF's successful community engagement that can help to overcome exclusionary experiences: knowledge of the cultural and historical context; legitimation of local political authority; representation of residents in key positions, such as health promoters and medication administrators; use of existing resources at primary care centers; opportunities for residents to voice concerns; and communication between PELF and target communities (Baker et al., 2007; King et al., 2014; Tindana et al., 2007). Respect has for its foundation, "the recognition [...] of certain powers and capabilities" among those to whom it is carried (Nussbaum, 1992, p. 239). In a context where many feel deeply disrespected – if not altogether ignored – such an approach helps to bring human rights ideals somewhat closer to reality.



# Everyday discrimination: results from a nationwide survey<sup>8</sup>

#### **ABSTRACT**

**BACKGROUND** Discrimination is a major driver of health disparities among minority groups and can impede the reach of public health programs. In the Dominican Republic, residents of *bateyes*, or agricultural "company towns," often face barriers to health care. This study examined the extent of perceived discrimination among *batey* populations and places the findings within the context of disease elimination efforts. **METHODS** In March – April 2016, a stratified, multi-stage cluster survey that included the 9-item Everyday Discrimination Scale (EDS) was conducted among residents (n=768) of *bateyes* across the Dominican Republic. Exploratory factor analysis, differential item functioning, and linear and logistic regression were used to assess associations between EDS scores, ethnicity, reasons for discrimination, and health-care-seeking behavior.

**RESULTS** Three ethnic groups were identified in the population: Haitian-born persons (42.5%), Dominican-born persons with Haitian descent (25.5%), and Dominican-born persons without Haitian descent (32.0%). Mean EDS scores (range 0–45) were highest among persons born in Haiti (18.2, 95% confidence interval [CI]=16.4–20.1), followed by persons with Haitian descent (16.5, 95% CI=14.9–18.0), and those without Haitian descent (13.3, 95% CI=12.1–14.5). Higher EDS scores were significantly associated with Haitian birth ( $\beta$ =6.8, 95% CI=4.2 – 9.4; p<0.001) and Haitian descent ( $\beta$ =6.1, 95% CI=3.2 – 9.0; p<0.001). Most respondents (71.5%) had scores high enough to elicit reasons for their discrimination. Regardless of ethnic group, poverty was a common reason for discrimination, but Haitian-born and Haitian-descended people also attributed discrimination to their origin, documentation status, or skin color. EDS scores were not significantly associated with differences in reported careseeking for recent fever ( $\beta$ =1.7, 95% CI= -1.4 – 4.9; p=0.278).

**CONCLUSION** Perceived discrimination is common among *batey* residents of all backgrounds but highest among Haitian-born people. Discrimination did not appear to be a primary barrier to care-seeking, suggesting other explanations for reduced

<sup>8</sup> Originally published as: Keys, H., Noland, G., Beau De Rochars, M., Taylor, T. H. and Blount, S. 2019. "Perceived discrimination in bateyes of the Dominican Republic: results from the Everyday Discrimination Scale and implications for public health programs." BMC Public Health 19, 1513. The text has been lightly edited.

care-seeking among Haitian populations. Public health community engagement strategies should avoid exacerbating stigma, build active participation in programs, and work towards community ownership of disease control and elimination goals.

#### **BACKGROUND**

Perceived discrimination, or perceptions of being treated unfairly among members of minority groups (Pascoe & Smart Richman, 2009), has harmful effects on mental and physical health (Cohen, Janicki-Deverts, & Miller, 2007; Fuller-Rowell, Evans, & Ong, 2012; Kessler, Mickelson, & Williams, 1999; Pascoe & Smart Richman, 2009; Seeman et al., 2004; Williams et al., 2008; Williams & Mohammed, 2009) and can impede the reach of public health programs (Chen & Yang, 2014; Smith & Whittaker, 2014; Van Brakel, 2006; Van Brakel et al., 2019; Weiss, 2008). Conceptually, the terms perceived discrimination and discriminatory experiences refer to the perspectives and experiences of stigmatized groups – those marked by some disqualifying attribute (Goffman, 1963; Link & Phelan, 2001. While stigma conjures individual-level attributes or "marks," discrimination and its cognates recall "the producers of rejection and exclusion" (Link & Phelan, 2001, p. 366) – that is, the structural context in which the stigmatized live (Jones, 2000; National Research Council, 2004). As commonly understood, a deeply discrediting attribute, such as race, ethnicity, or sexual orientation, feeds an ideology that construes members with that attribute as inherently inferior or as a threat to the dominant group (Goffman, 1963).

From a practical standpoint, studies of perceived discrimination can also inform public health programs that seek to collaborate with disadvantaged social groups. Community engagement refers to the broad set of practices that establish and maintain the human relationships within a public health program, including community members, public health practitioners, outside investigators, and funders (King et al., 2014; Lavery, 2018). Crucial to any public health program's success is active community participation, which community engagement strategies try to foster (Whittaker & Smith, 2015). Thus, an understanding of perceived discrimination can inform engagement strategies seeking to reach stigmatized groups who may harbor feelings of disempowerment or suspicion towards outsiders.

Hispaniola, shared by the Dominican Republic (pop. 10.6 million) and Haiti (pop. 10.8 million) (World Bank, 2016), is the only remaining malaria-endemic island in the Caribbean and the site of over 95% of lymphatic filariasis (LF) cases in the Western hemisphere (WHO, 2012). Both countries have committed to elimination of these mosquito-borne, parasitic diseases, though Haiti bears the greater burden of both diseases. More than 17,000 cases of malaria were reported annually in Haiti from 2013-2016, compared to less than 1,000 cases annually in the Dominican Republic (WHO, 2017b). Active LF transmission was identified in 88% of Haiti's communes (districts) and the entire country's population is considered at-risk and in need of mass drug administration (Beau De Rochars et al., 2004). In the Dominican Republic, LF was restricted to three geographic foci – a small urban focus in the capital Santo Domingo and two larger foci in agricultural areas of the Southwest and the East (Noland, Blount, & Gonzalez, 2015). Given the higher prevalence of both diseases in Haiti and generally porous border that separates the two countries, it is often assumed that labor migration from Haiti promotes disease transmission in the Dominican Republic (Herrera et al., 2015).

To explore prevalence of malaria and LF in the Dominican Republic, a 2016 nationwide, cross-sectional survey was conducted in Dominican *bateyes*, or agricultural shantytowns reliant on migrant labor from Haiti (Keys et al., 2019). Since the late 19<sup>th</sup> century, imported labor from Haiti has been integral to the Dominican economy (Baud, 1992; Martinez, 1999). Migrant workers settled in *bateyes*, settlement villages adjacent to sugar cane and other plantations throughout the Dominican Republic (Martinez, 1999). Haitian migrants and their descendants have contended with a history of discriminatory practices in the Dominican Republic rooted in legacies of race, class, and nationality (San Miguel, 2005; Torres-Saillant, 1998). In 2013, the Dominican Constitutional Court issued a verdict, colloquially known as *La Sentencia* (the Sentence), which stripped the right to citizenship of thousands of Dominican-born persons who are primarily of Haitian descent (Hintzen, 2014; IACHR, 2015). Lacking documents restricts access to healthcare, education, and job mobility in the country (IACHR, 2015).

The goal of this study was to measure perceived discrimination among *batey* residents, elicit reasons for discriminatory experiences, and determine whether perceived discrimination was associated with different ethnic groups using the Everyday Discrimination Scale (EDS), a common measure of perceived discrimination (Williams et al., 1997). The EDS displays good reliability (consistency in how people respond to EDS questions) and validity (that it truly measures an underlying discrimination construct) across diverse populations (Clark, Coleman, & Novak, 2004; Joy Pérez, Fortuna, & Alegría, 2008; Kim, Sellbom, & Ford, 2014; Kriegeret al., 2005; Lewis et al., 2012; Paradies, 2006; Williams et al., 2008). This study was nested within the investigation of malaria and LF prevalence in *bateyes* (Keys et al., 2019). While

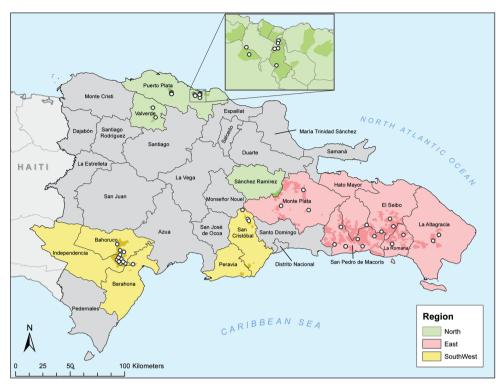
none (0%) of the *batey* study participants were positive for malaria or LF parasites, Haitian-born individuals more frequently reported recent fever and lower levels of care-seeking for the fever compared to Dominican-born *batey* residents (Keys et al., 2019). It was hypothesized that the main ethnic groups inhabiting *bateyes* (Haitian-born, Haitian-descended, and non-Haitian-descended people) would all endorse discriminatory experiences but vary in their explanations for them. For example, people with Haitian ancestry were predicted to attribute discriminatory experiences to their nationality or undocumented status. Furthermore, it was thought that perceived discrimination would be associated with reduced care-seeking behavior, particularly among the Haitian-born population. Exploring perceptions and explanations of discrimination can inform public health interventions that seek to reduce barriers to care and generate community-wide support for health programs (Cook et al., 2014). Therefore, the practical contribution of this study is to provide a descriptive profile of perceived discrimination in this context and recommendations for public health-oriented community engagement.

#### **METHODS**

#### Survey design

This study uses data from a nationwide, cross-sectional, multi-stage cluster survey of malaria and LF prevalence among *batey* residents conducted from March – April 2016 near the end of the sugar-cane harvest (*zafra*) (Keys et al., 2019). The survey was sponsored by The Carter Center, a US-based not-for-profit health and human rights non-governmental organization, and conducted in collaboration with the Dominican Ministry of Health's national center for control of tropical diseases (Spanish acronym, CENCET).

To generate representative disease prevalence estimates from each of the extant agricultural regions in the Dominican Republic, the survey defined three strata: Southwest, East, and North (Figure 1). Using lists of *bateyes* obtained from a nation-wide *batey* census done in 2012 as a sampling frame (Rodriguez, 2012), a total of 51 clusters (*bateyes*), 17 in each stratum, were selected using systematic (interval) selection from a random start with probability of selection proportional to population size. In each selected cluster, 15 households were systematically selected from a random start using sketch maps prepared by survey teams prior to sampling. For the disease prevalence survey, the target sample size of 482 persons per strata, or 2 persons per household, was sufficient to detect a prevalence of malaria and LF of 5% with absolute precision of ±2.5% at the 95% two-sided significance level with a design effect of 1.5 and a 10% non-response rate. Field teams were comprised of Haitian-born, bilingual (Haitian Kreyòl, Spanish) interviewers.



**Figure 1.** Map illustrating sampled *bateyes* (open circles) in the three geographic strata of *bateyes* in the Dominican Republic. Map prepared by Eric Griggs and The Carter Center.

#### Data collection

At each household, self-identified adult (age  $\geq$  18 years) heads-of-household or his/her spouse were informed about the survey and asked to participate in a household questionnaire. The questionnaire included relevant demographic variables (age, gender, country of birth, language of survey administration, residency status, documentation status, and occupation). Ethnicity was self-reported and based on birth location: 1) Haitian-born; 2) Dominican-born with Haitian descent; and 3) Dominican-born without Haitian descent. The questionnaire also explored recent illness and fever, with follow-up questions for care-seeking. Primary results from these modules, along with parasite diagnostic testing of blood samples collected from the questionnaire respondent and one other randomly selected household member of any age, are reported elsewhere (Keys et al., 2019). However, participation in the diagnostic module was not a requirement for participation in the household questionnaire and *vice versa* – i.e. selected participants could decline either of the two survey components.

The household questionnaire included the original nine-item Everyday Discrimination Scale (EDS) (Williams et al., 1997). The EDS elicits responses based on a Likert format to chronic or episodic discriminatory experiences that are essentially

minor, followed by suggested reasons for those experiences, such as ancestry, gender, or religion (Krieger et al., 2005). Answering "A few times" or more to any of the nine EDS items triggered a separate module at the end of the EDS, in which potential reasons for the experience(s) were provided and the participant was asked to what degree the reason accounted for the experience(s). Each given reason was preceded by the question, "Considering everything we just talked about, for those things that happened at least a few times or more, how much does it have to do with [reason]?" The reasons were provided in order of their presumed increasing sensitivity: 1) Poverty or economic problems; 2) Health problems; 3) Lack of education; 4) Language problems (trouble speaking Spanish); 5) Documentation problems; 6) Skin color; and 7) Origin, which was explained to participants as "your country of birth" or "where you are from." These reasons were selected a priori based on previous ethnographic fieldwork (see Chapters One and Five) and literature review of Haitian-Dominican relations and the political history of bateyes. A 4-point Likert scale was provided for each given reason (with "Don't know" coded as zero), where 1=No, [reason] has nothing to do with it; 2=Yes, a little; 3=Yes, a lot; and 4=Yes, very much so.

All survey questions were first translated from English to Spanish and Haitian Kreyòl and discussed in team meetings with native speakers of both languages. Then, the questionnaire was piloted to ensure comprehension and comfort. Survey questions were then back-translated by people not affiliated with the study to compare to the original English. Data were collected electronically using hand-held tablet computers running custom data collection software (Eagle Survey, The Carter Center).

#### **Analysis**

Only questionnaires with completed EDS modules, regardless of participation in the parasite diagnostic module, were included for analysis here. Descriptive statistics were calculated for bivariate associations between demographic factors and ethnic groups. Categorical variables were tested for independence using the adjusted Wald test (Lipsitz et al., 2015). Following previous convention (Krieger et al., 2005; Williams et al., 2008; Williams et al., 1997), an EDS total score was obtained by summation of responses to the nine items, with higher scores indicating more frequent experiences of perceived discrimination. First, mean scores for each EDS item were stratified by ethnic group. Next, mean EDS total scores were compared between relevant groups based on background variables: ethnic groups, demographics, and care-seeking for recent fever. Cronbach's alpha (a), a measure of internal consistency ranging from 0 to 1 with higher values indicating that survey items reliably measure the same underlying construct (Tavakol & Dennick, 2011), was also obtained within each ethnic group and ranged from 0.81-0.83.

After calculating descriptive statistics of the EDS, exploratory factor analysis (EFA) was conducted to determine dimensionality of the EDS. EFA was performed

for each ethnic group to assess whether the nine EDS items represent a single, latent construct or multiple constructs (or "factors"). EFA was based on polychoric correlation matrices, which have been shown to be more appropriate for creating common factor models originally based on categorical variables (Holgado-Tello et al., 2010). The factor loadings of each item were rotated to better interpret how strongly each EDS item is correlated with the underlying factor (Schmitt, 2011). EFA strongly suggested that the EDS captured a single, latent construct. Within each ethnic group, the eigenvalue of the first factor was high while the remaining eigenvalues for subsequent factors were all less than 1. Factor loadings of EDS items ranged from 0.44-0.85 across groups, except for the item "Less courtesy" among Dominican-born persons with Haitian descent (0.26).

Following EFA, the EDS was tested for differential item functioning (DIF) using the Mantel-Haenszel approach. Aside from determining if the EDS measures the same latent construct(s) across different groups, it is necessary to assess whether members of each group have equal probabilities of responding similarly to each survey item, after matching to members of a reference group based on EDS total score. There is potential for measurement bias when members of one group appear to respond differently (have a higher or lower probability of responding a certain way) to an item after matching to members of the reference group, which can lead to inflated scores compared to other groups and incorrect inferences about group differences (Stucky et al., 2011). Separate DIF analyses were undertaken for Haitian-born and Dominican-born persons with Haitian descent compared to Dominican-born persons without Haitian descent (reference group). A final DIF analysis was done in which responses from Dominican-born persons without Haitian descent were compared to both Haitianborn and Haitian-descended people (a combined reference group). Cole's criterion recommends considering DIF when the odds ratio (OR) of responding to a given item is >2.0 or <0.5 (Cole et al., 2000).

Next, linear regression analyses were done of the following independent variables to assess their significance in predicting EDS total score: age, gender, permanent residency, being documented, completing the survey in Spanish, being employed, seeking care for recent fever, and a categorical variable *Origin* where Haitian-born=2, Dominican-born with Haitian descent=1, and Dominican-born without Haitian descent=0 (reference group). After univariate analyses, significant (p<0.05) variables were then included as covariates in a multivariable linear regression model with EDS total score as the outcome. An interaction term was also included for *Origin* and *Completed the survey in Spanish* to account for its strong pairwise correlation (r=-0.81, p<0.001).

To explore relationships between each of the 7 potential reasons for discriminatory experiences and each of the 9 EDS items across ethnic groups, a series of 2x2 tables were made based on case-exposure pairs (n=63 pairs for each ethnic group).

The goal of this stage of analysis was to assess whether there were significant differences in the odds ratios across ethnic groups when members of a group endorsed an EDS item occurring at least "A few times" or more ("exposure") and attributing a given reason as having "A lot" or "Very much" to do with that EDS item ("case"). Responses to each reason were re-coded as a binary outcome ("case") where 1= [reason] has "A lot" or "Very much" to do with the EDS item and 0 = "A little," "Nothing to do with it" or "Don't know." Similarly, each EDS item was re-coded as a binary predictor ("exposure") where 1= [EDS item] was said to happen "A few times" or more and 0= "Almost never", "Never," or "Don't know." Logistic models were then made for each case-exposure pair of reason and EDS item, stratified by ethnic group. Significant differences in odds ratios were based on the Breslow-Day statistic, which tests for homogeneity of odds ratios across stratified groups (Breslow & Day, 1980).

All statistical analyses were done in Stata v.14.2 (STATA Corp., 2015). Population estimates, 95% confidence intervals (CI), and linear and logistic regressions were calculated using Stata's *svy* routine with sampling weights to account for sampling weights, clustering effects, and stratification. Polychoric matrices for EFA were made using the user-written Stata command *polychoric* and assessment of DIF was done using the *difmh* command. *P*-values less than 0.05 were considered statistically significant.

#### **RESULTS**

A total of 780 individuals participated in the household survey. The majority identified as the head-of-household (84.3%). A response rate could not be calculated because field personnel did not record rejection or absenteeism. Excluding individuals with missing EDS responses, a total of 768 completed questionnaires were included in the final analysis.

# **Demographics**

Table 1 summarizes population estimates of demographic characteristics, stratified by ethnic group. Haitian-born persons comprised 42.5% of the *batey* population, Dominican-born persons with Haitian descent 25.5%, and Dominican-born persons without Haitian descent 32.0%. There were significant differences in the composition of ethnic groups within each stratum: most Haitian-born persons were in the East (51.1%), most of those with Haitian descent were in the Southwest (50.3%), and most Dominican-born without Haitian descent were in the North (62%) (p<0.001).

**TABLE 1:** Characteristics of *batey* residents stratified by ethnic group, Dominican Republic, 2016, (n=768; population-level estimates shown).

Characteristic	Haitian-born	Dominican-born, Haitian descent	Dominican-born, no Haitian descent	p adj. Wald test*
% (95% CI)	42.5% (32.0 – 53.7)	25.5% (21.3 – 30.1)	32.0% (21.8 – 44.4)	
Region Southwest North East	18.7 (12.2 - 27.4) 24.4 (10.1 - 48.2) 51.1 (37.6 - 64.5)	50.3 (36.0 - 64.5) 13.6 (7.4 - 23.6) 23.1 (19.4 - 27.2)	31.1 (17.9 – 48.3) 62.0 (34.9 – 83.3) 25.8 (15.5 – 39.8)	<0.001*
Age in years, mean (SE)	43.7 (2.5)	41.3 (1.6)	50.0 (2.5)	0.024*
Female	39.2 (29.0 – 50.5)	68.8 (59.3 – 77.0)	62.6 52.3 – 71.8)	0.001*
Completed survey in Spanish	3.6 (1.3 – 9.4)	34.5 (24.8 – 45.8)	97.7 93.6 – 99.2)	<0.001*
Documented	73.2" (64.4 – 80.6)	85.8 (74.3 – 92.7)	99.5 (96.9 – 99.9)	<0.001*
Permanent resident	76.8" (67.8 – 83.9)	85.9" (79.2 – 90.6)	95.2 (90.9 – 97.5)	0.011*
Unemployed	27.1 (19.1 – 37.1)	39.0 (28.2 – 51.0)	46.5 (39.7 – 53.4)	0.001*

Abbreviation: CI – confidence interval; SE = standard error

There were fewer female Haitian-born residents (39.2%) compared to the other two groups (p=0.001), suggesting an active male-dominated migrant workforce. Unsurprisingly, most (96.4%) Haitian-born residents undertook the survey in Kreyòl, whereas 34.5% of Dominican-born with Haitian descent and 97.7% of those without Haitian descent completed the survey in Spanish (p<0.001). Third, most residents reported having some form of official documentation, though proportions were significantly different across ethnic groups: 73.2% of Haitian-born were documented, compared to 85.8% of Dominican-born with Haitian descent and 99.5% of Dominican-born without Haitian descent (p<0.001). Fourth, most of those living in *bateyes* were permanent residents (having spent at least 9 consecutive months in the *batey* at any point since the year 2013), with an upward trend in permanent residency across Haitian-born (76.8%), Dominican-born with Haitian descent (85.9%), and

<sup>\*</sup> Indicates statistically significant (p<0.05)

<sup>&</sup>quot; Missing=1

Dominican-born without Haitian descent (95.2%) (p=0.011). Finally, proportionally more Dominican-born persons without Haitian descent were unemployed (46.5%) compared to Dominican-born with Haitian descent (39.0%) and Haitian-born persons (27.1%) (p=0.001).

#### **EDS** characteristics

Table 2 displays total mean scores and mean scores of each EDS item, stratified by ethnic group. Total mean EDS scores were highest among Haitian-born persons (18.2) followed by Dominican-born with Haitian-descent (16.5) and lastly Dominican-born without Haitian descent (13.3) (p<0.001). Seven of the nine individual EDS items were significantly different across groups, with Haitian-born individuals tending to have higher mean scores followed by persons of Haitian descent and lastly those without Haitian descent. Mean scores of two EDS items were not significantly different across groups: "Not smart" and "Act afraid."

TABLE 2: Mean scores of Everyday Discrimination Scale (EDS) items, stratified by ethnic group, Dominican Republic, 2016 (n=768; population-level estimates shown).

	Haitian-born	Dominican-born, Haitian descent	Dominican-born, no Haitian descent	p adj. Wald test*
9-item EDS <sup>a</sup> , mean (95%CI) Cronbach's alpha, EDS	18.2 (16.4-20.1) 0.83	16.5 (14.9-18.0) 0.81	13.3 (12.1-14.5) 0.82	<0.001*
EDS item <sup>b</sup> , mean (95% CI) Haitian Kreyòl translation Spanish translation				
People treat you with less courtesy than others Moun yo bay'w mwens atensyon (afeksyon) ke sa yo bay yon lòt moun. Se siente usted tratada con menos cortesía en comparación con otras personas.	2.02 (1.88-2.17)	1.79 (1.57-2.01)	1.47 (1.29-1.65)	<0.001*
People treat you with less respect than others Moun yo bay'w mwens respe ke sa yo bay yon lòt moun. Las gentes le brindan menos respeto en comparación con otras personas.	2.23 (1.96-2.49)	2.17 (1.93-2.42)	1.66 (1.43-1.89)	<0.001*
You receive poorer service than other people in stores, bodegas, markets, or in the street Nan boutik, magazen, mache, bodega, oubyen nan lari, yo trete'w pi mal ke lòt moun. En las tiendas, almacenes, mercado, bodegas, o en la calle, le tratan con peor servicio que los demás.	1.94 (1.70-2.17)	1.51 (1.26-1.75)	1.31 (1.18-1.44)	<0.001*
People act as if they think you are not smart Moun yo kompote yo kom si yo kwe ou pa entelijan. La gente se comporta como si usted no fuera una persona inteligente.	1.95 (1.72-2.17)	1.57 (1.30-1.83)	1.55 (1.34-1.76)	0.088
People act as if they are afraid of you Moun yo kompote yo kom si yo pè'w. La gente se comporta con miedo hacia usted.	1.48 (1.32-1.64)	1.53 (1.25-1.81)	1.26 (1.08-1.45)	0.138
People act as if they think you are dishonest and do not trust you  Moun yo panse ke ou pa onèt ou byen kom si yo pa fe'w konfyans.  La gente se comporta como si usted fuera deshonesto/a y no le tienen confianza.	1.61 (1.31-1.91)	1.61 (1.37-1.85)	1.22 (1.13-1.32)	0.007*
People act as if they're better than you Moun yo kompote yo kom si yo panse yo pi bon pase ou. La gente se comporta como si fueran mejor que usted.	2.74 (2.37-3.12)	2.69 (2.43-2.96)	2.0 (1.59-2.38)	0.013*
People call you names or make fun of you Moun yo moke ou ou byen bay ou vye nom. La gente se burla de usted.	2.08 (1.74-2.42)	1.85 (1.58-2.12)	1.43 (1.20-1.66)	0.017*
You feel threatened by other people Moun yo konn menase ou. Se siente amenazado/a por otras personas.	2.19 (1.87-2.51)	1.75 (1.42-2.08)	1.36 (1.19-1.54)	0.001*

a Range=0-45; higher scores indicate higher reports of everyday discrimination.

b Range=0-5; higher scores indicate greater frequency of EDS item. Abbreviation: EDS – Everyday Discrimination Scale; CI – confidence interval.

<sup>\*</sup> Indicates statistically significant (p<0.05).

The differential item functioning (DIF) analysis revealed two EDS items with meaningful DIF: "Not smart" and "You feel threatened." The odds of answering "A few times" or more to "People act like you are not smart" were higher among Dominicanborn without Haitian descent (p=0.016) compared to both Haitian-born and Haitian-descended people. Conversely, the odds of answering "A few times" or more to the item "You feel threatened" was significantly higher among Haitian-born residents (p=0.001) compared to Dominican-born persons without Haitian descent, with a similar but not statistically significant trend (p=0.096) observed for Dominican-born individuals with Haitian descent. The remaining seven EDS items were not significant in DIF analyses, indicating that irrespective of ethnic group status, those items elicited similar responses among participants matched on EDS total score.

# EDS: linear regression analysis

Univariate linear regression sought to identify independent variables associated with EDS total score. Male gender, being employed, Haitian birth, and Haitian descent were all significantly associated with higher EDS total scores (Table 3). Conversely, completing the survey in Spanish was significantly associated with a lower EDS total score. Age, permanent residency, being documented, and seeking care for recent fever were not significantly associated with EDS total score.

**TABLE 3:** Univariate linear regression of total EDS score, Dominican Republic, 2016 (n=768).

Variable	ß	SE	95% CI	р
Age	0.03	0.02	-0.1-0.1	0.196
Male	1.8	0.7	0.4–3.2	0.012*
Permanent resident	-1.0	1.6	-4.3-2.3	0.551
Documented	-1.2	1.0	-3.2-0.8	0.221
Completed survey in Spanish	-4.2	1.1	-6.42.0	<0.001*
Employed	1.7	0.7	0.2–3.2	0.027*
[If had fever in previous 2 weeks]: Sought care for fever	1.7	1.6	-1.4-4.9	0.278
<b>Origin</b> <sup>a</sup> Dominican-born, Haitian descent Haitian birth	3.2 5.0	1.0 1.2	1.2–5.3 2.6–7.3	0.003* <0.001*

a Reference group: Dominican-born, no Haitian descent.

Abbreviations: SE-standard error; CI-confidence interval.

<sup>\*</sup> Indicates statistically significant (p<0.05).

Independent variables found to be significant in the univariate analysis were then used to fit a multivariable linear regression model of EDS total score (Table 4). The overall regression model was significant (p<0.001). Adjusting for other variables in the model, those born in the Dominican Republic with Haitian descent had a 6.1-point increase in their EDS scores (95% Cl= 3.2-9.0; p<0.001) and Haitian-born persons had a 6.8-point increase (95% Cl=4.2-9.4; p<0.001). Furthermore, Dominican-born persons with Haitian descent who completed the survey in Spanish had a -4.5-point decrease in EDS total score (95% Cl: -8.4--0.7; p=0.022). All other covariates were not significantly associated with EDS total score after adjusting for other variables in the model.

**TABLE 4:** Multivariable linear regression of total EDS score, Dominican Republic, 2016 (n=768).

Variable	Model significance: p<0.001			
	ß	SE	95% CI	р
<b>Origin</b> <sup>a</sup> Dominican-born, Haitian descent Haitian birth	6.1 6.8	1.4 1.3	3.2–9.0 4.2–9.4	<0.001* <0.001*
Completed survey in Spanish	2.1	1.2	-0.4-4.6	0.097
Origin*Completed survey in Spanish Haitian descent * Spanish Haitian-born * Spanish	-4.5 -4.7	1.9 2.9	-8.40.7 -10.7-1.2	0.022* 0.116
Male	0.8	0.7	-0.7–2.2	0.313
Employed	0.8	0.8	-0.8–2.3	0.308

a Reference group: Dominican-born, no Haitian descent.

Abbreviations: SE-standard error; CI-confidence interval.

# Reasons for EDS experiences

Most individuals (71.5%) were found to experience any EDS item at least "A few times" or more. This occurred most frequently among Haitian-born residents (81.7%) and Dominican-born of Haitian descent (76.2%), but also among more than half (54.4%) of those born in the Dominican Republic without Haitian descent (p=0.005). Among those who answered "A few times" or more to any EDS item, significant differences between ethnic groups were noted in the mean scores of the seven given reasons for EDS experiences (Table 5). First, mean scores of "Health problems" as a reason for any EDS item were not significantly different across groups (p=0.115); given that mean scores for this reason were low compared to mean scores of other reasons, all groups seemed to agree that "Health problems" were not particularly explanatory

<sup>\*</sup> Indicates statistically significant (p<0.05).

for discriminatory experiences. However, "Poverty/economic problems" seemed to be especially meaningful in explaining why EDS experiences were said to occur: within each ethnic group, mean scores of "Poverty/economic problems" were greater than all other reasons, although significant differences were noted across ethnic groups (p<0.001). Certain reasons appeared relevant for Haitian-born and Dominican-born persons with Haitian descent. For example, mean scores of "Documentation problems" were 1.98 among Haitian-born persons and 1.32 among Haitian-descended people, yet 1.03 among persons without Haitian descent (p<0.001). "Skin color" was another reason with notable differences across groups: among Haitian-born persons, mean score was 2.27 and 1.92 among Haitian-descended people, compared to 1.32 among those without Haitian descent (p<0.001). The reasons that appear more relevant for Dominican-born people without Haitian descent were "Poverty/economic problems" and "Lack of education."

**TABLE 5:** Degree to which reasons account for EDS experiences, Dominican Republic, 2016 (n=431; population-level estimates shown).

	Haitian-born	Dominican- born, Haitian descent	Dominican- born, no Haitian descent	p adj. Wald
Score above threshold to elicit reasons	81.7%	76.2%	54.4%	0.005*
Given reason, mean (95%Cl); range 0-4				
Poverty/economic problems	2.89 (2.68-3.12)	2.47 (2.20-2.74)	2.12 (1.82-2.41)	<0.001*
Health problems	1.43 (1.27-1.59)	1.17 (0.97-1.37)	1.46 (1.25-1.67)	0.115
Lack of education	2.26 (2.07-2.45)	1.78 (1.50-2.07)	1.55 (1.25-1.85)	<0.001*
Problems speaking Spanish	1.77 (1.50-2.03)	1.24 (1.05-1.43)	1.26 (1.13-1.39)	<0.001*
Documentation problems	1.98 (1.60-2.37)	1.32 (1.15-1.50)	1.03 (0.96-1.10)	<0.001*
Skin color	2.27 (2.10-2.44)	1.92 (1.68-2.15)	1.32 (1.11-1.52)	<0.001*
Origin	2.58 (2.34-2.81)	1.58 (1.38-1.78)	1.15 (1.02-1.28)	<0.001*

<sup>\*</sup> Indicates statistically significant (p<0.05). Abbreviations: Cl-confidence interval.

Breslow-Day tests of homogeneity predicted the odds of a reason having "A lot" or "Very much" to do with an EDS item occurring at least "A few times" or more. Of all the pairings between each EDS item and each given reason (n=63 pairs for each ethnic group), only 2 item-reason pairs were significant: the odds of endorsing poverty as having "A lot" or "Very much" to do with being treated with less respect were approximately 5 times higher among both Haitian-born (OR=4.5; 95% Cl=2.2 – 9.1) and Dominican-born persons with Haitian descent (OR=5.1; 95% Cl=2.3 – 11.3) (p=0.021). Second, Dominican-born persons with Haitian descent were 5.7 times more likely (95% Cl=1.3 – 33.7) to attribute being called names or insulted to documentation problems (p=0.029).

#### DISCUSSION

Most people living in *bateyes* of the Dominican Republic are permanent residents, rather than migrants, and appear to regularly experience some form of interpersonal discrimination that they interpret as a result of poverty. Haitian birth and Haitian descent were strongly associated with high EDS scores; in addition to poverty, members of those ethnic groups also linked discrimination to their origin, documentation status, or skin color. EDS scores were not significantly associated with care-seeking for recent fever, nor were discriminatory experiences understood to occur because of health problems or disease.

As anticipated, perceived discrimination was highest among persons of Haitian ancestry - including both Haitian-born and Haitian-descended people born in the Dominican Republic. In contrast to those born in the Dominican Republic without Haitian descent – whose interpersonal experiences may be subtle, such as being treated as though they are not smart - Haitian-born and Haitian-descended people appear to experience more overt forms of discrimination, like feeling threatened or being called names. Additionally, Haitian-born and Haitian-descended people attributed discriminatory experiences to individual-level "marks" that have been historically denigrated in Dominican society: skin color and origin (Torres-Saillant, 1998). Interestingly, poverty and documentation problems were linked to specific EDS experiences (being treated with less respect and being called names, respectively). Poverty likely serves as an index of social status and may be seen as a failure to meet social expectations (Williams, 2009). That Dominican-born persons with Haitian descent were more likely to attribute being called names to their documentation problems potentially indicates how institutional decisions like the 2013 Sentencia, which disproportionately affected this group by taking away their right to citizenship (IACHR, 2015), plays out in daily life. At the same time, it is notable that Spanish language capacity appeared to have a protective effect against perceived discrimination among members of this group; it is likely that linguistic differences also signal in- and outgroup status.

Persons born in the Dominican Republic without Haitian descent also linked poverty and interpersonal discrimination. There are some possible explanations for this finding. First, data from the linked head-of-household survey found that unemployment was highest among Dominican-born without Haitian descent (46.5%) (Keys et al., 2019). In the context of EDS module, "Lack of education" was the second highest reason for discrimination (after "Poverty/economic problems") for that ethnic group, while those without Haitian ancestry were twice as likely to endorse the EDS item "People act like you are not smart" even after matching to Haitian-born and Dominican-born, Haitian-descended people based on EDS total score. These findings suggest that in bateyes, Dominican-born persons without Haitian descent link their discriminatory experiences to having little economic or educational opportunities and possibly feeling shut out from a job market that prefers imported, Haitian labor. Aside from dynamics of labor migration from Haiti, it is also possible that economies in and around bateyes simply rely on a younger workforce, as the mean age of Dominican-born participants without Haitian descent was greater than Haitian-born and Haitian-descended people. Still, poverty itself seems to be stigmatizing for all those living in bateyes. In-depth, qualitative investigations could help tease apart how reasons for stigma (poverty, lack of education, skin color, or origin) are understood among batey residents.

Distinctions of economic position, documentation status, language skills, or ethnic origin constitute symbolic marks that shape a sense of place of both self and others (Bourdieu, 1989). While these marks provide substance for cognitive and evaluative beliefs about social positions, they result from material and social processes (Bourgois, 1988): economic exploitation as well as historical ideologies of race and nationality help to reinforce social hierarchies that can be both objectively differentiated (whether by income, language capacity, documentation status, or origin) as well as – and perhaps more importantly – perceived by those in a local world, "those agents who possess the code, the classificatory schemes necessary to understand their social meaning" (Bourdieu, 1989, p. 19). These classificatory schemes can be subtle or misrecognized (Link & Phelan, 2014). Given the history of anti-haitianismo (anti-Haitianism) in the Dominican Republic (Paulino, 2006), it may seem obvious that Haitian-born and Dominican-born, Haitian-descended people might suffer more interpersonal discrimination compared to Dominican-born persons without Haitian descent. Still, it is striking that so many - within all ethnic groups - linked their experiences to economic precariousness. Poverty, and class struggle more broadly, may figure into experiences and interpretations of everyday discrimination more so than such marks as skin color or Haitian origin per se. Of course, these elements can and do layer upon each other, or "conjugate," to compound the suffering of those who may bear more than one mark alone (Bourgois, 1988).

# Implications for community engagement and disease elimination

This study found high levels of perceived discrimination among Haitian-born individuals, who have historically been implicated in malaria and LF transmission in the Dominican Republic (Herrera et al., 2015; Vincent et al., 1981). However, the linked epidemiological survey did not detect any malaria or LF parasite-positive individuals (Keys et al., 2019). The apparent interruption of transmission in *bateyes* possibly reflects effective active surveillance for malaria and successful community engagement for LF (Baker et al., 2007; see Chapter Six), which must continue until islandwide elimination is achieved. While perceived discrimination itself did not appear to be significantly associated with reduced care-seeking, the discriminatory experiences endorsed by *batey* residents point to an overall sense of disempowerment as well as structural obstacles, especially poverty, that challenge active community participation and ownership of disease elimination goals.

Given higher prevalence of vector-borne disease in Haiti and history of discrimination against this population in Dominican society, public health programs that explicitly link the Haitian-born population to vector-borne disease can exacerbate stigma and blame (see Chapter Five; Smith & Whittaker, 2014). Most participants in this survey did not attribute their discriminatory experiences to health conditions, however, and malaria itself is rarely stigmatizing. Still, linking a specific disease to a particular ethnic or social group, no matter how implicitly, can fray social relations in a community (Nations & Monte, 1996). For example, as cholera spread from Haiti to the Dominican Republic, public health messages that emphasized individual-level, preventative behaviors were incorporated into narratives that ignored structural problems of healthcare access and sanitation coverage and instead cast Haitians as directly responsible for the epidemic (see Chapter Five).

A more positive example comes from the country's LF elimination program, which has fostered active participation in elimination activities by expressly avoiding the issue as one caused by Haitian migrants but rather one of collective responsibility (see previous chapter). It is important for any elimination message to emphasize the structural backdrop against which disease occurs, in addition to individual-level, preventative behaviors. While encouraging people to use bed nets, reduce mosquito habitats, and seek care for fever, for example, it will be just as helpful to develop messages that draw on themes of community cooperation. One approach to developing an appropriate public health discourse surrounding malaria and LF would be to collaborate with the communities themselves, which are frequently accustomed to external agencies and organizations initiating health projects. As one study in Haiti demonstrated, even misuse of certain terminology for program participation and purpose can have unintended consequences (Bardosh et al., 2017). Community dialogue, rather than top-down, educative "talks," can allow community members to have more active roles in shaping health messages (Briggs & Nichter, 2009).

This study also sheds additional light onto the complex entanglement of poverty, perceived discrimination, and risk for disease. It is easily understood that poverty is bad for health, but narrowly focusing on material deprivation (such as lack of clean water or mosquito nets) to control infectious disease has its shortcomings (Marmot, 2005). The cumulative effect of perceived discrimination, social exclusion, and psychological distress contributes to a chronically activated stress response that leaves the body more vulnerable to disease (Cohen et al., 2007; Fuller-Rowell, Doan, & Eccles, 2012; McEwen, 1998). Stigma-related stress also harms self-esteem and leads to feelings of disempowerment and loss of control in one's life (Major et al., 2007; Meyer, Schwartz, & Frost, 2008; Simbayi et al., 2007).

While perceived discrimination was not significantly associated with care-seeking in this study, it was still intimately related to economic hardship. These relationships among poverty, discrimination, and the likely toll on one's sense of control in life are relevant for disease programs. For example, in the prevalence survey, the most commonly endorsed reason for not seeking care for fever was that, "The illness was not serious enough" (Keys et al., 2019). In the early course of a febrile illness like malaria or LF, more pressing needs – such as economic demands – likely lead people to defer care. This is especially true in low-transmission settings, where the rarity of the disease can lead people to deprioritize treatment and prevention (Whittaker & Smith, 2015). Compounding matters, previous studies with this population have found an internalized sense of devaluation as well as feeling unable to change life's circumstances (see Chapters One and Five). Such "hidden distress" can in turn limit the degree to which people participate in, and ultimately take ownership of, a community health program (Smith & Whittaker, 2014; Weiss, 2008, p. 3). Public health programs can too easily conceptualize people as individual agents with control in their lives; based on these and other findings, eliminating malaria and LF will require more than simply encouraging people to seek care when ill.

As such, community engagement strategies should strive to align the goal of elimination with the day-to-day concerns of community members. A starting point would be to elicit the community's concerns and identify how malaria and LF elimination activities may (however partially) overlap with them. For example, generating interest and participation in community-level surveillance, or strengthening human relationships between communities and the health system, would all help to build resilience and human capacity in the face of more engrained problems of poverty and discrimination. Community-level workshops between health program staff and community members could incorporate cross-cutting interventions to reduce stigma and perceived discrimination, such as peer counseling, skills building, self-help groups, and microcredit instruments, all of which can positively impact health (Van Brakel et al., 2019).

Finally, malaria and LF elimination activities could be part of a larger, community-driven push for human rights, including the right to health and basic services

(Atkinson et al., 2011). Again, the country's LF elimination program is an example of how, despite decades of increasingly hostile immigration and citizenship restrictions, significant progress was made in reducing LF in *bateyes* (see previous chapter). This success has been attributed to an approach that favored going through local authority structures (*juntas de vecinos*, or neighborhood associations) and building on existing resources – mainly, local volunteers recruited from within *bateyes*. Such an approach could be considered in remaining areas of malaria transmission.

#### LIMITATIONS

There are important limitations to this study. First, while the EDS has been adapted for use in cross-cultural contexts (Krieger et al., 2005; Williams et al., 2008), it was originally developed among African-Americans in the United States (Williams et al., 1997). Consequently, the interpersonal experiences comprising EDS survey items were developed within a specific cultural milieu and may not fully capture experiences of those living in bateves of the Dominican Republic. While exploratory factor analysis of the EDS in this study revealed a unidimensional construct, more indepth, qualitative research could explore other discriminatory experiences relevant to the lives of batey residents. Furthermore, the two EDS items displaying differential functioning ("People act like you are not smart" and "You feel threatened") may have introduced measurement bias to inflate scores among Dominican-born without Haitian descent and Haitian-born and Haitian-descended individuals, respectively. These items deserve ethnographic exploration to ascertain why members of certain ethnic groups appear to more readily endorse those items even after matching to members of a reference group. Additionally, qualitative research could help to tease out the specific circumstances under which EDS experiences occur.

Because the survey was conducted in two languages (Spanish, Haitian Kreyòl), there is the potential for measurement bias in how certain questions were asked in their respective languages. While the survey team contacted participants on weekend evenings (when most residents were said to be home), some residents were no doubt missed, potentially introducing additional bias. The study relied on *a priori* reasons for discrimination based on the authors' previous fieldwork in this context and literature review. However, there could be additional reasons for discriminatory experiences that were missed by the study. Although consistent with previous studies (Williams et al., 2008; Williams et al., 1997), this study converted Likert responses into a summed, continuous outcome variable (EDS total score). Summation of Likert responses into a presumably continuous variable assumes that the categories of the response (never, almost never, a few times, etc.) are equally distant from each other regardless of item. Despite this limitation, conversion of responses to EDS items into

a continuous outcome variable was justifiable for several reasons. Within each ethnic group, the 9-item EDS displayed high internal consistency, uni-dimensionality, and near-normal distribution statistics: for Haitian-born, EDS total score skewness=1.1, kurtosis=4.2; for Dominican-born with Haitian descent skewness=1.4, kurtosis=5.4; for Dominican-born without Haitian descent, skewness=2.0, kurtosis=8.2 (skewness >2 or kurtosis >7 elicit concern for violation; see Curran, West, & Finch, 1996), supporting the assumption that a summed, continuous outcome provided a reasonable measure of perceived discrimination.

#### **CONCLUSION**

Perceived discrimination, a social stressor with adverse physical and mental health effects, is commonly experienced among residents of *bateyes* in the Dominican Republic. Haitian ancestry was significantly associated with higher levels of perceived discrimination. Participants tended to link discrimination to markers of inequality, such as poverty, skin color, documentation status, lack of education, and ethnic origin. The stigma of poverty appears to affect the lives of many, regardless of ethnic group. While there is little to no active transmission of malaria and LF in *bateyes* and perceived discrimination *per se* does not appear to impede care-seeking, active community participation will be essential for ongoing surveillance and elimination efforts. Consequently, community engagement strategies can draw on these findings to contextualize disease elimination goals with people's everyday concerns.

#### LIST OF ABBREVIATIONS

Confidence interval (CI)
Differential item functioning (DIF)
Everyday Discrimination Scale (EDS)
Exploratory factor analysis (EFA)
Lymphatic filariasis (LF)
Odds ratio (OR)

#### **DECLARATIONS**

# Ethics approval and consent to participate

The overall survey was approved by the Dominican Consejo Nacional de Bioetica en Salud (CONABIOS), the Ethical Review Board of the University of Amsterdam, and

considered a non-research public health activity by Emory University Institutional Review Board. All participants gave verbal informed consent in the language of their choice. This method for consenting to participate was approved by all ethics committees that reviewed the study protocol.

#### Consent for publication

Not applicable.

#### Availability of data and material

The dataset used and analyzed in this study is available from the corresponding author on reasonable request.

#### **Competing Interests**

The authors declare that they have no competing interests.

## **Funding**

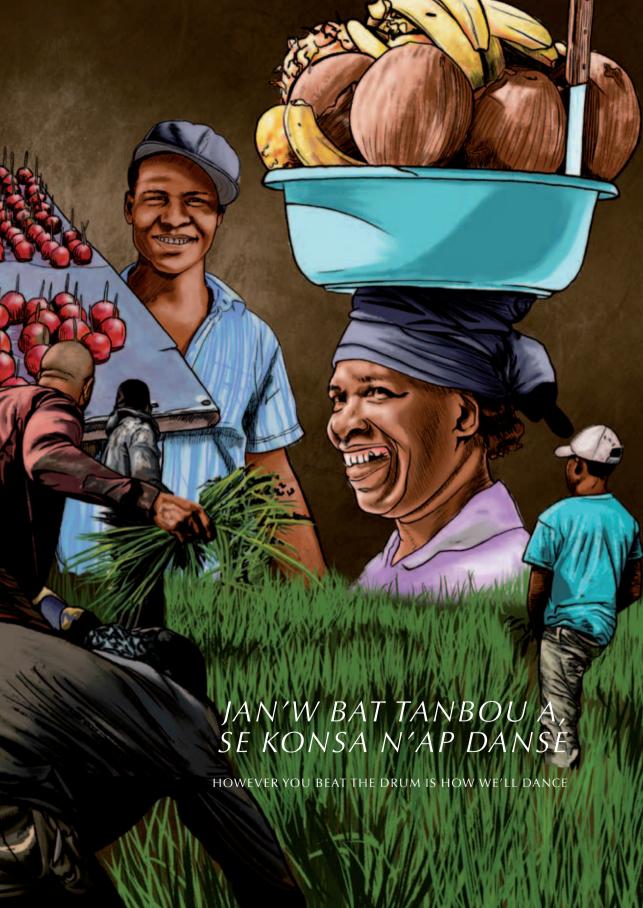
All field activities were financially supported by The Carter Center. Portions of this work were supported by a Research Talent Award funded by the Netherlands Organization for Scientific Research to HK, and a PAHO/TDR Small Grant Programme grant (number SCON2016-02343) to GSN. The funders had no role in the design, analysis or interpretation of the study or its results.

#### Authors' contributions

HK designed the study, supervised the survey team, analyzed the data, and drafted the manuscript. GN contributed to the study design, assisted with data analysis, and helped write the manuscript. MBR assisted with field activities. TT helped analyze the data. SB contributed to the study design. MG supervised field activities. All authors read and approved the final version of the manuscript.

# Acknowledgments

The authors thank the field personnel involved in data collection and Mr. Eric Griggs for assistance producing the map. In particular, HK thanks Prof. Max Petzold for his feedback on an earlier version of this manuscript. Most importantly, the authors thank the *batey* residents who gave their time to participate in this survey.



# Conclusion

The collection of articles assembled in this dissertation have sought to account for ways in which people in the Dominican Republic perceive discrimination, interpret and assign meaning to discriminatory experiences, and suffer bodily and psychosocial harm. These were the fundamental lines of inquiry that tied together these research projects. Put simply, I asked: What is the burden of perceived discrimination among the Haitian migrant and Haitian-descended minority? How is discrimination said to occur, and why? How do these findings fit into broader systems of power and history? And what are implications for public health programs?

Below their surface, however, the articles tell another story, one of personal and intellectual growth. I came to the Dominican Republic for the first time as a nursing student in 2011, a year after spending a summer in Haiti. I knew next to nothing about the Caribbean, had never visited either country beforehand, spoke very little Spanish or Haitian Kreyòl, and certainly lacked research experience. Despite this, from the very beginning, I felt pulled to understand the experience of Haitian migrants in the country. This feeling went beyond scientific curiosity and was inspired by my growing awareness of social justice and structural violence.

Over time, the research questions and various projects evolved. Field experiences, research findings, and the iterative process answered some questions while leading to yet still more. As the body of research grew, I, too, developed a stronger sense of my own positionality. I learned – and am still learning – how to account for the "data misfits," the observational surprises that catch the researcher off-guard (Timmermans & Tavory, 2012). Being open to these puzzles, and being honest with how you process them, is part of the learning curve. For me, another source of this "positional reckoning" also came from the diverse ways in which I was involved in this research over the years. I went from nursing student to technical advisor to doctoral student in anthropology; each of these roles had their own institutional affiliations and carried their own sets of expectations and dynamics that filtered into how I saw myself, interacted with others, and interpreted and disseminated the research findings. Life in the Dominican Republic challenged and humbled me. This "imagined island" was one of history and struggle but also one of community and strength, all there to be appreciated and accounted for.

Before closing this dissertation, I recall three examples of how this process unfolded, of seeing myself and life around me differently. Below, I reconstruct each memory based on field notes and reflections recorded at the time.

## Joseph and Elie, Haiti

In the summer of 2010, I befriended a family in the small village of Casse, in Haiti's rugged Central Plateau. Joseph was in his sixties, and like most men in the area, he devoted his life to "working the earth," or as they say in Kreyòl, *travay late*. He spent the evenings lying in his hammock, resting after a long day's work. He saw me passing by once, and yelled *Blanco!* with a grin, hardly any teeth left in his mouth. I stepped into his family's little *lakou*, or courtyard, and shook his calloused hand. *Nou la, nou la!* – we're here, we're here! he grinned, shaking my hand with enthusiasm, using that quintessential Haitian greeting that perfectly encapsulates the character of people in Haiti: that against all the odds, we exist.<sup>9</sup>

I grew close to this family during these informal visits outside my research. I had never traveled in "developing countries" before, let alone one that, just months earlier, experienced a horrific disaster that killed over 200,000 people. Through our research on mental health, people shared their own stories of the earthquake, the details of which come back to me in devastating, vivid fragments: as he searched for relatives amidst the rubble and chaos, a man smeared toothpaste under his nose because of the overpowering smell of bodies; that the shaking of the earthquake caused a bus driver to lose control and run over people on a sidewalk. And in the mountains far away from Port-au-Prince, at that precise moment on January 12, a Haitian nurse was sitting in a canoe, crossing a river to make medical rounds in a village, when the river eerily changed course and fish leapt out of the water.

These stories touched a nerve, but so, too, did the everyday conversations I had with people. There was a bluntness in explaining life's circumstances. *Lavi di*, life is hard, or *lavi che*, life is expensive, as if the very act of living had to be paid for, day in and day out. That some ate only the mangoes they could find on the ground. That some drank only the water that trickled through fields. The torrent of emotions that coursed through me found some expression in a line from Neruda. The insanity of pain and violence in Haiti made me want to sound an alarm, as Neruda said, "like a belfry in the hands of a madman."

But I came to discover a softer side to life, too. That day, when Joseph called me over, I offered to help shell peanuts, which involved a hand-powered grinder. Nearly everything in rural Haiti is done by hand. In short time, my hands were red

<sup>9</sup> Edwidge Danticat, "We Are Ugly, But We Are Here" (The Caribbean Writer, Volume 10, 1996).

and blistered from cranking the handle. Elie, Joseph's wife, took my hands in hers and teased me. "Come inside!" she said, *ou met chità* – please sit. Like most other homes in the area, theirs had a dirt floor. While I had been "busy" shelling peanuts, Elie's daughter had laid out a spotless, embroidered tablecloth on which they set ceramic dishware; we would be eating together. I was struck by contrasts: the dirt floors and worn, wooden planks; chickens and goats for slaughter; smoke drifting from cooking fires; hungry, plaintive facial expressions; the heavy feeling that life is, indeed, hard. But also the bright whiteness of the handmade tablecloth; the peals of laughter among family members; the cold nectarine drink Joseph offered me; the carrots, tomatoes and sauces neatly arranged on plates; the cool, clean water to wash our hands; the pride in showing me an old, tattered copy of Stendhal's *The Red and the Black* – likely the only book this family owned, aside from their Bible. How the evening sunlight filtered through cracks in the walls. A gentle breeze. The hymn they sang before eating.

Earlier, when Joseph invited me to enter their *lakou*, Elie was busy with a large metal basin at her feet. She was gutting the fish we would eat later, tossing the entrails to a lingering kitten. She rubbed lemons into the fish and then soaked the fish in the basin's clear water. *Blan!* she smiled at me, "white guy! Next time you come to Haiti, will you bring your parents? They are welcome here!" Joseph got out of his hammock, took a seat across from us, and pulled out a tin can of snuff. He took a big pinch and snorted. I must have looked surprised. His eyes sparkling, he gave me a look, wiped his nose, and laughed. He pointed at his family's house. *Se yon kay malere!* he cried – it's the home of wretched people! and again a hearty laugh. Elie looked up from her fish. "Hunter, you won't forget about us, will you?"

# Maritza, Dominican Republic

This raw, indigestible feeling sinks inside you – what do you think you really know about this place? This time anyway, you came here to "get away" from things and "try to write some articles." That morning, you slaved away (and would later keep slaving away) for four hours, only to come up with two paragraphs. You decide to take a break. Since you never really take breaks, you tote along Hoetink's *Two Variants in Caribbean Race Relations* as suitable "beach reading" and head down to Playa Los Mino, the public beach where local families gather.

There she is – Maritza, the woman you chatted with briefly on the bus on the way here from Santo Domingo. You sit nearby on a log under a tree, feeling like an idiot with your towel and sunscreen and book. Nonetheless, you somehow manage to articulate decent enough Spanish. She invites you over to her friends. Why not? One is a lady from Cotuí, only here for the day to visit friends; another is her brother, Leo, a surfer, wiry and chiseled, in sunglasses. He epitomizes cool. A few others – acquaintances who seem to come and go. "Acquaintances" isn't the right word – maybe *familiares*. There's an uncle, a brother-in-law, a cousin, a girlfriend,

even Maritza's mother. They all float in and out. You take a liking to the older uncle – white T-shirt and jeans, wrinkles under his eyes. He teaches you an expression that goes something like "every rooster his chickens," to reference the seemingly common situation in which a man sires multiple children with different women.

Leo sits shirtless and plays songs off his cell phone. He's dragged this big plastic sea kayak over. "Take it out if you want!" Maritza encourages you. You're awfully quiet, you think to yourself. Maritza seems to read your mind: "Jonter, di algo!" – Hunter, say something, she says. Your tongue feels thick and useless. Her brother tells you that he teaches surfing at Playa Hermosa. He even used to compete internationally. Only because it's relevant to your own obsessions, and maybe because you need to hear yourself talk, you somehow get on to American politics and Trump. Maritza recites being held for four hours in a New York City airport without any given reason. Leo stands up to go over to the seafood shack. You don't understand exactly what he (or really, anyone) says, but you gather that it has something to do with punching Trump in the face. You laugh at this. The weight of feeling awkward comes over you. Why? Because you're getting to know them, and you realize how far you have to go.

Your Hoetink book is sitting on the table, looking wildly out of place. "What's this about?" asks the lady from Cotuí, tapping the book with her finger. "Race in the Caribbean," you reply, realizing, as you say the word *raza*, that you've never once heard anyone actually say that word out loud in any of your time in this country since you started coming here in 2010.

"What do you do?" asks Maritza.

"Public health, but it has more to do with history and social relations between Haiti and the Dominican Republic," you hear yourself drone on.

"A mi no me importa..." she starts off, not to say that she doesn't care about what you study, but that she doesn't care about color or race and all the other baggage such topics unload.

Then what? You feel it's best to leave, for now, anyway. It's better that way. "I need to work some," you try to explain. If it strikes any of them as weird, they don't let it show. You walk back to the hotel, to your room with the balcony that overlooks the water. You feel a little better now. Later, from the terrace, you look down towards the beach and the sparkling water. Your eyes find Maritza, this time in the kayak with a little girl – maybe a *sobrina* or a friend's daughter – paddling around together, the sun dappling off the surface of the waves in the late afternoon. You can tell they're happy, even from way up here.

# Osner, Dominican Republic

We were driving out of Santo Domingo back to Barahona, to spend the next few days re-visiting *bateyes* to map them and possibly pilot-test the survey, time permitting. The windows of the government pick-up truck were rolled down. From his front pas-

senger seat, Osner turned back to me and said, "The A.C. broke some time ago, and we haven't been able to fix it." The traffic getting out of Santo Domingo was insanely congested – it was literally the word Osner used to describe it – *congestionado*. We were at a stand-still.

While stuck in traffic, a man came over to us, asking for money, his clothes ragged. "C'mon papa," he pleaded, looking across the driver to Osner, who simply stared straight ahead. The man seemed to recognize some authority presence in Osner, as if it would be up to him. Or maybe he figured his best chance was by asking Osner, sensing his generosity. Osner, as usual, just looked tired. He has worked for the tropical disease control agency for decades, in the slow work of trying to eliminate lymphatic filariasis, that persistent mosquito-borne disease present on the island since the slave trade. At times, when faced with budget shortfalls, he pays the employees he supervises out of his own pocket. His grey hair, bags under his eyes, and stubble attest to all that.

He reached up onto the dashboard where a few peso coins were stashed, and handed them over. *Gracias*, and the man walked off.

Finally, we were on the highway, heading west. Osner started to sing. The windows were down and the car radio was playing songs off Osner's USB stick he had put in the audio system. All love ballads, no Dominican bachata or merengue. José José from Mexico, Elio Roca from Argentina, "Te pido taaaantoo…" he sang. At first, I thought his singing would be the quiet kind that people softly exhale when in company, but instead, Osner kept going, really getting louder at certain points, and he was really on key. The driver didn't react at all, as though he was used to this. It turns out Osner sang as a boy in church.

"How did you learn to speak such good English?" I asked in Spanish. Most of our conversations are nearly all in Spanish, but he does speak good English.

"I spent one year in the United States, when I was 10 or 11 years old, living in Jersey City," he said. It reminded me of Junot Diaz, the Dominican-American writer, and his stories.

"Have you heard of Junot Diaz? Writes a lot about Dominican immigrants in that area." He hadn't, so I told him that I would try to find him one of his books.

Then I felt this spark, some kind of entry to start talking about a specific topic I've struggled with. I've been wondering how to broach the topic of "Haitian-Dominican relations" since coming here. I don't want to open it up that way, as "Haitian-Dominican relations." I'm trying to see how it comes out on its own – how do people here talk about what I think are "Haitian-Dominican relations?"

"You know Junot Diaz won one of the highest awards in the Dominican Republic," I said, "the Order of Citizen's Merit. But once he criticized the Dominican *Sentencia* in 2013, the government took it away from him." I left it there, figuring this was an easy enough way to see how Osner might consider talking about these things.

Eso fue un abuso – this was an abuse, said Osner, referring to the Sentencia, his eyes still ahead, watching the road. "And governments can be stupid the world over. Unfortunately, there's no higher court than that one, and they were manipulated."

"Who were?"

"The judges, by the politicians. Politicians have never been to the *bateyes*. If they did, they'd see that *los dos pueblos* – both people – can live together. That's where there's proof we co-exist." He went on to recount how politicians use the same recycled trope – that Haitians are invading the country – and how it's used to the advantage of those who profit off cheap, undocumented labor. *Es un abuso*.

The sun was setting and we were nearing Barahona by now. The landscape had changed to hillsides with scrub brush, reminding me of parts of the American West – arid, with a desert sunset. At a red light, shoeshine kids were trying to hitch a ride. Their dark skin was, as people say here, *moreno*; perhaps they were descended from Haitian parents, if not born in Haiti. After all, Haiti is only an hour and a half's drive from here. Coming to the Dominican Republic to try your luck shining other people's shoes, even as a grade-schooler, is one way to *chache lavi*, "to look for life," to find a way.

They wanted a ride. Osner told the driver to pull over on the side of the road. They didn't realize it at first, that we had stopped for them. I guess they didn't expect us to. One of them noticed, motioned to the rest of his friends, *Hey, they stopped for us*, and they ran over, all smiles, climbing in. We pulled off. One of the kids looked through the rear window, into the cab where we were sitting. We made eye contact and he gave me a big smile. There was only glass between us but we were a world apart, him in a tank top, his buddy holding onto his shoulder, telling him a story, their feet in flip-flops propped up on the spare tire in the bed of the pick-up truck, their little wooden crates with shoe polish and rags by their sides. I wondered what they were talking about.

A few miles down the road, once we were in town, they slapped the roof of the cab, the signal. The driver pulled over. One of the kids ran over to the passenger-side window to thank us. *Que vaya bien*, said Osner. May you, or it, go well.

# Perceived discrimination and stigma in the Dominican Republic

In their own way, experiences like these shook the foundations on which I stood. These internal puzzles arose from trying to absorb life's details through the filter of my own framework. The challenge, as always, was to adjust the framework. In Haiti, the poverty, struggle, and survival were omnipresent and confronting; but so, too, was strength, humility, and warmth like that of Joseph's family. Both dimensions had to be accounted for. At times, waves of self-doubt would occasionally sweep over me after seemingly mundane conversations. As soon as my understanding of things seemed to crystallize, yet another interaction or observation, ever so brief or routine, humbled

me. In the pick-up truck that evening, I was struck by so many juxtapositions: a rickety pick-up truck, endlessly crossing the country in the work of eliminating a neglected tropical disease, and how, through Osner, it was transformed into a source of generosity, no matter how small, for the man begging for change or the children needing a lift. Osner's singing, his indifference to an out-of-touch political class, and the joy of those kids for whom life was surely difficult carried a complicated mixture of pain, humor, and insight.

Recalling these unexpected encounters in the field helps to contextualize one of the most surprising and crucial findings to emerge in this work: the ways in which people actually talked about discrimination. There is a vast, far-reaching literature on discrimination and stigma, but their literal translation into Spanish or Kreyòl usually met befuddled looks. Like that day on the beach, when I realized how disconnected the word *raza* (race) seemed, there were other repertoires of language to discover, of ways people talked about and made sense of their lives.

Their vocabulary invoked a concreteness to life's experiences, usually turning on verbs in which something hurtful was done to someone else: they don't want to see us (yo pa vle we nou); they ignore me (no me hace caso); they humiliate us (yo imilye nou). Even a single, straightforward term in Kreyòl subsumed the complexity of poverty, class struggle, and their historical roots: lamize, or quite literally, misery. Metaphors of smallness communicated dynamics of power and privilege: us little miserable ones (ti malere nou ye); the people at the top (la gente de arriba); big men, or important and politically connected people (gwò nèg, alguien grande). And what was at stake in these social interactions and positions? A sense of self-worth, for one: we have no value (nou pa gen vale); the yearning to be recognized (reconocido); a dignified life, one in which being a person (yon moun) meant more than toiling away in dirty work (travay mikwòb); to work together in forms of mutual aid and support (tèt ansanm); in short, the "desire to be recognized as socially ratified persons" (Willen, 2012, p. 819). Following his work in Dominican bateyes, Samuel Martínez noted that "images of the country's origins are not held apart in a category called 'history' but are encoded in everyday talk" including certain idioms, proverbs, and gestures (Martinez, 1997, p. 228). The same may be said about discrimination or stigma. Rather than hanging "out there" as constructs, they are enacted, felt, and communicated through everyday social cues.

The Kreyòl idiom *imilyasyon* (humiliation) conveyed this feeling of exclusion, or of being "othered" (Grove & Zwi, 2006). Following our work on mental health in Haiti, where we uncovered idioms of distress related to mental health (Keys et al., 2012), *imilyasyon* in the neighboring Dominican Republic seemed to encompass broader aspects of life there: it signaled distress not only about the self but also about relationships with others and one's place in the world (Hinton & Lewis-Fernández, 2010; Kohrt & Hruschka, 2010). Idioms like "they don't see us," "we have no worth,"

and "they humiliate us" describe conflict at both interpersonal and societal levels: embedded in each idiom is the contrast between an "us" and a "them," one group marked with difference and held in low regard, the other more powerful, holding the power to see or recognize the other. Clearly, there are strong emotional currents that flow through these idioms, emotions that "affect the way in which the body, illness, and pain are experienced and are projected in images of the well or poorly functioning social body and body politic" (Scheper-Hughes & Lock, 1987, p. 28). Exploring the use of these idioms and their emotional valence helps to deconstruct the individual, social, and political body; *imilyasyon* speaks not only of the suffering individual but also the public stage of morality and ideology upon which that individual stands, or tries to stand.

In <u>Chapter Five</u>, we saw how the spread of cholera from Haiti to the Dominican Republic aligned with preexisting tropes about Haiti and Haitians: that Haiti was a culturally backwards country whose people were unable to care for themselves. Cholera, it seemed, had deepened rifts between Haitian and Dominican community members with repercussions for social support systems, which <u>Chapter Two</u> explored. In that study, certain idioms and terminology were insightful for understanding social support or lack thereof. For example, when we collected free-list responses to create a functional impairment survey (Bolton & Tang, 2002), a common response to the question, "What do you do to take care of your community?" was *viv trankil* – or, "live peacefully." This reply can be seen to emanate from a deep desire to avoid conflict with neighbors (both Haitian and Dominican) and Dominican authorities. Perhaps it is unsurprising that higher anxiety scores were associated with past interrogation or deportation, or from knowing another migrant who had had either of those two experiences.

"To live in peace" as a means to care for one's community also related to the goal of organizing mutual aid like *tèt ansanm* ("heads together"), which was found to be largely absent. This lack of cooperation may be due to the ways in which each group perceived each other: while some Haitians expressed the desire to work with their Dominican neighbors, they were also mistrustful, if not fearful. Meanwhile, Dominicans referenced "cultural differences" as not only barriers to mutual understanding but also as the very cause of the problems at hand. For example, a major finding from Chapter Five was the difference in where blame lay for cholera's spread. For their part, Haitian migrants framed cholera in more structural terms: lack of sanitation, hygiene, and public health outreach. Dominicans rarely, if ever, put forward blatantly racist explanations for the epidemic. Instead, ignorance, uncleanliness, and danger were rooted in the catch-all yet slippery term *culture*. "They have a much lower culture," said one man in reference to the Haitians living nearby; "they don't know how to take care of themselves," said one nurse in a rural clinic. In this way, the highly charged label of racism – of linking inferiority to biological difference –

could be more easily denied while still invoking difference (only now, via culture; see Kendi, 2019) to explain the uneven distribution of disease.

These explanations must be seen as part of prevailing value systems and ideologies, which are always rooted in history. The Dominican Republic declared independence from Haiti, rather than its colonial motherland, Spain; since its inception, the country's national identity has stood in opposition to Haiti, or what is imagined to be Haitian. Part of that imaginary is the idea of modernizing progress against a backwater tide, of instilling values of regularization and rationality into the body politic. This was evident, for example, in anti-vagrancy laws, tax collection, and centralizing state authority in the country's early days to ongoing debates on citizenship and bureaucracies of legal documents (Martínez & Wooding, 2017; Mayes, 2014). At the time of our study on cholera (2012), the Dominican Director of Migration justified more strict legalization requirements because of the "chaos of the labor market," a chaos that the country's political and economic elite have encouraged and profited from since the modernizing project began. As one informant in Chapter Six remarked, the oft-coveted cédula, or official identity card, was once mass-issued to batey residents so that they could vote in an upcoming election for the ruling political party; after the election, the *cédulas* were declared invalid. The self-fulfilling prophecy marches on.

Idioms of distress like *imilyasyon* bring into relief the individual-social-political axes along which they travel. They provide clues into the local worlds where discrimination and stigma take place. But like all idioms, they are ambiguous and shift in meaning, depending on use and context. For example, while imilyasyon was linked to present-day misfortune in the Dominican Republic, its use and significance in Haiti may be quite different. To gain a more complete picture, I coupled ethnographic exploration of idioms to traditional epidemiological methods. The article comprising Chapter Seven addressed a core issue raised above: how to account for an abstract construct like perceived discrimination, where such constructs are not understood as such? Both Chapters One and Seven used cross-sectional surveys that incorporated various questions about feeling mistreated by others. Chapter One was the first foray into operationalizing a variable about perceived mistreatment, which was endorsed by 30% of the sample and was significantly associated with worse depression symptoms. Furthermore, mean scores on the adapted Beck Depression Inventory was 27.1 – in range for clinical depression – and 30% higher than the average depression score among rural Haitians across the border (Wagenaar et al., 2012). Finally, 69% endorsed feelings of worthlessness.

But that quantitative survey, I knew, nicked only the surface. More details emerged from the study in <u>Chapter Seven</u>, based on a nationwide, representative survey of nearly 800 adults living in *bateyes*. This survey included the Everyday Discrimination Scale, a well-known measure of nine "everyday" experiences of perceived discrimination, ranging from feeling as though one is treated with less courtesy

or respect to feeling threatened or harassed (Williams et al., 1997). Of particular interest was to compare discrimination scores among all residents of *bateyes* – Haitian-born migrants (42.5% of the total *batey* population), Dominican-born persons with Haitian descent (25.5%), and Dominican-born persons without Haitian descent (32%). Reporting more frequent discriminatory experiences resulted in higher total scores.

As we found, the scale suggested that all members of the study population understood the scale items similarly, regardless of the language in which the survey was administered (Spanish or Kreyòl). Furthermore, based on factor analysis, the scale measured a single, underlying construct. Confirming our hypotheses, those with the highest discrimination scores were Haitian-born migrants (average total score, 18.2 out of maximum 45 points), followed by those with Haitian descent (16.5) and lastly those without Haitian descent (13.3). These differences were statistically significant. Based on regression models, ethnic origin was still associated with higher reports of discrimination after controlling for age, gender, residency (migrant or not), documentation status, Spanish language, and being employed. Persons born in Haiti or in the Dominican Republic with Haitian descent *still* had significantly higher discrimination scores compared to those without Haitian descent.

These findings provide a quantitative rendering of what has been elaborated at length in the literature about the Haitian minority in the Dominican Republic. "Origin," "skin color" and "documentation problems" were cited as reasons for discriminatory experiences by Haitian-born or Dominican-born, Haitian-descended individuals far more so than those without Haitian descent. Yet the perspective of this latter group – those without Haitian descent, or the so-called "dominant group" – cannot be ignored. More than half (54.4%) of those without Haitian descent still admitted to experiencing some form of interpersonal discrimination at least "a few times" or more in their daily lives, usually citing their poverty or lack of education as reasons for being discriminated against. In fact, poverty was the most commonly cited reason for discrimination for all three groups. The enmeshment of race and class in this context was partially revealed in some of the qualitative findings from the study in Chapter One, in which Haitian migrants described feeling discriminated against by poor Dominicans. In marginalized places like bateyes and other areas, poor and disenfranchised Dominicans may view Haitian migrants as a threat to economic security.

We are left, then, with the sense that anti-Haitian discrimination is indeed a distinct and pervasive experience in the Dominican Republic, where the history of *anti-haitianismo* is inscribed into present-day social conditions and interactions. Such history shapes how people understand themselves and others (Bourdieu, 1989). However, while these studies share many commonalities, each study location and population varied, affecting the generalizability of findings. For example, unlike the studies in <u>Chapters 1-5</u>, which were based in and around a large city, those compris-

ing <u>Chapters 6-7</u> were based in *bateyes*, geographically distinct communities with their own complicated histories (Martinez, 1995). Furthermore, <u>Chapter Seven</u> is based on a nationally representative sample of *batey* residents. The spatial and geographic differences of the studies in this dissertation range from densely-crowded, urban neighborhoods to isolated, rural *bateyes*. These spatial and economic differences across the study sites likely figure into both the *patterns* of racial and social inequalities found there and how people *understand* those patterns, whether through a Haitian-Dominican binary or another cognitive filter (Neely & Samura, 2011).

In sum, discrimination and stigma are a part of life in the country, especially for those of Haitian origin, and are understood to result from class struggle in addition to race or nationality (Williams, 2009). However, rather than debating which construct holds more explanatory power, class, race, or nationality can instead be seen as dynamic processes that interact together (Bourgois, 1988). Contemporary forms of oppression and exploitation are really an expression of the "violence of history," in which the past – from the near-total extinction of an indigenous population, the birth of a nation in opposition to its "blacker" neighbor, to racial capitalism – manifests in everyday inequalities, health disparities, and the ways people try to make sense of their world (Fassin, 2009).

# Evolution of a research question

The seven published works contained in this dissertation each examined, in their own way, perceived discrimination in the Dominican Republic. Each is an example of applied anthropology, in which anthropological theories and methodologies informed the various public health projects that called on them. Each study also reflects the professional role and institutional affiliation I had at the time, whether nursing student, technical consultant to a non-governmental organization, or doctoral candidate in medical anthropology. When I undertook the first study in 2011, I did not expect the others to follow, much less that they would be submitted together as a dissertation nine years later. Consequently, I cannot claim to have conceptualized a single, overarching research question about perceived discrimination from the very beginning. Rather, my research interests in discrimination and stigma, and their relationships to health, evolved iteratively over time based on my own educational training, professional role, and collaborations, friendships, and field experiences.

Early on, I was captivated by the literature on the Haitian migrant population in the country and historical legacy of colonialism. Rather quickly, I realized that this was a deeply complicated picture, yet also one in which the persistence of racism and economic exploitation were obvious. My "deep dive" into medical anthropology came about through work in Haiti and mental health. I knew enough to be open to the possibility that mental health among Haitian migrants in the Dominican Republic

would have some relationship (or association, in statistical terms) with discrimination and stigma. Of course, I gradually clarified concepts like *discrimination* and *stigma* over time, with more field experience and literature review.

It did not take long to appreciate the centrality of discrimination in the lives of Haitians in the country. A distinct memory from that first field project in 2011 was the late nights I spent reading the hand-written notes of field assistants, themselves Haitian-born and living in the Dominican Republic. As part of their work, the assistants conducted cognitive interviews after administering the Kreyòl version of the Beck Depression and Anxiety Inventories. Among respondents who reported a high burden of certain symptoms (such as feeling worthless, for example), assistants then asked, "Why did you give that answer?" thereby allowing the respondent to speak openly about their reasoning behind each answer. The assistant then jotted down key words and phrases used by the respondent.

I remember some of the notes written in the margins of those paper surveys: "because I'm not in my country;" "because Dominicans do not want to see us;" "because Haitians have no worth here." During that same project, I also interviewed people like Sylvie, the woman quoted at the beginning of this dissertation. Her indignation was palpable; I distinctly remember her saying that Dominicans treated her "like a little toy." It was clear to me, within the first few weeks in the field, that perceived discrimination would have an important role in these explanations of depression and anxiety.

Thus, Chapters 1-5 came out of my background in cross-cultural mental health research and from my growing awareness of discrimination and how people talked about it. As a nursing student at the time, I worked closely with mentors in the clinical sciences (nursing and psychiatry); consequently, we framed the findings based on their implications for meeting the mental health needs of this population. At the same time, the various projects and their lines of inquiry were also shaped by concurrent events on the island. Cholera was introduced to Haiti by a United Nations peacekeeping force less than a year after the 2010 earthquake (Transnational Development Clinic, 2013); in short time, it spread into the Dominican Republic (Tappero & Tauxe, 2011). I returned to the Dominican Republic in 2012 to explore the impacts of cholera on the psychosocial health of Haitians in the country. I was particularly motivated to build on the finding of imilyasyon picked up in the previous year's study. There appeared to be a more acute layer of experience to *imilyasyon* in the wake of cholera, "the disease par excellence of social inequality" (Briggs, 2001, p. 676)□7\*. The article in Chapter Five arose out of this sense of urgency to better understand the psychosocial effects of cholera and contextualize the findings within the historical legacy of anti-haitianismo and theoretical frameworks of stigma (Yang et al., 2007).

Additional events over the period 2013-2015 also shaped the way my research focus evolved. During this time, the Dominican Constitutional Court issued La

Sentencia (the Sentence), which effectively stripped upwards of 200,000 mostly Haitian-descended, Dominican-born persons of their citizenship (IACHR, 2015). At the time, I was nearing the end of my Masters program. Shortly after graduation, I was recruited as a technical consultant for The Carter Center, a health and human rights non-governmental organization working on malaria and lymphatic filariasis elimination in both Haiti and Dominican Republic. In this role, I drew on the usual suite of epidemiological methods: creating a survey questionnaire, developing a sampling strategy, training a local field team, measuring disease prevalence, and computing statistical outcomes. At the same time, I also included a qualitative component to this nationwide survey in *bateyes* to explore the tensions between the goals of disease elimination and human rights violations. Lastly, the article in <u>Chapter Seven</u> also came about through this same professional affiliation with The Carter Center. Thus, these studies were housed within – and *supported by* – larger institutional initiatives focused on disease elimination, initiatives that kept a clear eye on implications for health interventions.

The final word about how my research interests in discrimination evolved must go to the many conversations, interactions (no matter how brief), and friendships I had in the field among the large cast of people who had a hand in the articles shared here. I worked with Haitian and Dominican friends, research assistants, colleagues, and mentors. Fundamental to social science research is the iterative cycle among members of the research team, who, in this case, had a range of life histories, nationalities, educational backgrounds, and personal opinions. Certain interactions come to mind that illustrate the inherent messiness in dealing with sensitive research findings and the process of molding them into something so deceptively tidy as a published article.

For example, at the close of each of the projects in 2011-2012, our team of researchers shared preliminary findings with hospital staff at the nearby public hospital, whose director had been gracious enough to allow us to interview patients and staff. I recall those presentations in the hospital conference room, the windows open to let the hot afternoon air escape. Members of the hospital staff, mostly nurses, filed in, took seats, and politely listened to this group of American graduate students share findings about how Haitians in the surrounding area felt discriminated against – including by clinical providers like those in attendance. At the close of those presentations, I recall a few heated exchanges as audience members clamored to interject.

A central line to their argument was that these were *perceptions*, not necessarily reality, and that they, as healthcare providers, never discriminated against their patients. I would hear the same argument again from Dominican public health and clinical professionals, following the publication in Spanish of an editorial, coauthored with Haitian and Dominican colleagues, in the *Pan-American Journal of Public Health* (Keys et al., 2014). A few years later, I shared the findings from the Everyday Discrimination Scale described in <u>Chapter Seven</u> at The Carter Center's

annual Hispaniola Program Review. In attendance were The Carter Center's executive leadership as well as delegates from the Haitian and Dominican Ministries of Health. I remember a prominent Dominican executive who did not necessarily question the findings but nonetheless pushed back, saying that the disease elimination program did not discriminate against Haitians. As they did each time before, remarks such as these struck me; the findings were interpreted as an indictment of the clinical care provided for this population. No matter how careful I may have been to present the findings, the audience, or individual listener, would sometimes react strongly, seeming to deflect the core message.

The way in which these interactions occurred also depended on context. The instances recounted above took place in highly formal settings. In essence, there was some degree of public performance, implicating, perhaps, the need to save face. Sometimes, I asked myself: how would I feel as a nurse, if I was invited to attend a presentation on discrimination against African-American patients in the United States (or to add an additional layer of complexity, the American South), given by, say, a Japanese social scientist? Would I claim to "know more" simply by virtue of being "from there," or based on my occupational role? And how would my own political leanings affect how I would respond or interpret such findings? Other moments of introspection occurred in less formal settings. Sometimes, the exchanges were perplexing. In one manuscript, a Dominican colleague wanted to insert some remarks about the treatment of Mexican immigrants in the United States, as though to say, "but look who's talking!"

Aside from these examples, I had countless "micro"-interactions or observations, too, that shaped how I came to see this body of research: the way, for example, colleagues openly teased one another's skin complexions, without any hurtful intent; or, conversely, the vivid memory of a public bus driver in the Dominican Republic forcing a Haitian friend and research assistant to present his passport, after flippantly letting me, a white man, pass by without showing mine.

I realized something was wrong when I heard my friend's voice rising behind me. I turned and found him in a heated argument with the bus driver.

Without hesitating, I joined in. "Why did you ask him, but not me?" I demanded, my anger mounting.

"Because he's moreno," the driver said, matter-of-factly, because he's black.

In a flash of anger, I demanded our money back. "It's just the rules here," said the young man behind the ticket counter, handing us back our money.

After recounting the story to a Dominican colleague, he sighed. "Hunter, it's just the way it is. But all he had to do was show his passport," as though to say, yes, it's wrong, but why make such a fuss when there are other, more pressing problems?

Thus, my research into discrimination and its relationship to health responded to, and evolved from, situations like these. My personal interests, educational train-

ing, and even political leanings filtered into each study's methodology and dissemination style. Just as integral to this process were the institutional affiliations, research partnerships, and expected outcomes of the research among those involved. Through the reflexive style of anthropology, I sought to track my own emotions and interpretations of experiences and field data. Lastly, I cannot overstate the importance of the many conversations I had along the way, the back-and-forth dialogue with professional colleagues, field assistants, and interlocutors, about what the findings meant, how they related to a larger social reality, and how they should be appropriately contextualized.

## Perceived discrimination and stigma: relationships with health outcomes

Beyond characterizing discrimination and stigma, this dissertation explored their relationship with specific health outcomes and implications for public health programs in the country, with lessons that may be considered in other contexts. Chapters 1-4 focused specifically on mental health and social support of Haitian migrants; Chapter Five examined psychosocial stress and stigma in the wake of cholera, an enteric, infectious disease; Chapter Six explored loss of citizenship in *bateyes*, where lymphatic filariasis, a mosquito-borne, parasitic disease has been most prevalent in the country; and lastly, Chapter Seven linked findings from the Everyday Discrimination Scale to broader issues in community engagement for disease elimination.

One of the clearest links uncovered in this work was between perceived discrimination and poor mental health, particularly increased depression and anxiety symptoms. Chapter One found a statistically significant association between endorsing the statement, "Dominicans mistreat Haitians in my community" and higher depression symptoms. Of course, in cross-sectional studies like these, it is impossible to determine causation between these two variables; one may wonder if perceived discrimination is a consequence of mental illness. However, even longitudinal studies have shown changes in mental health symptoms over time with more exposure to discriminatory experiences (Broudy et al., 2007; Greene, Way, & Pahl, 2006), so one may assume, then, that discrimination encountered in the Dominican Republic as a Haitian migrant likely worsens mental health.

Perceived discrimination was also associated with constrained daily functioning, or the ability to fulfill responsibilities for one's self, family, and community (Bolton & Tang, 2002). Perceived discrimination, functional impairment, and economic insecurity interact together in a vicious cycle (Schulz et al., 2006). First, economic reasons motivated the majority (81%) of the sample to migrate to the Dominican Republic from Haiti; nearly the same proportion advised sending remittances back to Haiti (79%) and undertook periodic round-trips between the two countries (78%), indicating how interdependent these trans-border families and social networks are (Martinez, 1995). Yet once in the Dominican Republic, life was still precarious for migrants, evi-

dent in the alarmingly high proportion – nearly half (48%) – who spent more than three months out of the year without enough money to buy sufficient food for self or family. These findings demonstrate the pernicious relationship among perceived discrimination, poverty, and mental health, especially for a largely undocumented population such as this (Fuller-Rowell, Evans, & Ong, 2012; Lund et al., 2011).

Both qualitative and quantitative findings uncovered connections across economic, legal, and social spheres of life. According to some Haitian key informants, the nearly insurmountable hurdles to obtain authorized status was simply a way for the Dominican government to keep them in exploitable jobs. The idiom "Haitians have no worth" connected the race/nationality construct to ideas of value or worth. Aside from the juridical and administrative labyrinth migrants were expected to navigate to obtain authorized status – institutional pathways of discrimination (Jones, 2000) – interpersonal experiences also reinforced feelings of worthlessness. These interactions included being called names, being passed over for respectable work, being treated with less respect in clinical settings, or being arbitrarily stopped by immigration officials, all of which were vividly recounted by key informants in Chapters One and Three. Moreover, in the nationwide survey of bateves, the reasons, "Medical personnel do not treat me with respect" and "Documentation problems" were endorsed almost exclusively by Haitian-born batey residents to explain why they did not seek care for recent fever (Keys et al., 2019), although discrimination itself was not associated with reduced care-seeking (discussed below).

Another consequence for health was the breakdown in social support and ability to meet expectations for one's social networks, explored in <u>Chapter Two</u>. Loss of social support, particularly among migrant groups, compounds already difficult life circumstances and contributes to poor health outcomes (Almedom, 2005; Bhugra & Becker, 2005; Hakulinen et al., 2016; Uchino, 2006). This can become all the more deleterious during a public health crisis, as shown in <u>Chapter Five</u>, which documented how the cholera epidemic exacerbated anti-Haitian stigma. Furthermore, the public health response to cholera became intertwined with harsher legal and immigration restrictions, which drew on a narrative of control against a perceived backdrop of chaos emanating from Haiti. Similar findings were found in a separate study on the border with Haiti (Mallon Andrews, 2017). Cholera-related stigma, with its connotations of ignorance and contamination, helped to construe the Haitian migrant population as a threat to Dominican safety and national integrity, a practice that has long been in place (Torres-Saillant, 1998).

Yet while these narratives may smack of bald racism, they are better understood by asking what purpose stigma serves for those doing the stigmatizing (the dominant group) (Link & Phelan, 2014). In this case, the island was beset by the spread of a frightening disease that kills its victims in a quick and rather unglamorous way – causing profuse diarrhea, dehydration, and death. In the Dominican Republic, where a

quarter of the rural population still lacks adequate sanitation and 15% go without safe drinking water (WHO/UN, 2016), cholera may have been especially worrisome. Thus, while the impact of cholera at the study site was low (at the time, six total deaths were reported), it certainly had meaning for people (Sontag, 1990). For Dominicans, stigmatizing others could be interpreted as a defensive mechanism to protect what matters most to them: a safe and clean living environment for themselves and their families, for example. Of course, this stigmatizing process only reinforced a collective sense of powerlessness among Haitians, who drew on the idioms *imilyasyon* (humiliation) and *oblije*, or to feel resigned to suffer. Thus, stigma threatened what mattered most to them: personal health and security, a livelihood, or forming solidarity and mutual aid initiatives like *tèt ansanm* ("heads together").

One noteworthy finding from these studies was that the absence of health-related stigma, or stigma related to a specific health condition (Weiss, Ramakrishna, & Somma, 2006). While the study in <u>Chapter Five</u> may be seen in this light, it contextualizes cholera as part of a larger, moral narrative in Dominican society that blamed Haitians for the disease. Furthermore, cholera itself was never cited as a reason for discrimination in the nationwide survey of *bateyes*. In fact, for Haitian-born and Haitian-descended residents (i.e., those with the highest discrimination scores in the nationwide survey), the *least common* reason for discriminatory experiences was "health problems;" poverty, origin, skin color, and documentation problems were far more salient for explaining discrimination.

The study in <u>Chapter Seven</u> was part of a larger cross-sectional survey of malaria and lymphatic filariasis (LF). The disease prevalence outcomes from this survey are shared in a separate publication from this dissertation (Keys et al., 2019). While the disfiguring effects of filariasis-induced lymphedema can be highly stigmatizing (Pearson et al., 2008, 2009), malaria rarely is (Smith & Whittaker, 2014). Remarkably, in that survey of 1418 individuals who donated blood samples, no cases of active malaria infection were detected and only six were found to have presence of LF antigens from past infection. Transmission of both diseases has moved into other areas of the country, particularly the capital region, which now accounts for the majority of malaria cases nationwide (Valdez et al., In press). It appears, then, that disease-related stigma is less common than stigma related to poverty or ethnic group status. Still, a final word of caution is needed: while disease-related stigma was low if not altogether absent in these studies, it certainly exists in other contexts and among specific populations in the Dominican Republic, particularly sex workers who contend with HIV-related stigma (Barrington, Moreno, & Kerrigan, 2007; Padilla et al., 2008).

The study in <u>Chapter Seven</u> also measured associations between perceived discrimination and whether the individual sought care for recent fever, a cardinal symptom of many infectious diseases. Proportionally more Haitian-born individuals reported recent fever but did not seek care for the fever (Keys et al., 2019).

Surprisingly, perceived discrimination did not appear to be a primary reason for not seeking care, as no statistical association was found between outcomes from the Everyday Discrimination Scale and care-seeking for recent fever. Other reasons must explain reduced care-seeking within this population. According to most respondents, the most common reason for not seeking care was that "the illness was not serious enough," endorsed by an estimated 62% of the total batey population, and the most common reason for all groups regardless of ethnic background. This rationale underscores how other life demands in bateves likely take priority over certain health problems (Keys et al., 2019). The lack of association between perceived discrimination and reduced care-seeking may also be explained by the fact that residents of bateyes and other marginalized areas have few options for healthcare anyway. Frequent experiences of interpersonal discrimination, or anticipated discrimination in the clinical setting, may not deter an individual from seeking care if the illness prompts careseeking. At the same time, the survey asked about care-seeking for recent fever only, leaving open the possibility that perceived discrimination may influence care-seeking for other illnesses and health conditions.

A final health outcome measured in the 2016 nationwide survey was diabetes, a chronic, metabolic disease (Beau De Rochars et al., under review). Diabetes, as measured by hemoglobin A1c blood samples, was highest among permanent residents of *bateyes* compared to migrant Haitians, who were disproportionately affected by prediabetes. The higher prevalence of prediabetes among Haitian migrants will likely worsen over time because of the greater frequency of certain risk factors: more undiagnosed diabetics were found among Haitian migrants compared to persons born in the Dominican Republic; more Haitian migrants advised they had never heard of diabetes nor could name a symptom of diabetes; and more Haitian migrants had never been tested for diabetes by a healthcare provider in the country. Strikingly, differences in discrimination scores across diabetics, prediabetics, or those with normal blood glucose values were not statistically significant. This suggests that there are barriers to obtaining a diagnosis and long-term care for diabetes, but again, perceived discrimination (as measured by the Everyday Discrimination Scale) was itself not associated with those outcomes.

These findings recall an important point raised in the <u>Introduction</u> about the utility and pitfalls of measuring risk as a public health concept. *Risk*, when operationalized in cross-sectional surveys like those here, references events, circumstances, or behaviors located in a particular point in time. They are useful for reducing the complexity of health and disease into discrete variables that measure exposures, susceptibility, and effect modifications (Krieger, 1999). The analysis moves from the immediacy of those circumstances or behaviors to medical solutions for them (Fassin, 2009; Nguyen & Peschard, 2003). Given the findings of "poor knowledge" about diabetes, a logical solution would be to "increase knowledge" about diabetes. This perspective

implicitly considers "knowledge" as people's knowing about biomedical concepts, while their "beliefs" are generally seen as factually incorrect (to say nothing about the limits in arguing that knowledge translates into behavior, or that an individual has the ability to enact such behavior) (Pelto & Pelto, 1997). This approach ignores how the perceived distinction between the objectivity of science and subjectivity of culture is itself a social fact (Napier et al., 2014); that there are alternative ways of understanding the body and illness (Kleinman, 1988; Kleinman, Das, & Lock, 1997); and how health outcomes are historically determined (Farmer, 2004; Fassin, 2009).

According to the ecosocial perspective, health outcomes such as perceived discrimination and measures of risk can be seen as a register of oppressive social relations, occurring along the lifespan and over generations (Kirmayer, Gone, & Moses, 2014; Krieger, 2012). From this angle, discrimination, stigma, and psychosocial stress are examples of how Haitian migrants and their descendants born in the Dominican Republic *embody* their material and social conditions, which structure exposure and risk in the first place (Krieger, 2012). Those conditions hinge on the distribution of power in society, which either fosters or limits human potential and life chances (Marmot, 2005; Nussbaum, 1992; Sen, 2000). As detailed in Chapter Six, loss of citizenship entailed downstream rights violations, including access to healthcare, education, job mobility, and due process, all of which bear consequences for health and well-being. More examples can be found in the descriptions of daily struggles shared by people like Sylvie, quoted at the beginning of the Introduction and profiled in greater depth in Chapter Three. Sylvie's life was one marked by a chronic, steady-state of invisibility and worthlessness, punctuated by unpredictable traumas.

Through the lens of ecosocial theory (Krieger, 2012), dualisms of past and present, biology and history, and individual and society are inseparable when considering the pattern of health outcomes among minority groups. In this dissertation, the body of evidence to support these claims rests on two complementary approaches. Epidemiological methods and statistics provided a means to infer general patterns of certain phenomena of interest (constructs like depression, anxiety, or perceived discrimination). From another perspective, these constructs came alive through the words of people who contend with this reality. In-depth, qualitative methods revealed how idioms of distress like *imilyasyon* (humiliation), *oblije* (feeling resigned to life's hardships), and *pa gen vale* (feeling worthless), along with metaphors of smallness like *ti malere* (little miserable ones) and *ti jwèt* (little toys), communicate the struggle to live a dignified life, participate in what matters most, and ward off danger in an uncertain world. Additional idioms that hinged on life – *chache lavi* (to look for life); *jwenn lavi* (to find life) – expressed motivation, and perhaps, hopefulness. Idioms of hope and resilience deserve more exploration.

# Perceived discrimination: implications for health programs and community engagement

These studies were nested within projects interested in specific health domains, such as mental health, cholera, and mosquito-borne diseases. Of course, beyond measuring and contextualizing these phenomena, the next step is to formulate ways to address them. Below, I argue that the broadest application of these findings comes from their insights into community engagement.

The Alma-Ata Declaration (1978) recognized primary health care as a universal human right and called on governments to make investments in primary care services. A core element of the Declaration was community participation, based on ideas of social justice, empowerment, and democratic decision-making (Rifkin, 1996; WHO, 1978). Over forty years later, expectations of community participation are largely unfulfilled, a failure attributed to three core challenges: 1) the dominance of the biomedical paradigm, which views participation as a "magic bullet"; 2) lack of indepth analysis of the perceptions of community members; and 3) lack of an evaluative framework to understand what works, why, and how in communities (Rifkin, 2009). In short, a paradigm that expects a linear, causal relationship between community participation and health outcomes generally falls short, since health improvements implicate complex issues of power, politics, and human relationships (Michener, 1998; Rifkin, 2009).

These limitations have led to a broader conceptualization of the role of communities. Rather than seeing participation as a discrete intervention, ideas of *engagement* try to account for the web of human relationships comprising health programs, from community members and local health workers to program leadership, technical experts, and international funders (King et al., 2014). The power dynamics inherent to this web of relationships are too often overlooked or ignored, leading to not only programmatic failures but also mistrust and resentment, reinforcing a historical pattern of injustice between disadvantaged communities and powerful, outside groups (Biehl & Petryna, 2013). Furthermore, the lexicon of community engagement and development more broadly is replete with controversies. From a critical angle, breaking down terms such as *community, engagement, empowerment, participation*, or even *poverty reduction* reveals them to be buzzwords that "encode seemingly universal values" but in actuality mask local realities and the politics of meaning-making (Cornwall, 2007, p. 472).

While the following list is not exhaustive, community engagement principles involve rigorous site selection done alongside community members; building formative knowledge about the community, its assets, and changing needs; ensuring that the purpose of the intervention or program is clear to the community; building trust with relevant authorities; understanding community perceptions and attitudes about the program or intervention; and maximizing opportunities for community owner-

ship, stewardship and shared control (Lavery et al., 2010). In essence, these principles call for a re-examination of what community participation means, and to whom. One may ask: is participation simply a means to an end, or does it connect with broader concerns, such as equity, structural inequalities, politics, and citizenship (Draper, Hewitt, & Rifkin, 2010; Sen, 2000)?

A running theme of powerlessness winds through each of these chapters. One can infer that people who feel worthless, humiliated, or resigned to suffer lack control in life. The wide gap between what they actually do (functioning) and what they can do (capabilities) is apparent in these accounts (Anand, 2005). Given these conditions, a defining question for political and social activity is: what are people able to do, or able to be (Nussbaum, 2002)? A benchmark for progress is the expansion of people's capabilities, rather than their functioning. Following this line of reasoning, community engagement also draws on values of *empowerment*, which seeks to change power relationships at levels from individuals and households to whole spheres of economic and political life (WHO, 2008)½²a". To note, such discourse has met its share of criticism (Draper et al., 2010). In policy circles, empowerment and participation have been boiled down into "efficiency devices" to achieve programmatic goals, while at the field level, stakeholders may co-opt those concepts to further their own interests (Michener, 1998).

Nonetheless, there are two noteworthy examples of community engagement and empowerment that are worth sharing from the Dominican Republic. At a publicly-funded tertiary care hospital, Dominican nurses were faced with a startling situation: women with obstetric complications were delaying medical care to such a degree that maternal mortality had suddenly increased. Healthcare personnel assumed that attitudes and beliefs about medical or obstetric care had led to their delay. Following principles of community-based participatory research (which follows nearly identical principles as those outlined above; see Wallerstein & Duran, 2006), a team of researchers, including health workers, community members, and external investigators, found that expectant mothers were generally dissatisfied with the quality of maternal care. Rather than pinning the blame on over-worked and under-resourced health workers, however, community members and clinical staff came to know each other in new ways by working towards a common goal: to improve maternity care. In effect, the catalyst for change – in both community and clinical settings – was the research process itself (Foster et al., 2010a).

The second example comes from the country's program to eliminate lymphatic filariasis (Spanish acronym, PELF). As the study in <u>Chapter Six</u> elaborates, PELF has had to negotiate its mandate to reach and care for the *batey* population despite an increasingly aggressive, anti-Haitian political climate. Furthermore, PELF, and the health system at large, has had to decentralize its expertise and responsibilities to local districts in the face of increased financial pressures (Baker et al., 2007). As part

of these changes, PELF integrated mass drug administration (MDA), a core component for LF elimination, into primary care units that serve nearby *bateyes*. PELF also collaborated with local neighborhood associations (*juntas de vecinos*) to establish trust, identify community gate-keepers, and recruit and train community members to take leading roles in MDA campaigns, which require at least 65% of the population to participate in order to be successful (WHO, 2005b). Following these strategies, PELF and the *batey* residents achieved an average participation rate of 80% per round of MDA. Since 2002, when MDA campaigns began, LF antigen prevalence (a marker of past infection) has dropped to less than 2% in previously endemic areas – the point at which MDA can be stopped.

Based on these experiences, how can public health programs follow principles of community engagement to counteract the harmful effects of discrimination and stigma? One way to address both the mental health needs of this population and issues of disempowerment is the task-sharing model for strengthening psychosocial support services. Task-sharing refers to the delegation of clinical skills to less specialized workers in low-resource settings (Padmanathan & De Silva, 2013; Singla et al., 2017). This approach has already been applied in rural Haiti since the 2010 earthquake (Kaiser & McLean, 2015; McLean et al., 2015). In communities like those in this study, task-sharing could come about through apprentice models, in which trained specialists partner with lay community health workers and other key figures to train and supervise them in mental illness screening, diagnosis, and treatment such as counseling, skills-building, and peer support. This approach could also incorporate locally meaningful idioms of distress identified here into screening instruments to identify persons who are suffering and establish therapeutic relationships (Cork, Kaiser, & White, 2019; Kohrt et al., 2016). Still, efforts such as these should be mindful to not inadvertently conceal the dysfunctional aspects of a health system (Okello et al., 2019).

One crucial component of task-sharing and strengthening clinical care in general is cultural competency. In these studies, Haitian patients perceived Dominican clinicians as less inclined to care for them because of their Haitian origin and poverty. Meanwhile, Dominican healthcare workers interpreted these perceptions as "cultural misunderstandings" on the part patients (findings shared in <u>Chapter One</u>). A more engaged approach could use ethnographic methods, such as soliciting explanatory models and asking patients how their illness or suffering affects what matters most to them (Kleinman & Benson, 2006). This process of acknowledgment avoids framing cultural difference as "something to be fixed" (such as a presumed misunderstanding or misperception) and instead uncovers the moral significance of suffering, enabling more negotiated and tailored treatment decisions.

Public health programs can also identify ways to strengthen social support and encourage intergroup contact, which can help to reduce discrimination and stigma

in the community (Pettigrew, 2008; Pettigrew & Tropp, 2006). Across diverse contexts, intergroup "positive contact events" generally reduce prejudicial attitudes and increase empathy for minority-status groups (Pettigrew & Tropp, 2006, 2008). Of course, it is ironic to propose intergroup contact as a public health intervention in a setting where, as discussed in the Introduction, there has been "nothing but contact" (Trouillot, 1992, p. 22). In fact, the structure and function of many mutual aid collectives in the Dominican Republic go back to the colonial era. For example, systems of rotating credit among low-income people in the Dominican Republic have origins in Africa (Deive, 2007 [1981]). An ethnographic study in 2015 identified how an inclusive system of credit at small food stores brought together both migrant Haitians and Dominicans (Hippert, 2017). The convite (or in Haiti, konbit), too, has roots in West Africa (Deive, 2007 [1981]). Juntas de vecinos (neighborhood associations) are widespread throughout the Dominican Republic and often already have relationships with public health programs, as shown in Chapter Six. While under-explored in this dissertation, these culturally meaningful aid societies – which already have traction in the general population – could serve as a model for developing public health interventions.

Reducing stigma and discrimination need not occur in a vacuum. It should be integrated into existing health programs, regardless of disease or condition. This generic approach recognizes stigma's intersectionality with multiple domains of health and maximizes the reach of those strategies (Van Brakel et al., 2019). Furthermore, approaching stigma reduction through a framework of "what matters most" helps external investigators and health practitioners align the goals of an intervention with the needs and concerns of community members (Yang et al., 2014). For example, a central challenge for vector-borne disease control programs is engaging people whose experience of everyday discrimination and structural hardships prevent them from prioritizing otherwise rare diseases like malaria. When a research team in Haiti held discussions about larval source management, the conversation quickly turned to poverty, lack of basic services, fracturing social cohesion, and distress over the burden of being asked to address what was seen as a problem for the government (Bardosh et al., 2017, p. 11). Ultimately, a range of community dialogue and engagement activities were instrumental in fostering trust and willingness to participate, but the investigators acknowledged that such interventions were no replacement for what was really needed: accountability at municipalities and consistent pay for trained staff.

While malaria, dengue, or chikungunya are not necessarily stigmatizing diseases, the people affected by them in the Dominican Republic are very often stigmatized themselves, whether on the basis of their origin, documentation status, or poverty. While these aspects of their lives may seem beyond the reach of public health programs, they are important, if not vitally at stake, for the people those programs try

to reach. Rather than adhering too closely to a reductionist paradigm, vector-borne disease programs could first acknowledge this complicated social and political world, be sensitive to the fact that people's everyday concerns are usually rooted there, and consider how the traditional suite of interventions – motivating people to reduce mosquito habitats, enact certain preventive behaviors, and trust community health workers for diagnosis and treatment – might reveal new opportunities for social support and stigma reduction. Public health and global governance are increasingly defined by cost-saving, efficiency, and quantitative indicators (Merry, 2011). Along with charting measurable outcomes, health programs could also begin to incorporate qualitative and quantitative components to track stigma, perceived discrimination, and the quality of human relationships at the heart of any intervention. This, in turn, would help account for shared values between programs and communities, which very likely include mutual respect and shared decision-making.

# Closing vignette: Nerita, or how to heal

My last rounds of fieldwork in the Dominican Republic focused on malaria outbreaks in the capital, Santo Domingo. Until recently, malaria was a rural disease in the country, thought to be linked to migration from Haiti, where it is far more prevalent. Since 2014, cases of malaria in Santo Domingo have sky-rocketed, accounting for the majority of all cases nationwide (Valdez et al., 2020). This presents a rather paradoxical situation. Santo Domingo, the largest city in the Caribbean, is a bustling metropolis, one where government-sponsored billboards proclaim, in a public relations campaign, that *Aquí*, *hay futuro* – here, there is a future. And yet, there is a seemingly intractable outbreak of malaria, the "classic economic disease" that blocks the steady march of progress (Brown, 1997). I cannot keep track of how many surprised looks I get, whether from the tourist seated next to me on a plane or a Dominican cab driver, when I say that I'm studying malaria.

"Where is there malaria?" they ask with interest.

To find malaria, or rather, the people who suffer from malaria<sup>10</sup>, I recommend that you go meet Nerita. She lives in a crowded, loud neighborhood near the heart of the city that we'll call Esperanza. Upon entering Esperanza, you immediately sense a sort of closing in around you – houses perched on top of houses; concrete rebar sticking out of the top floors and roofs of houses still under construction; concrete sidewalks and small *callejónes* (side streets) with rudimentary, cement gutters. Esperanza is not very far from *la zona colonial*, where the original Spanish ramparts still stand against the

<sup>10</sup> The phrase is borrowed from Fassin, D., 2009, "A violence of history: accounting for AIDS in post-apartheid South Africa," in B. Rylko-Bauer, L Whiteford, and P. Farmer (eds.), <u>Global Health in Times of Violence</u>, Santa Fe: School for Advanced Research Press, p. 117.

backdrop of the Caribbean sea. Those in this neighborhood who find work, any kind at all, are called *chiriperos* – "lucky ones."

In my work on malaria in the capital, I became attuned to how physical vulnerability to malaria was deeply enmeshed with political corruption. For example, malaria has taken hold in another area of the city called *La Ciénaga*, or "the swamp." *El nombre se lo dice*, a woman there once told me, the name says it all. Depending on whom one asks, long ago, some unknown bureaucracy once declared La Ciénaga uninhabitable, its topography too vulnerable to flooding. But eventually, as people's livelihoods in the outlying provinces dried up, they came to the city in search of work. Those in power saw this as an opportunity: there was money to be made in selling plots of land that was never meant to be sold in the first place. Besides, votes were to be found among the masses. Surreptitious land deals in exchange for votes was just another iteration of the long history of clientelism in the country (Moya Pons, 2007 [1981]), of greasing the wheels of the country's political machinery.

Nerita has dealt with her fair share of political shenanigans. She is the president of the local neighborhood association, and as such, she works through whatever channels she can for her constituents, whether at the city hall or the district public health office. A few years ago, a political scandal erupted when a few well-connected businessmen tried to sell off the *terrenos*, or land plots, of the mostly poor residents living there in order to make way for a major construction project. After months of street protests and a court verdict, the plan was halted.

I met with Nerita in her home during one of my last days of fieldwork in October, 2019. Nerita and I had met nearly two years before, during a focus group with other women involved in the malaria response. I interviewed her on a few other occasions in the time since. Given her stature in the neighborhood, Nerita was approached by the country's malaria program to help recruit and train volunteers to assist in the malaria outbreak. She and her fellow *promotoras*, or community health promoters, were pivotal in the response (Valdez et al., In press). They went door-to-door in their neighborhoods, asked about fever, and tested for malaria, one problem among many, given life's other hardships, and not really an urgent one at that. With their characteristic humility, the *promotoras* told me that they simply wanted to *mejorar la vida*, improve life, which, they explained, could only come about through *la aceptación*, or acceptance, from their fellow neighbors, and *la confianza*, or trust.

This work on malaria has presented complicated knots to unravel, among them, the politics of health system reform amidst ongoing malaria outbreaks; power dynamics in recruitment of local community health workers; how knowledge about malaria is produced for interventions; and the breakdown in diagnosis and treatment. These components are wide-reaching in scope, but all circle back to one of malaria's singular lessons: it implicates our relationships with each other and the environment. The irony is that malaria, the classic rural disease that blocks development, has taken hold

in Santo Domingo, the historical epicenter of progress in an imagined New World, where Spain laid claim to a new territory, where the Savage Other was born, and where the first shipment of enslaved human cargo brought along malaria parasites from Africa (Rodrigues et al., 2018). Malaria on Hispaniola, then, has always carried a distinctly exploitive side to it – from the inception of a slave economy to the explosion of urban "sacrificial places" like La Ciénaga or Nerita's neighborhood, where people are sent ricocheting from one precarious livelihood to the next (Nixon, 2011, p. 151).

The studies shared in this dissertation provide a springboard for taking these ideas further, since social exclusion and perceived discrimination ultimately reflect dynamics of power, identity, and understanding one's self in relation to others. *Ti malere nou ye*, us little miserable ones, as some key informants said. Elsewhere, in a separate geographic and historical context, malaria, rural poverty and hopelessness were encapsulated in the term *miseria* (Brown, 1997). And of course, the term itself, *malaria*, was borne out of centuries-old miasma theories of disease, meaning "bad air." Terms like *malere*, *lamize*, or *miseria* do more than share an etymological root; they signal qualities about human relationships. Indeed, something rotten is in the air.

But here, with Nerita in her little kitchen, one feels welcomed and cared for. *Aie*, Nerita. You told me that you just want to *sanar la población*; you want to heal. You set a pot of coffee on the stove and warned me about getting too close to the electric wires dangling from the ceiling. You got involved in a vaccination campaign in the 1980s and eventually found your way into politics. You said the average person here makes about \$10 dollars a day and earlier, you said that it's the community that takes care of you. It was a funny twist; here I was, thinking that you and your fellow *promotoras* care for the community, but as you said, *a veces, es la comunidad que nos cuida* – it is the community that cares for us – because some neighborhoods are dangerous and you need to be escorted by those who live there, to let you go about your work, to ask if there's anyone with fever.

You scoffed when I asked about politicians. *Esa gente ve las cosas ciegos* – that they're blind, that they don't see reality. I tried to say, awkwardly, that I admire what you do, and you turned from the coffee pot to look at me and your eyes twinkled and your hair was in a net and you had those dark little freckles under your eyes. You said that in January you'll be 61 years old. You offered me coffee, twice, and it was delicious coffee, too.

After, you stood on the sidewalk outside with another neighbor, engrossed in conversation. The evening twilight was falling over the street as kids played around us. You and this other woman had such concerned looks on your faces, talking about your disgust with the status quo, about your desire for change. Nerita, you who proudly called yourself *la negrita de Esperanza*. Soy de *la calle*, you said – I am from the street.

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## LIST OF THESIS-BASED PUBLICATIONS

# **Chapter One:**

Keys, H., Kaiser, B. N., Foster, J. W., Burgos, R. M., and Kohrt, B. A. (2015). Perceived discrimination, humiliation, and mental health: a mixed-methods study among Haitian migrants in the Dominican Republic. *Ethnicity and Health* 20(3): 219-240.

## **Chapter Two:**

Kaiser, B., Keys, H., Foster, J., and Kohrt, B. (2015). Social stressors, social support, and mental health among Haitian migrants in the Dominican Republic. *Pan-American Journal of Public Health* 38(2): 157-162.

## **Chapter Three:**

Keys, H. (2015). Life "under the wire:" perceived discrimination and mental health of Haitian migrants in the Dominican Republic. In *Global Mental Health: Anthropological Perspectives*. Kohrt, B. and Mendenhall, E., (eds.). Left Coast Press, Walnut Creek, CA.

## **Chapter Four:**

Keys, H., and Kaiser, B. (2017). Language, measurement, and structural violence: Global mental health case studies from Haiti and the Dominican Republic. In *The Palgrave Handbook of Global Mental Health: Socio-cultural Perspectives*. White, R., Jain, S., Orr, D., and Read, U. (eds). Palgrave Macmilan UK, London

#### Chapter Five:

Keys, H., Kaiser, B., Foster, J., Freeman, M., Stephenson, R., Lund, A., and Kohrt, B. (2017). Cholera control and anti-Haitian stigma in the Dominican Republic: from migration policy to lived experience. *Anthropology and Medicine* 26(2): 123-141.

#### Chapter Six:

Keys, H., Gonzales, M., Beau De Rochars, M., Blount, S. and Noland, G. (2018). Building trust through lymphatic filariasis elimination: a platform to address social exclusion and the right to health in the Dominican Republic. *Health and Human Rights Journal* 20(1): 41-52.

#### **Chapter Seven:**

Keys, H., Noland, G., Beau De Rochars, M., Taylor, T. H. and Blount, S. (2019). Perceived discrimination in *bateyes* of the Dominican Republic: results from the Everyday Discrimination Scale and implications for public health programs. *BMC Public Health* 19, 1513.

# EXPLANATION OF THE RELATIVE CONTRIBUTIONS OF THE CO-AUTHORS TO THE CHAPTERS

## **Chapter One:**

This was the first article I published after completing my first round of fieldwork in the Dominican Republic in 2011. As lead author, I designed the study, recruited and trained local research assistants, constructed a sampling frame for the survey using a household census, collected in-depth interviews, and analyzed all data (both quantitative and qualitative). I also took the lead in drafting and revising the manuscript based on feedback from co-authors and reviewers. B. Kaiser, J. Foster, and B. Kohrt were close academic advisors who assisted in data analysis and manuscript revisions. R. Burgos was my mentor in the country and helped with logistics of the project.

# **Chapter Two:**

This article was also based on the first round of fieldwork in San Francisco de Macorís. Bonnie Kaiser and I both drafted the manuscript, while she took the lead in data analysis. J. Foster and B. Kohrt served as academic mentors.

## **Chapter Three:**

This was a book chapter that I wrote following an invitation by Brandon Kohrt and Emily Mendenhall.

# **Chapter Four:**

This is also a book chapter, which I co-authored along with Bonnie Kaiser. I took the lead in drafting the bulk of the chapter, while Bonnie wrote a section on measurement of mental illness in Haiti. We were invited by Ross White, now Researcher at the University of Liverpool.

# **Chapter Five:**

This article is the published version of my thesis for my Masters in Public Health (MPH) degree. I conceptualized the project, wrote a grant application to Emory University for funding, and recruited a multidisciplinary graduate student team. In the field, I was the project lead, coordinating data collection activities. I took the lead in drafting and revising the manuscript based on feedback from colleagues and peer review. B. Kaiser assisted with data analysis and writing; J. Foster, M. Freeman, R. Stephenson, and B. Kohrt were academic mentors, and A. Lund was a fellow graduate student who contributed to all data collection activities.

# **Chapter Six:**

This is the first article published after starting my work with The Carter Center. I was in charge of all data collection activities (training and supervising the survey team; conducting in-depth interviews), data analysis, and manuscript writing. M. Gonzales was a mentor and colleague in the field who remains in charge of the country's lymphatic filariasis elimination program. M. Beau De Rochars was a colleague who assisted in the survey design and training of research assistants. S. Blount and G. Noland were colleagues from The Carter Center who supervised the entire project and provided guidance as needed.

# **Chapter Seven:**

This article was also based on work from the 2016 survey of *bateyes* in the Dominican Republic. I conceptualized the study design by incorporating the Everyday Discrimination Scale (EDS) into the survey; supervised the field team; analyzed the data; and wrote the manuscript. G. Noland and S. Blount, colleagues from The Carter Center, supervised the survey project and assisted with manuscript writing. M. Beau De Rochars was a colleague who assisted in the survey design and training of research assistants. T. Taylor was a statistician at the Centers for Disease Control and Prevention in Atlanta and a personal friend who helped me with data analysis.

The Caribbean island of Hispaniola, shared by Haiti and the Dominican Republic, has been called "the imagined island" for its long history as a contested space of identity, nationalism, and meaning-making. This ongoing process of differentiating self and other has continued since European colonists, indigenous people, and African slaves converged on the island in the late 15th century. In the Dominican Republic, contemporary forms of discrimination and stigma against the Haitian and Haitian-descended minority are rooted in the two countries' intertwined histories, in which ideas of race, nationality, and class shape how people understand themselves and each other in a fraught and at times injurious social world.