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Potential Contributing Factors for Declining Mass Drug Administration Coverage for Lymphatic Filariasis in Port-au-Prince, Haiti: A Qualitative Study of the Word on the Street

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Master of Public Health

Hubert Department of Global Health

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Committee Chair

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Bachelor of Arts
Virginia Commonwealth University
2014

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ABSTRACT

Potential Contributing Factors for Declining Mass Drug Administration Coverage for Lymphatic Filariasis in Port-au-Prince, Haiti: A Qualitative Study of the Word on the Street

Lymphatic Filariasis (LF) is a mosquito-borne parasitic disease that affects nearly 120 million people globally. Causing lymphedema, elephantiasis, and hydrocele, LF is responsible for a profound degree of suffering and disability worldwide. The World Health Organization (WHO) recommends annual mass drug administration (MDA) to eliminate the disease in areas where it is endemic. The success of LF-MDA programs depends upon achieving and sustaining high levels of adherence to the treatment regimen for the duration of the campaign and minimizing "systemic non-compliance." To effectively interrupt transmission of the disease, the WHO recommends a minimum coverage of 65% sustained for 4-6 years. In its first round of MDA in 2011-2012, Haiti's National Program to Eliminate LF (NPELF) successfully achieved a 79% coverage in urban Port-au-Prince. In 2013, coverage fell below the WHO threshold and has since continued to decline year-over-year.

The objective of this study was to identify potential contributing factors that may be responsible for the observed decline in MDA coverage in Port-au-Prince over the 2011-2017 period. A retrospective qualitative case study was conducted to identify key factors contributing to the observed declines in coverage. The study involved brief 'on-the-street' interviews with a convenience sample of the general public in Tabarre (a high-coverage commune) and Carrefour (a low-coverage commune).

Specific rationales for non-compliance to LF-MDA discussed by participants were similar to those described in previous studies. These included, among others: fear and avoidance of adverse events, lack of availability of food to take with medication at distribution sites, frustrations with the program's directly-observed treatment policy, and a general perception that the program lacks public health credibility. Beyond these specific rationales, the absence of differences in practice by program staff between high- and low-coverage areas suggests that issues of non-compliance may be due to broader aspects of the program's design.

Analysis of participant responses within the broader context of the program's design and the biosocial factors that mediate the LF-MDA 'experience' suggests that the issue of "systematic non-compliance" by prospective MDA participants has been overemphasized in the literature, and among the program partners, obscuring systemic weaknesses of the program itself.

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TABLE OF CONTENTS

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GLOSSARY

TERM	DEFINITION
AE	Adverse Event
Blan	Haitian Creole for “white.” Refer to foreigners, often white Americans
C/NC	“Compliant”/ “Non-Compliant” community member, in quote attribution
C/NC: [QUOTE]	Quote from compliant / non-compliant community member
CDC	Centers for Disease Control and Prevention
CDD	Community Drug Distributor
CHWs	Community Health Workers
DEC	Diethylcarbamazine
DOT	Directly-Observed Therapy
DO-MDA	Directly-Observed Mass Drug Administration
CSE	Community and Stakeholder Engagement
ESH	External Stakeholder
Filaryoz	Haitian Creole for “Lymphatic Filariasis”
GPELF	Global Program to Eliminate Lymphatic Filariasis
Gwo Grenn	Haitian Creole for “hydrocele” (literally, “big testicles/scrotum”)
Gwo Pye	Haitian Creole for “lymphedema” or “elephantiasis” (literally, “big foot”)
HCD	Human-Centered Design
HELP	Human Engagement Learning Platform for Global Health
I: [QUOTE]	Quote from Interviewer
IDA	Combination of Ivermectin, DEC, and Albendazole
ISH	Internal Stakeholder
LF	Lymphatic Filariasis
LF-MDA	Mass Drug Administration of Lymphatic Filariasis
MDA	Mass Drug Administration
MF	Microfilariae
MSPP	Ministère de la Santé Publique et de la Population; Haiti Ministry of Health
NPELF	Haiti’s National Program to Eliminate Lymphatic Filariasis
NTDs	Neglected Tropical Diseases
PAP	Port-au-Prince
RDS	Respondent-Driven Sampling
TAS	Transmission Assessment Surveys
TCC	The Carter Center
UND	University of Notre Dame
UX	User Experience
WHO	World Health Organization

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CHAPTER I: INTRODUCTION

1.1 Background

Lymphatic Filariasis (LF) is a mosquito-borne parasitic disease affecting over 120 million people globally [1]. In advanced stages of the disease, infected individuals can develop debilitating lymphedema, elephantiasis, and hydrocele. LF is responsible for a profound degree of suffering worldwide and is a leading cause of permanent disability [2]. In addition to the physical symptoms of the disease, affected individuals suffer mental, social, and economic consequences arising from stigma and reduced capacity to participate in activities of daily life [3]. The World Health Organization (WHO) has targeted LF through its Global Programme to Eliminate Lymphatic Filariasis (GPELF) with a goal of eliminating the disease by 2020 [4]. GPELF strategy is based on two objectives: 1) interrupt transmission through annual mass drug administration (MDA) in affected communities; and 2) alleviate the suffering through morbidity management and disability prevention [5]. MDA for Lymphatic Filariasis (LF-MDA) involves yearly administration of medication to entire populations, regardless of infection status. To effectively interrupt transmission and clear infected individuals of the parasite, a treatment coverage of at least 65% must be maintained for 4-6 years [6]. The GPELF has been highly successful since its inception in 2000, though many challenges remain in the global elimination effort. When a large proportion of individuals do not participate in MDA, they serve as a potential reservoir of infection allowing transmission to persist, necessitating additional rounds of MDA [7]. Reaching these “non-compliant” individuals to meet the required coverage thresholds for elimination has been a major challenge and focus for many LF-MDA programs.

Haiti bears a disproportionally large burden of LF, accounting for 90% of all cases in the western hemisphere [8]. Following a nationwide mapping exercise of LF from 2000-2001, it was

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determined that all of Haiti's communes would require MDA [9]. The results of this study led Haiti's Ministry of Public Health and Population (MSPP) to form the National Programme to Eliminate Lymphatic Filariasis (NPELF) [8]. Haiti's first round of LF-MDA was conducted in the Leogane commune, though the program was quickly scaled up to reach all hyperendemic communes by 2005. MSPP and partners, including the University of Notre Dame (UND), the Centers for Disease Control (CDC), and the Carter Center (TCC) among others, have faced tremendous challenges in their ongoing efforts to eliminate LF, including interruptions in funding, frequent political strife, civil unrest, the devastating 2010 earthquake and subsequent cholera outbreak. Persevering through these challenges, the program achieved full geographic coverage of LF-MDA in 2012, reaching more than 8 million people across all of Haiti's communes [8].

While the NPELF has made remarkable progress, many challenges remain in the LF elimination effort, particularly in Port-au-Prince (PAP) and other urban, high-prevalence "zone rouge" (red zone) communes [10]. MDA implementation in metropolitan Port-au-Prince began in 2011/12. Following a successful first round, MDA coverage has since progressively declined, year-over-year, consistently falling below the 65% threshold necessary to achieve elimination (Figure 1).

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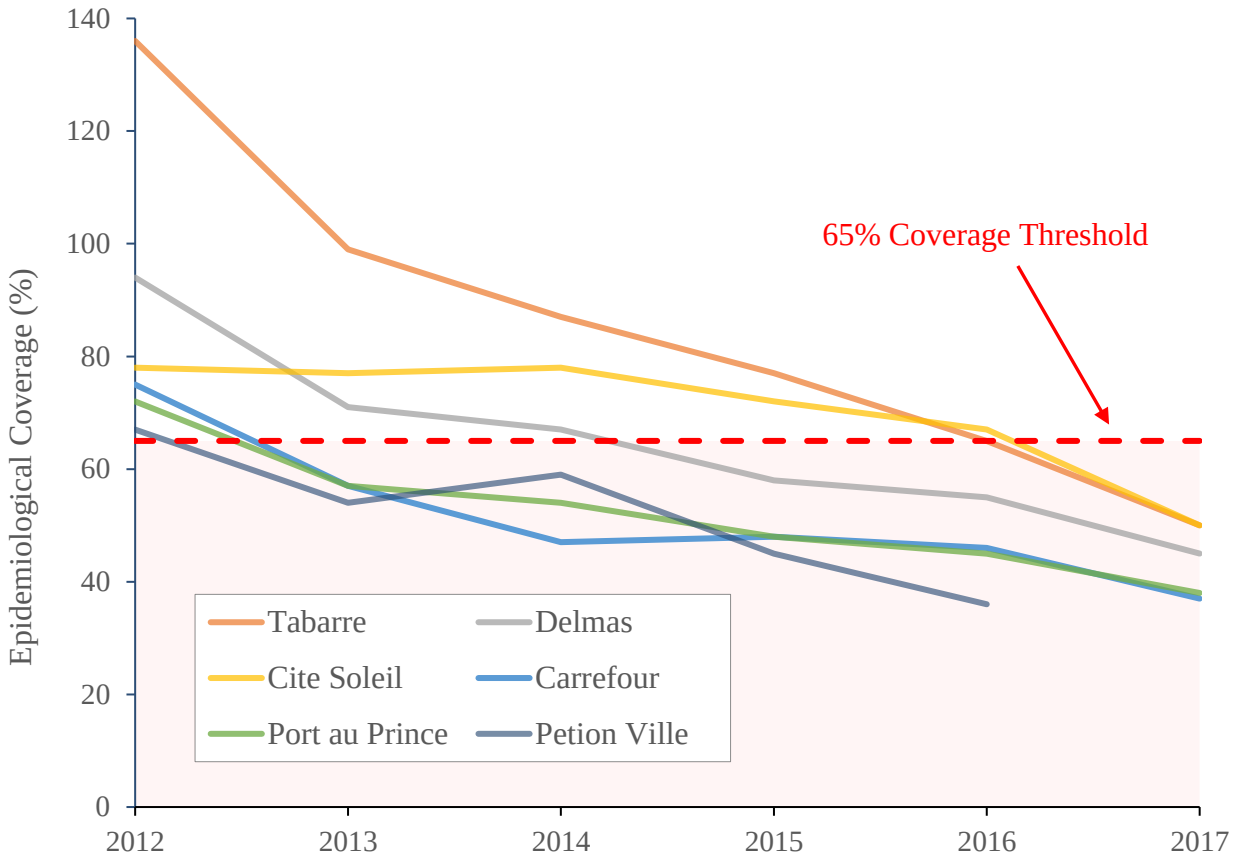

Figure 1. Declining annual LF-MDA coverage by Commune in Port-Au-Prince, Haiti. Data provided by TCC.

This consistent decline is thought to be related to issues of systematic non-compliance and the unique challenges of urban MDA, though the exact reasons for the loss of coverage remain unclear.

1.2 Introduction to the HELP study

In 2018, TCC commissioned the Human Engagement Learning Platform (HELP) at Emory University to assist in the broader effort by NPELF to better understand the potential contributing factors that may be responsible for the observed decline in epidemiological coverage prior to the annual MDA implementation for 2019. TCC engaged HELP for several reasons. The program suspected that coverage losses might be due in part to the nature and

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effectiveness of community and stakeholder engagement (CSE) practices, and HELP has extensive experience with the evaluation of complex CSE strategies in global health programs and a proven qualitative case study method. Placing a strong emphasis on programmatic issues, the HELP CSE model could be used to help elucidate an explanatory account of declining LF-MDA coverage [11]. Finally, HELP has seen significant success with academic publication of CSE studies, broadening the value of TCC's investment beyond the potential benefits to Haiti's LF-MDA program to a greater understanding of CSE processes for global health that can be applied in other contexts.

The HELP study had three overall objectives: 1) to describe the MDA activities and loss of coverage in metro Port-au-Prince from 2011-2017 by reviewing the relevant literature and program materials; 2) to identify specific contributors to the declining coverage by conducting semi-structured interviews with key internal stakeholders (ISH) and external stakeholders (ESH)[1], applying a conceptual model based on prior HELP case studies [11]; and 3) to develop a set of recommendations for how these factors might be addressed to improve coverage rates in future LF-MDA rounds [12].

Two different types of interview methodology were employed in this case study: 1) In-depth interviews, primarily with ISH, but also including several ESH; and 2) brief "on-the-street" interviews with a larger convenience sample of ESH to gauge the general public's attitudes about, and experiences with, LF-MDA in PAP. Data collected from these "street" interviews will be the focus of this thesis.

[1] Internal stakeholders include program "staff" (e.g., community leaders, promoters, and drug distributors). External Stakeholders include compliant and non-compliant community members.

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1.3 Purpose

The purpose of this study was to identify potential contributing factors that may be responsible for the observed decline in MDA coverage in Port-au-Prince over the 2011-2017 period. To achieve this goal, this study aimed to conduct interviews with members of the general public to elicit their personal experiences with LF-MDA compliance or non-compliance, reasons driving their decision, their views about facilitators and barriers to LF-MDA compliance for themselves and others, and ultimately, their perceptions of the LF-MDA program itself.

1.4 Significance

A more comprehensive understanding of the complex factors that influence individuals' decision-making regarding participation in LF-MDA will be used to generate recommendations for improvements to the design and implementation of Haiti's LF-MDA program. These improvements have the potential to increase coverage for the 2019 MDA. If coverage continues to increase and is held at a sufficiently high level for 4-6 years, LF will potentially be eliminated from metropolitan Port-au-Prince. In addition, the findings of this study have value beyond the benefits to Haiti's LF-MDA program, providing guidance for MDA in other contexts and also for community engagement strategies for global health programs facing similar challenges.

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CHAPTER II: LITERATURE REVIEW

2.1 Lymphatic Filariasis

Lymphatic Filariasis (LF) is one of the world's oldest and most debilitating parasitic diseases. Evidence of its presence is seen in historical artifacts, including an ancient Egyptian statue of Pharaoh Mentuhotep II depicting swollen limbs (2000 BCE), statuettes from West Africa that depict scrotal swelling (500 AD), and ancient medical writings by Arabian, Chinese, Greek, Indian, Roman, and Persian physicians [13]. It is a mosquito-borne neglected tropical disease (NTD) that affects approximately 120 million persons globally and is a leading cause of disability worldwide [14]. LF is caused by infection by three filarial parasites: *Wuchereria bancrofti*, which is responsible for approximately 90% of infections worldwide, and *Brugia malayi* and *Brugia timori*, which are responsible for the remaining minority of cases [5]. Humans are the only known reservoir for *W. bancrofti* and transmission occurs person-to-person via a mosquito vector. Several species of mosquito can be infected by *W. bancrofti*, though in Hispaniola, LF is spread by *Culex quinquefaciatus*, a night-biting mosquito that breeds profusely in areas with standing water [15]. LF, or *filaryoz* as it is referred to locally in Haiti, has historically been considered a rural disease, with sugarcane fields providing ideal breeding grounds [9]. However, rapid urbanization around Haiti's crowded metropolitan centers which have inadequate sanitary and sewage facilities has fostered an environment where *Culex* mosquitos can thrive and proliferate.

After entering the bloodstream through a mosquito bite, the juvenile worms, known as microfilaria (MF), travel to the lymph nodes, primarily in the lower limbs and male genitalia, where they mature for 6-9 months [16]. After reaching sexual maturity, the adult worms mate and release thousands of MF, which then migrate to the peripheral circulatory system. Once in

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the circulating bloodstream, MF can be ingested by the mosquito vector, and the cycle begins anew. Unlike malaria, a single bite from an infected mosquito will not typically result in LF. A full, persistent LF infection requires a sufficiently high filarial load which can only be delivered by many bites over time.

2.2 Clinical Manifestations

LF is usually acquired in early childhood, though symptoms may take many years to develop. Many individuals with LF are asymptomatic. However, despite having no outwardly visible signs of LF, these asymptomatic infections still result in multiplication and transmission of the parasite and damage to the host's lymphatic system. As the disease progresses, LF can present with acute adenolymphangitis (pain in the lymph nodes, chills, fever), skin rashes, joint pain, and a general sense of malaise [16].

In late-stage chronic cases, over-abundance of parasites can cause blockages in the lymphatic system, clogging the circulation of fluid through tissues. These blockages lead to severe lymphedema and fibrosis (elephantiasis), and hydrocele (scrotal swelling) [17]. In addition, the flow of immune cells is restricted, exacerbating the infection. In these late-stage infections, patients are often amicrofilaraemic, and progression of the disease is mainly caused by secondary bacterial and fungal infections of the affected area, worsened by the damaged lymphatic system . Non-intuitively, those who show the most visible signs of LF are often the least likely to transmit it to others, while those with no symptoms represent a significant reservoir of potential transmission [16]. Beyond extreme pain, disfigurement, and permanent disability, there are significant mental, social, and economic impacts for individuals suffering from LF-related morbidity [3,18–22].

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2.3 Detection, Treatment, and Prevention

Beyond the visible manifestations of LF, there are a wide variety of definitive diagnostic techniques used to detect parasites in individual patients and to monitor active transmission in communities, all varying in sensitivity, specificity, and cost. Stained blood slides, which must be prepared from blood collected at night,[2] can be used to directly observe the presence of MF [23]. More commonly, various types of rapid assays are used to detect circulating antigens to *W. bancrofti*, which indicate prior exposure to the parasite. These types of assays are widely used in transmission assessment surveys (TAS), which measure active, community-level transmission [6].

LF is treated with a variety of anti-filarial medications, though these drugs mainly kill the circulating MF, with lesser effect on the adult worms [17]. Interfering with the lifestyle of the parasite, anti-filarial drugs prevent person-to-person transmission and halt the progression of infection. Though the adult worms will naturally die over time, severe advanced-stage lymphedema caused by LF is irreversible without surgery or major physiotherapy. Often, the risks of surgery outweigh the potential benefits, as further damage to the lymphatic system may exacerbate the lymphedema.

Severe adverse events (AEs) due to anti-filarial medication are rare, though mild to moderate AEs induced by the die-off of MF can be expected after ingestion of the drugs, especially if a patient consumes the medication on an empty stomach [17]. In rare cases, mass filarial death can trigger an acute adenolymphangitis attack, mirroring the symptoms of untreated disease. The likelihood and severity of AEs increase with MF density in the blood, and thus, AE

[2] Being adapted to transmission by night-biting *Culex* mosquitos, *W. bancrofti* shows nocturnal periodicity, i.e., migrates to the peripheral circulatory system at night time.

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rates are higher at the beginning of MDA campaigns and tend to decrease with successive rounds [6].

2.4 LF in Haiti

LF has been recognized in Haiti since at least the mid-1700s, first referred to as "pied-botte"[3] by the country's early French colonizers [24]. Endemic to Hispaniola since its importation during the transatlantic slave trade, *W. bancrofti* was detected using blood smears in the 20th century among Haitian workers in Cuba [25]. The first nationwide survey of LF in Haiti would not be conducted until nearly 100 years later, by Dr. Madsen Beau de Rochars in 2000 [9].

In Haiti, LF-associated lymphedema and elephantiasis of the legs is colloquially known as *gwo pye*, and hydrocele is known as *gwo grenn or makloukou*[4]. Haitians with *gwo pye* or *gwo grenn* are subjected not only to physical suffering but also to isolating social stigma.

Early onset of *gwo pye* has especially large impact on Haitian women [26]. Women are more than 10 times more likely than men to develop *gwo pye*, and the debilitating lymphedema associated with the disease prevents many women from pursuing economic opportunities and decreases chances of marriage [27–29].

A relationship between LF and poverty has been clearly established [30]. With the highest poverty rate and poorest health indicators in the Western Hemisphere, Haiti also bears the greatest burden of LF. Average national prevalence of filarial antigenemia has been estimated to be 7.3%, though there is considerable variation across Haiti's 145 communes, ranging from 1% in the southern communes and eastern border with the Dominican Republic, to as high as 45% along the northern coast and in the areas surrounding Port-au-Prince [9]. Within communes,

[3] "Pied-botte" translates to "club foot" in French. LF and club foot were not differentiated by medical science of the time.
[4] "Gwo pye" literally translates to "big foot" in Haitian Creole. "Gwo grenn" translates to "Big testicles/scrotum."

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W. bancrofti transmission rates are highly variable and appear to be influenced by environmental conditions.

Accurate morbidity data are much more elusive. Individuals suffering from LF are often isolated from social interactions and routine activities, effectively becoming a 'hidden population' that is difficult to study [31]. It is plausible, however, that these hidden individuals share social connections with others suffering from LF, creating an interlinked social network. Innovative applications of respondent-driven sampling, a technique historically used to observe hard-to-reach populations, such as drug users or sex workers, have recently been developed to generate more accurate estimates of LF morbidity [31–34]. This technique offers the promise of producing a more-complete picture of LF burden in Haiti and provides a unique, cost-efficient pathway for utilizing social networks in the design and delivery of public health programs.

2.5 Mass Drug Administration

The World Health Organization recommends mass drug administration (MDA) – treating every member of a defined at-risk population at the same time, repeated annually– as preventative chemotherapy in LF-endemic areas [5]. With consistent MDA, the density of MF in the blood of infected individuals is reduced to a level at which the parasites can no longer be transmitted by the mosquito vector. As community-level MF loads are continually reduced, year-over-year, the cycle of transmission is eventually broken as the adult worms die off [1]. There are three drugs recommended for LF treatment: albendazole, diethylcarbamazine (DEC), and ivermectin. Depending on location[5], the drugs are typically used in combination to enhance their anti-filarial effectiveness, as either DEC/albendazole or ivermectin/albendazole . Recent trials

[5] DEC use is contraindicated in areas of the world where *Loa Loa* or *Onchocerca volvulus* are endemic due to the high likelihood of severe adverse events in patients infected with these parasites. Neither are present in Hispaniola.

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have now demonstrated that a triple-drug therapy, combing ivermectin, DEC, and albendazole (IDA) can safely eliminate MF from the blood within 2-3 weeks, rather than multiple years using the standard two-drug combinations [35,36]. Several countries, including Haiti, are currently preparing strategies to integrate IDA into MDA campaigns.

To assess the effectiveness of MDA over time and determine when MDA can be safely stopped, three measures are used to evaluate MDA coverage: 1) *geographic* coverage (% of a geographic area where pills are available); 2) *drug* coverage (proportion of individuals in a target population who ingest the drug); and 3) *epidemiologic* drug coverage[6] (proportion of individuals in the implementation unit who ingest the drug of the total population in the implementation unit) [6]. To effectively reduce transmission, the WHO recommends drug coverage of at least 65% for 4-6 years [4].

2.6 GPELF

In response to World Health Assembly resolution WHA50.29, which encouraged member states to work towards eliminating LF as a public health problem[7], the World Health Organization (WHO) launched the Global Programme to Eliminate Lymphatic Filariasis (GPELF) in 2000 [4]. GPELF strategy is built around two primary objectives: 1) preventing transmission; and 2) alleviating the suffering of those already affected by LF through morbidity management and disability prevention. The WHO's NTD roadmap sets 2020 as the target date for achieving global elimination of LF [37].

In what has been called a "mass uprising of compassion," GPELF has been one of the most rapidly expanding global health programs in the history of public health and has been

[6] Also known as *programme* coverage

[7] "Elimination as a public health problem" refers to the achievement of measurable targets, set by WHO, in relation to a specific disease. After elimination is achieved and validated, action is still needed to maintain these targets [2].

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highly successful in many areas around the world [38,39]. As of 2017, 7.1 billion single-dose antifilarial treatments have been administered to more than 890 million people in 68 countries. In its first 13 years alone, the program prevented or cured an estimated 96.71 million cases of LF [4]. Of the 68 countries initially targeted, 16 have now officially achieved elimination of LF as a public health problem. Although they have made commendable strides toward achieving elimination, the remaining countries face a variety of complex challenges in the last mile of the LF elimination effort, particularly in urban areas, that result in low coverage and non-compliance[8] by the communities [40–45]. Challenges include the difficulty of convincing asymptomatic individuals to participate in MDA and maintaining sufficient coverage over the recommended 4-6 year time period [45]. Much of the literature on LF-MDA has focused on the issue of "systematic non-compliance" and individual's specific rationales for not participating in MDA, with less attention paid to aspects of program design and how interactions between participants and these design elements impact the "user experience" (UX) of the program and ultimately affect MDA compliance and coverage [46].

2.7 LFMDA – Factors Affecting Compliance and Coverage

Non-compliance represents a major obstacle to LF elimination, as non-compliant individuals serve as a reservoir of infection, sustaining transmission of LF at a community level. There have been many studies exploring participant characteristics associated with LF-MDA compliance [47]. A 2008 study in Orissa State, India found that knowing about the MDA in advance, knowing the MDA was to prevent LF, and knowing that LF is transmitted by mosquitos were significant predictors of MDA compliance, controlling for age, gender, and education [48].

[8] Non-compliance refers to participants who do not ingest the medication. Reasons could include refusal, lack of awareness of the MDA campaign, or simple inability to participate.

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Studies from the Philippines, Sierra Leone, Sri Lanka, and Vanuatu have also demonstrated that advance knowledge of the MDA, and having received an LF-related message before the MDA are major predictors of compliance and drivers of increased coverage [49–52].

Misinformation and misconceptions about the drugs used in MDA have been shown to negatively impact compliance across multiple countries and contexts of MDA implementation. Common misconceptions include rumors that MDA is used by the "government" to sterilize the population, that the pills can induce miscarriages of future pregnancies, and that the medicine acts as a contraceptive or inhibits libido [47,53,54].

Individuals who have an awareness of their risk of LF and the benefits of MDA have been shown to be more likely to comply [55,56]. Personal experiences with LF, including having a family member with LF or having seen someone with visible symptoms of LF are strong motivators of compliance [48,51]. Participants who have not had a personal experience with LF, or do not perceive themselves to be at risk have been less likely to comply [57,58].

The antifilarial drugs used have additional health benefits beyond LF treatment, namely a reduction in intestinal helminths. Studies have suggested that participant awareness of these corollary benefits encourages compliance [59]. Several studies have demonstrated that when information is communicated effectively about AEs, participants consider them as evidence of the medication's effectiveness, drawing the connection between filarial-death and AEs [41,60,61].

The most frequently cited factor associated with non-compliance is fear of adverse events (AEs). A large number of studies examining LF-MDA have cited individuals who feared side-effects caused by the MDA, often due to misunderstandings about possible AEs and actual rates of severe events [41,48,49,51,55,62–65]. LF-MDA program communications must compete with

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rumors about AEs [42]. When these rumors are not addressed or acknowledged, they spread quickly and become recalcitrant, negatively affecting compliance [66]. Findings from studies conducted in Haiti regarding systematic non-compliance have echoed those of studies in other countries [10,42,63,67,68].

In Haiti, and many other countries, greater attention has been drawn to the challenges of achieving sufficient coverage for LF-MDA in urban environments [43–45,69,70]. Urban populations tend to be both highly heterogeneous and highly mobile, leading to unique social dynamics that impact MDA. Residents frequently change addresses and may live and work in different areas of the city. Compared to rural areas, urban neighborhoods are characterized by relative anonymity and higher fluctuation or residents. As neighbors are more likely to be strangers, there are fewer opportunities for collective community interaction, which poses a challenge for MDA-related community engagement. Additionally, urban environments are characterized by greater security risks, more complex governance, accessibility issues, and populations that are generally distrustful of institutions [45].

2.8 A Brief History of LF-MDA in Haiti

Following Rochars' nationwide mapping of LF prevalence, it was determined that all nine of Haiti's departments met threshold levels of *W. bancrofti* transmission to require MDA [9]. Using the results of this study to guide its implementation, Haiti's Ministry of Health and Population (MSPP) launched its National Program to Eliminate LF (NPELF) in 2000 [8]. The country's first round of MDA was initiated in the Leogane commune using a chemoprophylaxis of albendazole + DEC [8]. Hyperendemic areas (>10% antigenemia) were prioritized for early rounds of MDA. From 2000-2005, the MSPP quickly scaled up the program to reach all hyperendemic communes.

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With technical and financial assistance from partners including the Centers for Disease Control and Prevention (CDC), the Carter Center (TCC), the University of Notre Dame (UND) Haiti Program, IMA World Health, and the Task Force for Global Health, the MSPP achieved full geographic coverage of all 140 endemic communes in 2012 to include Port-au-Prince and other urban, high transmission "zone rouge" communes [10]. In 2014, 20 communes met WHO criteria to stop MDA and enter the surveillance phase of the program. Considering the staggering challenges faced by MSPP, this achievement is all the more tremendous. These challenges have included devastating hurricanes, the 2004 coup d'etat which precipitated an interruption of funding in 2005[9], persistent civil strife, the catastrophic 2010 earthquake, and a deadly cholera outbreak introduced by U.N. peacekeeping forces [8]. After 19 years, Haiti is nearing its goal of eliminating LF by 2020. However, the urban "zones rouges" have proven particularly challenging for LF-MDA implementation.

2.9 Challenges of the Last Mile to Elimination

In 2011, MDA began in metropolitan Port-au-Prince's six communes (Port-au-Prince, Delmas, Carrefour, Cite Soleil, Pétion-Ville, and Tabarre). Although the first round of MDA was successful with an epidemiological coverage of 79%, coverage has since continually declined year-over-year, now falling below the 65% coverage threshold that must be consistently maintained to achieve elimination. In addition to the urban MDA challenges listed above, funding for MDA in metropolitan Port-au-Prince (PAP) has continually declined. The initial successful MDA round in 20011/12 was funded by the CDC and UND. Afterward, the program's budget and contributions continually declined - nearly 50% by 2014. Contributions from the

[9] This year-long interruption in funding paralyzed the program, preventing MDA from being conducted in 2005. This one year of missed MDA set the progress of the program back by two years [71].

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United States Agency for International Development ENVISION project helped offset funding gaps, beginning in 2006, though other funders have continued to reduce their contributions.

Declining coverage and persistent transmission in PAP (among other "zones rouges") even after ten years of MDA, has led to program fatigue among staff and participants. The causes of the continuing decline in coverage for LF-MDA in PAP remain unclear. In preparation for annual MDA implementation in 2019, MSPP and partners have now made significant commitments towards research and activities to better understand the factors that have precipitated this decline in coverage and are determined to operationalize these insights towards innovation in program design and MDA implementation to achieve the goal of LF elimination by 2020.

CHAPTER III: METHODS

To identify specific contributors to the loss of coverage, this study employed a retrospective qualitative case study approach using grounded theory data collection and analysis, a method that has been used successfully in previous CSE case studies [72,73]. This case study involved interviews with both internal stakeholders (ISH; i.e., MDA program staff) and external stakeholders (ESH; i.e., potential MDA participants) at one high-distributing zone and one low-distributing zone in each of two communes, Tabarre and Carrefour. Two different types of interview methods were employed: 1) In-depth interviews, primarily with ISH, but also including ESH; and 2) brief "on-the-street" interviews with ESH to gauge the general public's attitudes about, and experiences with, LF-MDA in Port-au-Prince (PAP). These street interviews will be the focus of this thesis.

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3.1 Population

Interviewees were selected from the populations of Tabarre and Carrefour, two communes within the metropolitan area PAP. The PAP arrondissement[10] officially contains eight communes in total, though the IHSI has defined the metropolitan area as containing only six communes: PAP, Delmas, Cite Soleil, Tabarre, Carrefour, and Petion-Ville [74]. As of 2015, metropolitan PAP is estimated to have a population of just 2.6 million and a population density of approximately 16,500/km^2. To the northeast of the city center, Tabarre is relatively small commune with an estimated population of 130, 283. Carrefour is south of the city, bordered to the west by Leogane and Gressier. It is one Haiti's largest communes, with an estimated population of 511, 345. Carrefour contains exceptionally mountainous terrain, complicating accessibility to certain areas throughout the commune.

3.2 Sampling Strategy

To gain insights about more- and less-effective MDA strategies, the sampling strategy was developed with the goal of identifying differences in practice that may have impacted coverage between high-distributing and low-distributing zones, each within one high-coverage commune and one low-coverage commune.

To determine which of metropolitan Port-au-Prince's five communes still participating in MDA should be targeted, epidemiological coverage data from 2011/12 through 2018 was averaged to identify the most consistently high-coverage and low-coverage communes. Tabarre and Carrefour were identified as having the most consistently high coverage (90%) and low coverage (54.5%), respectively (Table 1).

[10] From the French *arrondir* ("to encircle"), arrondissements are sometimes referred to as "districts." Subdivisions of Haiti's ten departments, the 42 arrondissements are further divided into 145 communes and 571 communal sections.

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Table 1. Average epidemiological coverage by five communes still participating in annual MDA.

Commune	Average Epidemiological Coverage, 2011/12 - 2018
Tabarre	90.0%
Cite Soleil	73.6%
Delmas	65.6%
Port-au-Prince	56.4%
Carrefour	54.5%

Zone performance data were reviewed to identify a high- and low-distribution zone in each commune. Distribution data by post was only available for 2018, and denominator data were unavailable, preventing calculation of true epidemiological coverage. However, each distribution post was expected to serve approximately 1,000 people [75], and thus, zones were selected based on comparing the average number of people treated per distribution post in each zone to the median number of people treated per post in those zones (Table 2). In 2018, the median number of people treated per post in Tabarre and Carrefour were 807 (range: 250-1,726) and 819 (range: 140-2,579), respectively.

Table 2. Average number of people treated per post in the 2018 MDA in the four selected zones. Data provided by IMA World Health.

Zone	Commune	Average Number of People Treated Per Post in 2018 MDA
Zone 1 High-Distributing Zone, High-Coverage Commune	Tabarre	1,593
Zone 2 High-Distributing Zone, Low-Coverage Commune	Carrefour	1,413
Zone 3 Low-Distributing Zone, High-Coverage Commune	Tabarre	341
Zone 4 Low-Distributing Zone, Low-Coverage Commune	Carrefour	376

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By selecting communes and zones across varying levels of coverage and distribution, this study aimed to identify if differences in practice by program staff were reflected in the attitudes and experiences of members of the general public.

3.3 Research Design

Street Interviews: Rationale

Due to the nature of this study design, drawing a natural sample of ESH to gauge attitudes about, and experience with, MDA campaigns in Port-au-Prince, was not possible. The original sampling frame for in-depth key informant interviews originally included multiple compliant and non-compliant individuals from each zone. The HELP team, however, decided to include a convenience sample from the general public in order to complete these interviews. In order to simulate how community drug distributors (CDDs) organically encountered passers-by, an interviewer was positioned at 9 of the 12 distribution posts (Figure 4; Zone 4 was inaccessible at the time of the interviews, due in part to Carrefour's mountain terrain in addition to significant civil unrest related to the recent PetroCaribe scandal [76] which made study-related travel impossible for several weeks). By employing semi-structured interview methodology among a convenience sample of the general public, the study aimed to gain insights into, as noted by Seidman (2006), "how their individual experience interacts with powerful social and organizational forces that pervade the context in which they live and work, and we can discover the interconnections among people who live and work in a shared context" [77].

3.4 Interviewer Training

In September 2018, the HELP team led interviewer training sessions in Haiti with the Haitian team. In addition to a two-day session focused on the in-depth key informant interviews,

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an additional half-day training session was held with the local, independent journalist who contracted to conduct the street interviews. Topics covered included the goals of the interviews, timeline and data collection expectations, the informed consent process, proper electronic and hard-copy data management, overview of the street interview guide developed by HELP, instructions for GPS and photo documentation, and a brief overview of the PAP LF-MDA program.

3.5 Interview Procedures

Street interviews were conducted in Haitian Creole with 34 participants at distribution post sites in each of 3 zones. In Tabarre, street interviews were conducted at both the high- and low-distributing post sites. In Carrefour, interviews were conducted at high-distributing posts only. The remoteness of Carrefour's low-distributing zone, combined with significant civil unrest, prevented the interviewer from traveling to the selected site.

After consent was obtained, passers-by were asked about their knowledge of LF, if they had ever taken the medication during prior MDAs, the reasons for their decision, and any general thoughts or observations about the program. The interviews were approximately 4-6 minutes in length. The physical surroundings of each distribution post were documented through video or photographs and the GPS location was marked. Interviews were audio recorded, and all audio recordings were uploaded to a secure, password-protected location accessible only by the HELP team.

In keeping with grounded theory methods, interviews were semi-structured, allowing participants to express their perspectives and experiences in their own words and framing, rather than restricting them to a rigid questionnaire designed from the interviewer's perspective. The interviewer was encouraged to be conversational, adapting the interview as new ideas were

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brought up by participants, though an interview guide was provided that described potential questions and themes to be explored based on the HELP conceptual framework [11]. Data were analyzed by the HELP team between interviews, and any new insights were further explored in successive interviews.

3.6 Data Analysis

Data analysis was guided by the principles of grounded theory, allowing for qualitative data to be analyzed and understood from the data itself, rather than from comparison to existing theory or the researcher's hypotheses [72,78]. MAXQDA version 18.1.1 was used at all stages of transcription and data analysis [79].

Audio recordings were not transcribed verbatim in the original language, but rather, were translated and transcribed from Haitian Creole directly into English by the author (see notes on translation below). Transcripts were annotated with memos, then coded to identify key concepts and themes.

Notes on Translation

As the identity of the transcriber, translator, and researcher were one and the same, and the author is not a native-speaker of Haitian Creole, many ethical issues and the potential for bias were considered prior to translation. These issues included "hierarchies of language power, situated language epistemologies of researchers, and issues around naming and speaking for people seen as 'other' " [80]. Language is power, and translation is not a neutral exercise [81]. The act of translation is itself a form of subjective analysis, involving cultural brokerage and assumptions of meaning [82]. Given the constrained nature of the research project in both time and funding, the author completed translation with as much due diligence as reasonably possible, with the understanding that solutions to dilemmas of translation "are not to be found in

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dictionaries, but rather in an understanding of the way language is tied to local realities, to literary forms, and to changing identities" [83].

Interviews were translated as word-for-word as possible, save for cases where a direct, verbatim translation would impair meaning. For example, a direct translation of the Haitian Creole "gwo pye" to the English "lymphedema" or "elephantiasis" connotes a more medicalized understanding of the condition than how it is typically conceptualized in the local context [84]. In such cases, the Haitian Creole terms are retained in the transcript. In cases where the meaning of participants' words could be interpreted in multiple ways, the author consulted with native speakers of Haitian Creole who were approved by Emory University's IRB to participate in analysis of study data. Where meaning of idiomatic phrases would be lost in a direct translation, the original phrase in Haitian Creole is footnoted with a brief explanation.

3.7 IRB statement and Ethical Considerations

Institutional Review Board (IRB) approval was obtained from Emory University and Haiti's MSPP for this study. Consent for participation was obtained prior to each interview through signed consent forms. Electronic data, including audio files and de-identified transcripts, were stored in a secure, password-protected folder accessible only to the study team, and were accessed only on password-protected computers. Hard-copy data were stored in a secure, locked area.

3.8 Limitations

Data Collection was interrupted on several occasions due to civil unrest in Port-au-Prince. These circumstances prevented members of the HELP team from traveling to Haiti to work with the local Haiti team and oversee data collection and analysis. Intermittent phone and internet access made communication difficult during these times. These delays significantly

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impacted data analysis and collection timelines. The “street” interviewer was unable to visit the low-distribution zones within Carrefour due in part to the aforementioned civil unrest, as well as the remoteness and mountainous topography of the selected zone. Because of these limitations, specific comparisons could not be drawn between zones as planned in the study’s sampling strategy.

CHAPTER IV: RESULTS

The sampling strategy was designed with the goal of being able to conduct a comparative analysis between high- and low-distributing zones. However, the limitations described above prevented the study from generating sufficient data to draw specific comparisons between zones. That said, there were no significant differences between the three zones that were visited in terms of perceptions of, and experiences with, the LF-MDA program.

Interviews with ISH from the other “arm” of the HELP study were able to be conducted across all four zones, allowing for a more precise comparison to be drawn. However, as in the street interviews, there were no consistent differences between the four zones in distribution approach, attitudes, or other characteristics. The absence of differences between zones was a significant finding, suggesting that the issue of “systematic non-compliance” by prospective MDA participants has been overemphasized in the literature, and among the program partners, obscuring broader, systemic features of the program itself.

Participants’ specific rationales for compliance or non-compliance echoed those widely reported in previous studies in Haiti and other countries. While there were many individual, specific reasons for compliance or non-compliance cited by participants, all ultimately impact, and are impacted by, the perceived credibility, legitimacy, and trustworthiness of the LF-MDA program.

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In analyzing the street interview data, six major themes emerged: 1) Convenience and Accessibility; 2) Adverse Events; 3) Familiarity with LF and Perceived Risk; 4) Influence of Social Networks; 5) Program Communications; and 6) Perceptions of Program Credibility.

Convenience and Accessibility

The inconvenience of the distribution posts' limited operating hours and frustration with the program's required Directly-Observed-MDA (DO-MDA) policy was, by far, the most frequently discussed concerns among both compliant and non-compliant community members. Participants complained that even if they wanted to consume the pills, they simply couldn't because they were at work while the posts were open.

> *I work all day. If I can only take the pills when they want me to, this is not possible. They tell me it has to be this way, but it is not possible for me. I don't understand why it must be this way.* – NC

> *A long time ago, they used to give pills where people work, but the pills can make you sick if you haven't eaten yet and people don't want to get sick at work.* – NC

Participants frequently lamented about the lack of food at distribution posts. According to program policy, CDDs must ensure that participants have eaten prior to taking the pills to prevent adverse events, yet distribution hours do not necessarily overlap with participants' mealtimes. Food had been provided in earlier MDA rounds, though interviews conducted with participants and program staff suggest that this is no longer the case. The lack of food availability at distribution posts, combined with the frequently cited concern that participants are often unable to plan their mealtimes day-to-day, prevents many prospective participants from consuming the medication. In addition, there is strict enforcement by CDDs of the program's DO-MDA policy, preventing participants to take the pills home to consume at their convenience [15].

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> *If I pass by them while they're giving pills, because I can't eat, I won't take. If I haven't eaten, they tell me to leave and eat and come back for the pill. They used to give food and water. If they don't give food, I won't take it. I don't want to feel sick.* – NC

> *When they give us the pills, they don't tell us anything about them. They tell us we can't take it without food, but I don't know when I will be able to eat."* – NC

> *When I happen to pass them* [CDDs] *on the street, I haven't eaten yet. They don't have food to give. I don't know when I can eat. Sometimes I can only eat in the morning, sometimes only night, I don't know. I want to take the pill home so I can eat before I take it so I don't feel sick.* -NC

Adverse Events

Nearly every interview contained a lengthy discussion regarding fear of potential side-effects from taking the medicine.

> *I don't take it each year, I won't lie to you. Some years I take it, some years I don't. It makes you nauseous. It makes you not able to do anything, it causes you troubles. When I took it, it made me dizzy, made me vomit, gave me chest pain. It gave me problems. There are people who say it confuses you, makes you tired. Because of that, people are scared of it, they don't take it.* – NC

Gwo grenn (hydrocele) was the most frequently mentioned side-effect, followed by *gwo pye* (lymphedema/elephantiasis).

> *The medicine gives you gwo grenn. It hasn't happened to me personally, but I know it's happened to a lot of people. That's one reason why I don't take them. A lot of people don't take the pills for this reason.* - NC

Several participants described weighing their fear of side-effects against their fear of the disease's symptoms.

> *"The pills made me feel bad. They give me a lot of problems. Even though I am afraid of this happening again, it's important to prevent gwo pye. If we don't want the worse thing to happen to us, we are obliged to take the pills!"* – C

Other participants discussed the fact that the side-effects of the medication can mirror the symptoms of LF, negatively impacting their perceived value of participation.

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I: What do you know about LF?
NC: All I know is that it gives you gwogrenn, gwopye… but I don't know exactly how you get it or why that happens
I: Are you aware of the prevention campaign?
NC: Yea, of course man! They are in the streets. They go to the prison, they go to the schools. But I choose not to take the pills.
I: Why?
NC: Because I don't want gwogrenn.
I: But didn't you say that the disease causes gwogrenn? What do you mean?
NC: Man… They both cause gwogrenn. With the disease, I don't know maybe some people get gwogrenn, but I think more people get gwogrenn from the pills. There was a man who took the pill and it gave him this, really bad. Everyone knew about it. He complained to everyone about the pills. If you see that only one time, you won't want anything to do with it. Now I don't pay attention to any of it at all. A lot of people think this way.

Another oft-mentioned fear concerned potential reproductive side-effects, frequently tied to narratives of an American-led conspiracy to sterilize the population.

"I took the pill once a long time ago. Now, I don't take it. There are a lot of people who say the pills are toxic. For example, they make you unable to have children. They do all kinds of bad things to your body. That's why I'll never take the pills... I only took them when I was in school and they made us do it. The people who give the pills don't talk about these things or give information. They just say that it's important."- NC

People say that the blans send the pills to make us sterile. The 'white shirts' in the street say they are from the government, but… I don't know. – NC

You hear this thing a lot on the street, that if you're pregnant and want a free abortion the pills are good for that. I'm serious![11] I wouldn't do that, but I believe it's true because I think the pills do something to your body. They make you unable to have children. – NC

Familiarity with LF & Risk Perception

While all participants were aware of LF, most had no personal experience with the disease. None of the participants reported experiencing symptoms of LF, such as *gwogrenn* or *gwopye*, and very few had first-hand encounters with anyone who has.

[11] "*M p'ap voye flé!*" : "I'm not throwing flowers!" To 'throw flowers' is to talk nonsense, exaggerate, be silly, etc.

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I: Has something like that, gwogrenn or gwopye, happened to you, or have you seen it affect other people?
C: No, not me. I think I saw it one time… maybe one time a long time ago. I don't remember.
I: Was this here, in this zone?
C: No, it wasn't around here. Almost in the same zone, but not in this neighborhood.

I: Have you ever seen a person that has LF?
NC: Only on TV. They talk about it on the radio when they [CDDs] *come. There's a doctor who shows pictures of* [laughs] *bad things, you understand? Big testicles, big vaginas, big legs to make you afraid of the disease. I've never seen it myself though.*

Many participants stated that they lacked specific knowledge about the etiology or pathology of LF, despite being exposed to a large volume of general communications regarding the LF-MDA campaign. These same participants expressed a general lack of concern about the disease.

I: What do you know about LF?
NC: I don't know anything. I only know that they say the pills will prevent gwopye. I took them 3 times a long time ago. They made me sick so I don't take them anymore. I don't see gwopye anywhere so I don't think about it.

One participant acknowledged the lack of concern among the in community.

I: Do you think that people hear enough information about Lymphatic Filariasis?
C: Yes! They know about it. But they don't truly have... they don't truly give it importance... they don't understand the seriousness of it.

Influence of Social Networks

The influence of participants' social networks and relationships on compliance was apparent in the interviews. Compliant community members mentioned that seeing other members of their community, particularly community leaders, was a motivating factor.

"I passed by them on the street. They were telling everyone that the pills are good for filaryoz, that everyone should take it. I didn't really want to take it. But I saw a lot of people taking the pills. I saw them at the school, giving pills to all the students. So, when I saw them outside, I took the pill too!" - C

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> "*When I see my friends take it and see they are ok, and when I see other official people, government people, take it, that makes me feel ok about taking it.* - C

The same effect was also seen with non-compliant community members being influenced by fellow non-compliers, or even actively prohibiting their family members from consuming the drugs.

> *"I hear from my friends about the bad things the pills can do to you. The people giving the pills say they are good, but I believe my friends. They tell me the pills made them sick, made them sleepy. So, I don't take them"* – NC

> *I: Are there other people in your house that take the medicine?*
> *NC: No, they don't take it.*
> *I: No one at all?*
> *NC: No, the young children at school – they give it to them at school, but the older children don't take it. I don't let them take it.*
> *I: Why not?*
> *NC: Because, you know all these bad things that the pills can do to you. I don't want them to be hurt by the pills.*

According to recruiting requirements detailed in the Haiti NTD protocol (cite), all CDDs should reside in the area of their assigned distribution post. However, several participants mentioned that CDDs were not from their community, with their perceived identity as 'outsiders' negatively impacting perceptions of the program.

> *I: Do you personally know anyone who helps give the medicine each year?*
> *NC: I don't know anyone, they come in from another place, from somewhere else… They are total strangers.*

Program Communications

Participants frequently mentioned their frustrations with program communications, both in general messaging and in their direct interactions with CDDs at distribution posts.

> *I: When they gave you the meds, did they give you any information about it? Like, why you should take it?*

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> *C: Yes, they said if we don't take the pills… when the bugs bite us, they'll give us gwo pye. That's all they told us. Nothing else at all. They don't tell you the pills will make you feel bad. Haitians all talk about this. The 'white shirts' don't.*

Despite near-universal worries regarding side-effects, participants often stated that their concerns went unacknowledged in program communications and in interactions with CDDs.

> *I: Have you ever talked with them* [CDDs] *about your concerns* [about side-effects]*?*
> *NC: No, they are too busy, and I don't want to bother them.*
> *I: Is there anyone you can talk with to get more information or to tell them your concerns?*
> *NC: No… I don't think so. There's no one like that I can talk to*
>
> *When they give us the pills, they don't tell us anything about them*. - C

In addition, many Haitians are unclear about the overall aims and rationale of the program's MDA strategy.

> *I don't know when it* [the program] *will ever end. They said a long time ago that it would be over soon, but now years later they are still giving us pills. Things don't change.*[12] *Nobody knows why. They don't tell us. They don't talk about it.* - C

Program Credibility

All aforementioned themes ultimately relate to participants' implicit perspectives on the credibility of the program. Along with expressions of general distrust in institutions, many participants were more explicit in describing their doubts about the legitimacy and credibility of individual CDDs and of the overall program. Several participants voiced doubts about CDDs' credibility as agents of a supposedly legitimate medical and public health intervention. Participants spoke about how their experiences at street-based distribution posts were divergent from their expectations about what a serious medical encounter ought to be.

[12] *"Li p'ap monte, li p'ap desann*" : "It doesn't go up, it doesn't go down" i.e. things never / will not change.

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> *It's not that they* [pills] *are difficult to find – I choose not to take them. The people are easy to see, with their t-shirts. I don't want to take medicine from these people with t-shirts. If a doctor told me I needed this medicine for a disease, then I would take it.* - NC

> *If a doctor gave me a prescription for the pharmacy, then I would take it. The medicine can do a lot of bad things to your body, but if a doctor tells you to take it, you ought to take it.* - C

Cost of the pills and of the overall program were mentioned as motivating factors by both compliant and non-compliant individuals. Several compliant community members mentioned the perceived high costs of the impressive efforts of the program.

> *I: What motivates you to take the pills every year?*
> *C: It's a good thing if everyone takes the pills. It's good for the people. It's good for the country. Even though the pills are free, I think that it's all very expensive*[13] *so I think it's important.*

In contrast, many more non-compliant community members called into question the rationale behind the pills being given for free.

> *We don't like that the pills are free like that. It makes us doubt. Maybe the pills are old or bad. Haitians don't like when things are free you know?* - C

Additionally, participants expressed a general sense of indignity regarding their experience at distribution posts.

> *I don't like that I have to wait outside with all these people for medicine, like we are waiting for food or clothes*[14]*. I don't like to get my medicine from the street. You don't know if it's good or bad.*

[13] *"Koute tet neg"* : costs a man's head i.e. is very expensive
[14] *"Pèpè"* : Secondhand clothing, usually imported en-masse from the United States. Also sometimes called "rad kennedi" (Kennedy clothes), as the import of *pèpè* began in the 1960's during the Kennedy administration.

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CHAPTER V: DISCUSSION

The participants of this study painted a very clear picture of the generally poor reputation of the LF-MDA program in Carrefour and Tabarre. Their responses draw attention to elements of a complex 'ecosystem,' comprised of various stakeholders, relationships, program design features, contextual factors, and the complex interactions that occur between them which characterize the 'user experience' (UX) of the LF-MDA program. While much of the literature has focused on individual, specific rationales associated with "systematic non-compliance," this reductionist mode of thought offers a fragmented, incomplete conceptualization of the irreducibly complex set of interrelated factors that shape participants' overall experiences and perceptions of the program. Many of the contextual factors that shape the LF-MDA UX are outside the control of the program, though nearly all participants referred to negative interactions with specific elements of the program's design that contributed to negative perceptions about the overall program.

The full report from the HELP study, which provides additional analyses of the program's "business-facing" elements, offers several instructive analogies from the business management and marketing fields that aid in understanding how specific programmatic issues likely contributed to the observed declines in MDA coverage [12]. In this thesis, which specifically examines the general public's attitudes and experiences with the LF-MDA program (i.e. "public-facing elements"), concepts from the broader literature on design, and its many sub-disciplines, prove useful in demonstrating how the interactions between prospective participants, the various manifestations of the program, and contextual mediating factors may shape the overall experience of the program, which in turn impacts compliance and coverage.

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Various design elements of the MDA distribution post UX were particularly disconcerting to participants. A basic objective of graphic design, and UX design in general, is the intentional triggering (or at least accounting) of *a priori* mental models with the goal of eliciting a desired emotional response or guiding a particular gesture [85]. Mental models are a cognitive shorthand, an often-subconscious mechanism of individuals' expectations of how something *should* work [86]. For example, the color green in food packaging triggers mental associations of "freshness" or "nature," priming prospective consumers' expectations about the product. Designing products and services that meaningfully account for, or even capitalize on, these expectations is a key component of establishing the trustworthiness of a brand (or in this case, a program) [87]. When an experience is discordant with expectations, trust can quickly erode. Participants' negative experiences at distribution posts are a clear example of how the distress that occurs when a mental model of what an experience of a medical encounter *should* be conflicts with what the experience is *actually* like, negatively impacting the perceived trustworthiness and credibility of the program.

Not only did the actual implementation of distribution posts *not* align with participant mental models of a legitimate medical encounter, but it also appeared to trigger *a priori* mental models with negative associations. Several participants referred to the generally questionable quality of medication obtained on the street. A thriving, though illegal, street-market for medication has been well established for decades in Port-au-Prince, long before the city's first round of MDA [84]. Vendors are often no more knowledgeable than customers regarding the effects or quality of their products. That the current implementation of LF-MDA in urban Port-au-Prince may bear more resemblance to the familiar practice of commercial exchange for medicine of dubious quality than a serious medical intervention for many Haitians should not be

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overlooked. In addition, many participants expressed that particular aspects of the distribution post experience engendered feelings of indignity. Specifically, the act of waiting in line for donated, free medication, which bears resemblance to the long lines of people waiting for *manje sinistere*[15] or other types of aid, was described as potentially demeaning by several participants.

The concept of human-centered design (HCD), distinct from the similar concepts of 'user-centered design' and 'design thinking,' offers additional perspective on the LF-MDA experience [88]. Although HCD's basic principles have their roots in computer science, engineering, and ergonomics, HCD has recently seen a striking rise in popularity in the field of global health as a mindset for addressing complex social problems [46]. The HCD framework provides a more holistic lens that centers the whole person in the broader socio-cultural context, highlighting the additional complexity of the socio-contextual factors that mediate many of the interactions that occur within the LF-MDA 'ecosystem.'

Perhaps the most troubling finding of this study was that many participants expressed an explicit desire to "comply" with LF-MDA yet were precluded from participating by specific aspects of the program's design, which do not appear to account for broader socio-contextual factors. This finding suggests that certain manifestations of "systematic non-compliance" may be better understood as "systematic exclusion." Among many other exclusionary design features, nearly every interview contained a lengthy discussion about the lack of food provided at distribution posts. Participants' spoke about how consuming the drugs on an empty stomach is likely to trigger AEs, with oft-mentioned rumors about exaggerated rates and severities of AEs, likely contributing to the insistence on having something to eat prior to taking the medication. Program policy requires drug distributors to ensure that participants have eaten prior to

[15] "*Manje sinistre*" : Sinister food. Refers to imported food-aid

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swallowing the pills, yet no food is provided at the posts. Framed against metropolitan Port-au-Prince's notably high rates of food insecurity, many participants mentioned that not only are they are often unable to plan their meals day-to-day, but they also must work long hours that overlap with the operating hours of distribution posts. Considering the interrelated social, economic, cultural, and political factors that mediate the LF-MDA experience, timing a meal to coincide with a visit to a distribution post (if one even has the time available) is nearly impossible for many prospective participants. As a young man from Carrefour put simply, "If I can only take the pills when they want me to, this is not possible. They tell me it has to be this way, but it is not possible for me. I don't understand why it must be this way."

Studies throughout Haiti and many other countries have demonstrated the importance of addressing socioeconomic barriers in concert with targeted health interventions, including the simple, yet significant act of providing food with medication [89]. In describing the process of designing a comprehensive tuberculosis care program, Farmer (2005) quotes his patients' insistence that providing drugs without food is akin to "*lave men, siye até*" (washing your hands, then drying them off in the dirt) [90]. This broader perspective, taking inspiration from HCD, obliges a rethinking about how we ought to frame causality in MDA compliance. Operating within challenging environments, like metro Port-au-Prince, requires that MDA programs make informed, deliberate design choices that are responsive to the local context and directly address structural barriers that prevent access to care.

Future Directions & Recommendations

The findings of this study contribute to a growing body evidence calling for greater attention to how prospective participants' interactions with MDA program elements are mediated by highly complex, interrelated social processes that cannot be reduced to discrete 'factors' that

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may be associated with compliance. An over-emphasis on "systematic non-compliance" and technical solutions has obscured from view the broad, biosocial factors that shape both individuals' decision-making processes and, ultimately, the long-term success of the program. As Haiti prepares for its next round of LF-MDA (and rounds beyond 2020 if necessary), a more comprehensive understanding of the LF-MDA 'ecosystem,' and the biosocial processes that occur within it, is vital to the continued success of the program. The need for more biosocial inquiry becomes all the more important in the constantly-evolving socioeconomic environment of metropolitan Port-au-Prince, where the program must overcome many structural barriers in the provision of treatment for the city's population.

Admittedly the charge to "address structural barriers" feels both overly-nebulous to the point of being unactionable, and overly-daunting to the point of seeming unfeasible, though HCD offers a concrete framework and methodologies that can provide guidance in generating non-obvious solutions to highly complex social problems that may go unelicited by the 'status-quo' modes of inquiry in global health [91]. Rather than treating end-users as simple 'informants' through interviews and focus groups, HCD involves the active participation of users at all stages of the design process, from inspiration through ideation and implementation [92]. Users are reconceptualized from 'informants' to 'co-designers' in the innovation and prototyping of solutions that are directly-tailored to their needs.

MSPP and partners have recognized the need to gain a more meaningful understanding of the individuals who have been "systematically non-compliant," especially in communes like Leogane and Gressier, which still require MDA even after 12 rounds of treatment. HCD, which places primary emphasis on building deep understanding through empathy, offers a useful framework towards this end. In addition, innovative applications of techniques like respondent-

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driven-sampling may be used to leverage the social networks of prospective participants, both to generate more detailed insights into factors affecting compliance and to co-produce innovations in program design that are responsive to the needs and values of participants [31,88]. In his influential text, *A Theology of Liberation*, the theologian Gustavo Gutiérrez proclaims that our humanity lies in our "struggle to construct a just and fraternal society, where persons can live with dignity and be the agents of their own destiny" [93]. In trying to reimagine how we might engage more meaningfully with one another, this may be a good place to start.

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