



# Understanding Linkage to Care for Patients With Heart Failure in Rural Haiti

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UNDERSTANDING LINKAGE TO CARE FOR PATIENTS WITH HEART FAILURE IN  
RURAL HAITI

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A Thesis Submitted to the Faculty of

The Harvard Medical School

in Partial Fulfillment of the Requirements

for the Degree of Master of Medical Sciences in Global Health Delivery

in the Department of Global Health and Social Medicine

Harvard University

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## Understanding Linkage to Care for Patients with Heart Failure in Rural Haiti

### **Abstract**

#### **Background**

Heart failure is a final common pathway of many cardiovascular diseases (CVDs), which together represent the leading causes of death and DALYs worldwide. The limited existing data on heart failure in low-income countries demonstrate a set of etiologies distinct from high-income countries and a significant burden of disease caused by these etiologies. In this study, we focus on post-discharge outpatient follow-up characteristics for patients admitted to a tertiary care hospital in rural Haiti admitted with a primary diagnosis of heart failure in order to better understand factors influencing retention in chronic disease management for heart failure, irrespective of heart failure etiology.

#### **Methods**

This study is a retrospective cohort analysis of patients ( $\geq 18$  years old) admitted to Mirebalais University Hospital (HUM) with a primary diagnosis of heart failure between October 2013 and September 2014. Data on heart failure etiology, inpatient mortality rates, readmission rates, post-discharge “linkage” (30-day) and “retention” (60-day) to outpatient heart failure follow-up care at HUM, and demographic data (age, sex, and distance from HUM as approximated by referral zones) were collected and analyzed in this study.

#### **Results**

A total of 311 patients met eligibility criteria. The average age of patients admitted with heart failure was 52 with nearly 1 out of 3 patients admitted under the age of 40 years. Among this cohort, 81 received an etiologic diagnosis of heart failure by echocardiogram and/or clinical

history. Cardiomyopathy was the leading etiology of heart failure (43%; n=35), followed by peripartum cardiomyopathy (21%; n=17), right heart failure (12%; n=10) and multiple other etiologies (all <10% of total). In-hospital mortality for patients admitted with heart failure was 11.9% (n=37). Of patients who survived admission, 6.6% of patients were readmitted within 30 days of discharge. Of these, 37% (n=101) returned for outpatient follow-up at HUM within 30 days of discharge, and 48% of these patients (n=48) returned for a second follow-up appointment within 60 days post-discharge. Stratifying post-discharge patients into 4 geographic zones of ascending distance from HUM demonstrated decreasing “linkage” to care rates with distance from the HUM clinic (45%, 39%, 35%, and 25%, respectively).

### **Conclusions**

Distance from HUM represents one likely factor influencing the low 30-, 60-, and 90-day outpatient follow-up rates observed in this study. This observation fits into a broader set of literature on chronic disease management in rural Haiti indicating that structural barriers to care, such as the economic burdens associated with increasing distance from outpatient follow-up care, require close attention and intervention in order to improve chronic disease management for conditions like heart failure in rural Haiti and other similar settings globally.

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## **INTRODUCTION**

### *Heart Failure as a Cardiovascular Disease*

Cardiovascular diseases (CVDs) are the leading causes of death and disability-adjusted life-years (DALYs) worldwide, estimated to have caused 30% of global deaths and 151 million DALYs in 2010 (10, 19, 38). This category of diseases includes ischemic heart disease, stroke, hypertension, peripheral vascular disease, congenital heart disease, rheumatic heart disease, other valvular heart diseases, arrhythmias, and various cardiomyopathies. These diseases generally require lifelong medication therapy, often on a daily basis, to mitigate disease progression and death (38). Thus, most CVDs are considered “chronic diseases” necessitating health delivery strategies to ensure that patients have continuous, lifelong access to medications and follow-up with medical providers to monitor disease progress. In resource-poor settings where access to healthcare infrastructure is limited and often unreliable, CVDs therefore create an important global health delivery challenge.

The term “heart failure” represents a final common pathway or “syndrome” of many CVDs in which the heart becomes unable to pump an adequate volume of blood to meet the body’s metabolic demands (1, 2). A comprehensive description of heart failure pathophysiology and its causes is beyond the scope of this paper; however, some of the more predominant etiologies of heart failure are worth describing here in relation to study aims, as the precise etiology of heart failure can influence approaches to disease prevention and treatment. The following CVDs are the most common underlying causes of the heart failure syndrome: cardiac ischemia, hypertension, rheumatic heart disease, non-ischemic cardiomyopathies (including peripartum cardiomyopathy), myocarditis (secondary to viruses, etc.), endocarditis, HIV-induced

cardiomyopathy, cardiotoxic substances (e.g. alcohol), pericardial disease, non-rheumatic valvular abnormalities, arrhythmias, and congenital heart diseases (1, 2, 3, 4).

Regardless of etiology, heart failure is characterized by a shared set of symptoms and physical signs. Symptoms of heart failure include dyspnea, fatigue, nocturnal cough, wheeze, palpitations, and confusion progressing to the extent that patients are unable to breathe comfortably while at rest and are effectively homebound.\* Physical signs include lower extremity edema, wheezing and rhonchi, tachycardia, hepatomegaly, and cachexia (1, 2, 3). If left untreated, heart failure can and often does progress to death. No single gold standard exists for the diagnosis of heart failure, which can make the diagnosis of heart failure difficult especially in settings with limited diagnostic resources (5). However, the diagnosis of heart failure can be established from a variety of approaches—from clinical history, response to treatment, and diagnostic evaluations such as electrocardiogram and echocardiography (39, 40). The approach to heart failure treatment depends in part on the underlying disease etiology but also on the use of medications to relieve symptoms irrespective of etiology. Once a patient develops heart failure, a reduction in the etiology-specific risk factors can control symptoms and prevent worsening of the underlying heart disease but rarely completely cure the syndrome. Thus, prevention and/or reduction of these specific risk factors are a key recommendation in heart failure management guidelines (1, 6). Table 1 below provides a summary of modifiable risk factors that contribute to the leading etiologies of heart failure syndrome:

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\* Patients with heart failure are often classified by symptomatic functional status as defined by the New York Heart Association (NYHA), ranging from Class I (asymptomatic with exercise) to Class IV (unable to carry out any physical activity without discomfort) (6)

**Table 1**

| <i>Heart Failure Etiology</i>                                      | <i>Modifiable Risk Factor(s)</i>   |
|--|--|
| Ischemic (1, 7)  | Smoking, diabetes, obesity, hypertension, high dietary salt intake, physical inactivity, lack of access to acute management of myocardial infarction |
| Hypertensive (1, 9)  | High dietary salt intake, smoking, particulate air pollution, obesity, lack of access to management of hypertension                                  |
| Rheumatic (2)  | Poor access to pharyngitis antibiotic treatment, poor sanitation & hygiene, overcrowding, lack of access to definitive cure of valvular disease      |
| Cardiomyopathy (HIV, nutritional deficiencies, viral, etc.) (8, 9) | Poor access to infectious disease treatment, poor sanitation & hygiene, overcrowding, food insecurity  |

Once heart failure symptoms develop, though, lifestyle changes (e.g. reduced dietary sodium and fluid intake) and daily medications (diuretics, ACE-inhibitors, beta-blockers) can be used to improve symptoms and minimize progression of disease (1, 2, 6).

### *Global Epidemiology of Heart Failure*

Because of the many underlying etiologies of heart failure and differential access to its prevention and treatment, heart failure epidemiology appears to vary markedly among high-, middle-, and low-income countries. While heart failure has been studied extensively in high-income countries (HICs) (1, 3, 6, 26, 39, 40) no population-wide studies of heart failure exist for low- and middle-income countries (LMICs), thus estimates for these areas can only be extrapolated from a relative paucity of smaller cohort studies (4, 11, 14, 16, 17, 25, 44, 57). In HICs, the prevalence of heart failure is estimated at roughly 2-3% (1, 3) and increases dramatically with age, estimated at a prevalence of over 8% after age 75 (3, 12) with an average age of onset at just over 70 years (16). Notably, heart failure patients in the US cost on average \$100,000 per lifetime due to frequent rehospitalizations (1). These rehospitalizations result from

the significant morbidity caused by heart failure symptoms, as well as its tenuous and often individually-tailored treatment regimens. Furthermore, heart failure carries with it a high mortality rate, with a 5-year mortality after diagnosis in the US estimated at approximately 50% and a 30-day post-diagnosis mortality among US Medicare recipients over 10% (1).

Even within HICs, though, heart failure outcomes can vary markedly between different sub-populations given the syndrome's significant morbidity and mortality rates. Regular access to healthcare providers for disease monitoring and medication management is a necessity for slowing disease progression and delaying morbidity/mortality. Thus, differential access to these prevention and treatment measures results in significant outcome differences—most often along socioeconomic, geographic, and racial lines. For example, a recent high-quality review of socioeconomic and demographic factors in the United States showed black race, lower income, lower socioeconomic status, unemployment, and lower social support factors to significantly increase risk of readmission for heart failure (41).

From the existing literature on heart failure in LMICs, it appears that the social and economic burden of heart failure is far higher than in HICs—which should come as no surprise given the importance of regular access to treatment on disease outcomes. In LMICs, the average age of heart failure onset begins in the mid-50s (4, 16, 17, 57, 66), roughly 20 years younger than those in HICs where heart failure patients “younger than 50 are hardly ever found” (3). This significant difference in age of onset between HICs and LMICs results, in part, from the difference in heart failure etiologies between these settings. In studies among HICs, generally 50-80% of heart failure is due to ischemic heart disease (1, 3), followed by hypertension (approximately 30-60%), and rarely valvular heart disease or other cardiomyopathies (57). However, the available literature on heart failure etiologies and prevalence in LMICs uniformly

demonstrates an inverse picture, in which cardiomyopathies, rheumatic heart disease, and hypertensive heart disease far outnumber ischemia as the underlying causes of heart failure. For example, in Sub-Saharan Africa (SSA) heart failure secondary to ischemic heart disease generally accounts for no more than 10% of cases, with rheumatic, hypertensive, cardiomyopathy, and peripartum heart failures instead as generally most prevalent (4, 11, 15, 16, 17, 25, 72, 75).

From a pathophysiologic standpoint, these age of onset differences stem from different natural histories of the underlying heart failure disease etiology. In ischemic heart failure, a gradual, progressive narrowing of the arteries supplying blood to the heart takes decades to develop, resulting in heart failure manifestations that generally do not appear before age 60 (1, 2). Rheumatic heart disease and some cardiomyopathies, on the other hand, are often acquired in childhood or young adulthood and cause damage to the heart that progresses more rapidly into heart failure (65).

However, pathophysiology does not account for why these etiologies of heart failure distribute differently among populations of different socioeconomic status. Rheumatic heart disease and the various cardiomyopathies are easily preventable with basic medical services like antibiotics and nutritional support. Thus, the improvements in healthcare infrastructure and access that accompany increasing socioeconomic status have rendered these diseases nearly non-existent in HICs. However, many people in LMICs still lack access to these basic medical services. Accordingly, they develop diseases like rheumatic heart disease and rarely live long enough to develop ischemic heart failure (65).

To highlight the importance of access to basic medical treatment on the etiologies of heart failure, one author has traced the historical evolution of heart failure in United States, in



which the predominant etiologies of heart failure have changed dramatically over the last century. In the 1950s in the US, ischemic heart disease accounted for only 22% of heart failure cases. Rheumatic heart disease and hypertension were the two leading causes of heart failure, and the average age of onset was 57. However, with the discovery and eventual widespread availability of antibiotics like penicillin and antihypertensive medications, rheumatic heart failure and hypertensive heart failure steadily declined. By 1980s in the US, ischemic heart failure had grown to account for approximately 68% of heart failure cases with an average age of onset greater than 70 (15, 26) (as it remains to this day) followed almost exclusively by hypertensive heart failure (15). However, as demonstrated by the existing literature on heart failure in LMICs, a majority of the world's population remains in a pre-1950s epidemiologic era of heart failure treatment (65).

Nonetheless, the etiologies and relative importance of heart failure, especially in LMICs, is not immediately obvious in many published accounts of cardiovascular diseases globally. Despite a specific set of diagnostic and treatment guidelines for the heart failure syndrome (6), “heart failure” often does not qualify as its own disease category in many epidemiologic studies because it is a manifestation of other underlying disease processes, as described above. For example, the current International Classification of Disease (ICD) system does not allow for heart failure to be listed as a cause of death, and thus estimates of heart failure as a cause of mortality are often not possible (57). The widely cited 2010 Global Burden of Disease Study (GBD) is a prime example. In this most recent GBD study, DALYs resulting from ischemic heart failure are aggregated with DALYs caused by other ischemic heart conditions, such as myocardial infarction. As a result, estimates of the burden of heart failure due to ischemia in LMIC settings are not explicit and thus can appear inflated by the general prevalence of ischemic

heart disease (10). This tendency to overestimate ischemic heart failure in LMICs has been noted elsewhere (15) and may also be due to the GBD study's methodology of extrapolating ischemic heart disease prevalence in LICs from largely urban upper- and middle-income countries due to the paucity of reliable, population-level data in low-income countries (10, 18).

### *Principles of Healthcare Delivery for Heart Failure*

Because prevention and treatment approaches for heart failure vary based on the particular heart failure etiology, these epidemiologic discrepancies have important implications for how heart failure care delivery policy priorities are set. In HICs, where ischemic heart disease is indisputably the predominant cause of heart failure, leading experts and institutions promote “primary prevention” of risk factors for coronary artery disease as the most effective approach for reducing ischemic heart disease (1, 2, 3, 6). These risk factors are largely considered “lifestyle” dependent, such as tobacco use, poor diet (contributing to diabetes, hypertension, and hyperlipidemia), and insufficient exercise. In addition to lifestyle change, expert guidelines exist for the use of appropriate pharmacologic treatment of hypertension, diabetes, and hyperlipidemia, as these diseases are upstream causes of ischemic heart failure (6). This focus on “primary prevention” has been adopted in the policy prescriptions for LMICs by prominent global health institutions like the WHO and WHF and other influential policy publications (1, 2, 3, 6, 8, 38, 42), despite conflicting data on whether ischemic heart disease is a significant cause of heart failure in these settings. For example, the WHO and Global Cardiovascular Taskforce have identified a set of “Best Buys” for LMICs for the risk factor reduction of CVDs which are applicable only for ischemic and hypertensive heart disease,

including recommendations on “tobacco use, harmful use of alcohol, salt intake, physical activity, and replacement of *trans* fat with polyunsaturated fat” (42).

In addition to the data suggesting ischemic heart disease as the predominant cause of heart failure in LMICs, a model of population change called the “epidemiologic transition theory” is often cited or implied as the rationale for primary prevention policy prescriptions (4, 8, 10, 11, 16, 17, 22, 23, 42, 53, 54). In short, this theory proposes four progressive stages of disease epidemiology that evolve as societies advance economically and technologically. In the first stage (“pestilence and famine”), poor societies with minimal public health infrastructure and widespread food insecurity suffer predominantly from diseases caused by infectious disease and malnutrition, such as rheumatic heart disease and nutrient-deficient cardiomyopathy, in the case of heart failure. In the second stage (“receding pandemics”), socioeconomic advancement brings improved public health to society, and as a result, fewer die from infectious diseases and malnutrition. Diseases of older age thus emerge, including hypertension, stroke, and coronary heart disease. The third stage (“degenerative and man-made diseases”) lies effectively on a spectrum with stage two and is characterized by further economic and public health improvements, thus giving way to more risk factors associated with ageing and more affluent lifestyles, of which ischemic heart disease is among the most prevalent. The fourth and final stage (“delayed degenerative disease”) is one reflective of most present-day HICs, in which life expectancy is greater than 70 years and leading causes of mortality are cardiovascular disease (ischemic disease, in particular) and cancer (8, 20, 21); however, this theory does provide the caveat that even within “stage four” societies, citizens of lower socioeconomic class may lack access to public health advances and thus fit characteristics of earlier stages in the epidemiologic transition (8, 20, 21).

While much of literature on heart failure in LMICs places significant emphasis on targeting ischemic risk factors in the treatment of heart failure for the reasons cited above, some authors advocate for alternative approaches (25, 73, 74, 75, 76). These groups, mostly based in SSA, propose intervention models focusing on the etiologies of heart failure that have been demonstrated at their institutions, of which ischemic heart disease appears relatively infrequent. In these smaller cohort studies, hypertensive heart disease, rheumatic heart disease, peripartum cardiomyopathy, and other nutritional and infectious cardiomyopathies present more commonly, with ischemic heart disease accounting for generally no more than 10% of heart failure presentations (4, 11, 15, 16, 17, 25, 72, 75, 76). For these disease etiologies, “primary prevention” largely takes the form of access to treatment for the proximal, upstream causes of the heart failure types observed in LMIC settings, in addition to protocol-driven diagnostic and treatment approaches to patients who have already developed heart failure (24, 25, 73)—rather than a predominant focus on prevention of lifestyle risk factors as in ischemic heart disease. Specifically, prophylactic treatment measures include antibiotic treatment for streptococcal pharyngitis (RHD), anti-hypertensives (hypertensive heart disease, as well as reduction of risk factors like dietary sodium intake), and alleviating the poverty, overcrowding, and poor sanitation that lead to various infectious and nutritional causes of the cardiomyopathies.

Regardless of the approach to heart failure prophylaxis, the few published data on outcomes for heart failure management in LMICs share strikingly similar patterns of post-hospitalization outpatient follow-up rates, often referred to as “retention.” Retention, or the timely engagement of patients in outpatient care, is an essential component of heart failure management. Retention rates reflect a number of variables, from patient-level cognitive factors to external, macro-level social forces, all of which may influence a patient’s ability to return to

clinic within an appropriate timeframe. Once heart failure develops, it is rarely cured, and morbidity/mortality are dependent on successful inpatient diagnosis, initial inpatient management, and continued medication treatment as an outpatient. In many settings, outpatient follow-up care intervals range from 30 to 90 days. Thus, when patients are admitted to a hospital for decompensated heart failure, linkage to an outpatient care provider to manage the chronic symptoms of heart failure is critical. Yet, in the very few existing studies in LMICs of heart failure post-hospitalization outcomes, at most 62% received the appropriate 30-day follow-up care (4, 25).

This steep decline in follow-up after initial linkage to the medical system reflects a general trend in chronic disease treatment, especially in low-resource settings, known as the “cascade of care,” in which a significant number of patients are lost to follow-up at various steps in the care pathway (77, 83, 84). A care pathway for heart failure (Figure 1 below, adapted from Kim et. al. [82]) is proposed for heart failure in the format of a “care delivery value chain.” The care delivery value chain is a useful framework for visualizing the full scope of activities required to care for a patient throughout the entire course of a given disease and its associated comorbidities—from prevention, to diagnosis and treatment (82). Patients who become lost at any point in this pathway will progressively suffer from significant morbidity and possible mortality due to their chronic disease. While little has been described on why so many patients with heart failure are lost to follow-up, experience from other chronic diseases may provide useful extrapolations, as will be explored in detail below.

**Figure 1**



|  |  |   |   |  |   |
|--|--|---|---|--|---|
|  | <p><b>Preventing/ Screening</b></p> <ul style="list-style-type: none"> <li>- ensuring primary care access to diagnostics &amp; treatment for upstream heart failure causes (anti-hypertensives, antibiotics, lipid-lowering agents, anti-platelet therapy)</li> <li>- alleviating conditions of poverty leading to various infectious &amp; nutritional cardiomyopathies</li> <li>- clinical history &amp; physical exam</li> <li>- modifying behavioral risk factors (reduction of high-salt intake, increasing physical activity)</li> <li>- creating patient medical record for continuity of care</li> <li>- connecting patient to care team, including community health worker</li> </ul> | <p><b>Diagnosing Staging</b></p> <ul style="list-style-type: none"> <li>- clinical history &amp; physical exam</li> <li>- basic laboratory assays (BNP, creatinine)</li> <li>- x-ray</li> <li>- echocardiography</li> <li>- screening for common comorbidities (anemia, chronic kidney disease, peripheral vascular disease, hypertension, diabetes, hyperlipidemia)</li> <li>- creating treatment &amp; follow-up management plan</li> </ul> | <p><b>Delaying Progression</b></p> <ul style="list-style-type: none"> <li>- regular outpatient medication management</li> <li>- treat comorbidities</li> <li>- improving patient awareness of disease progression and prognosis</li> <li>- connecting patient to care team, including physical therapist, if not already connected</li> </ul> | <p><b>Ongoing Disease Management</b></p> <ul style="list-style-type: none"> <li>- monitoring clinical progress with history, physical examination, basic laboratory assays, and echocardiography</li> <li>- regular primary care &amp; health maintenance</li> <li>- financial, nutritional, and psychosocial support</li> </ul> | <p><b>Management of Clinical Deterioration</b></p> <ul style="list-style-type: none"> <li>- identifying clinical and diagnostic deterioration</li> <li>- managing acute decompensation with inpatient clinical services</li> <li>- ensuring access to hospice care</li> </ul> |
| <p><b>Informing &amp; Engaging</b></p> | <ul style="list-style-type: none"> <li>- preventive counseling on risk factor reduction</li> <li>- alleviating structural barriers to primary care for patients</li> </ul>   | <ul style="list-style-type: none"> <li>- providing health literacy on disease diagnosis, course, management and prognosis</li> </ul>  | <ul style="list-style-type: none"> <li>- providing health literacy on disease diagnosis, course, management and prognosis</li> </ul>  | <ul style="list-style-type: none"> <li>- counseling on adherence and factors contributing to non-adherence</li> </ul>  | <ul style="list-style-type: none"> <li>- providing health literacy on comorbidities and disease decompensation</li> <li>- end-of-life counseling</li> </ul>   |
| <p><b>Measuring</b></p>                | <ul style="list-style-type: none"> <li>- baseline demographics</li> <li>- risk factor assessment by clinical history (childhood</li> </ul>   | <ul style="list-style-type: none"> <li>- basic laboratory assays (BNP, creatinine)</li> <li>- x-ray</li> <li>- echocardiography</li> <li>- screening for</li> </ul>   | <ul style="list-style-type: none"> <li>- clinical history &amp; physical examination</li> <li>- basic laboratory assays (BNP, creatinine)</li> </ul>  | <ul style="list-style-type: none"> <li>- clinical history &amp; physical examination</li> <li>- basic laboratory assays</li> <li>- echocardiography</li> </ul>   | <ul style="list-style-type: none"> <li>- clinical history &amp; physical examination</li> <li>- basic laboratory assays</li> <li>- echocardiography</li> </ul>  |

|                  |  |  |   |   |   |
|------------------|--|--|---|---|---|
|                  | infections, living conditions, nutritional status, dietary practices)<br>- physical examination<br>- basic diagnostics (blood pressure, height/weight, creatinine) | common comorbidities (anemia, chronic kidney disease, peripheral vascular disease, hypertension, diabetes, hyperlipidemia) |   |   |   |
| <b>Accessing</b> | - primary care clinics<br>- prenatal & postnatal services<br>- food services<br>- sanitation services<br>- pharmacy<br>- community health workers                  | - primary care clinics<br>- on-site laboratories<br>- food services<br>- pharmacy  | - primary care clinics<br>- on-site laboratories<br>- food services<br>- pharmacy<br>- community health workers | - primary care clinics<br>- on-site laboratories<br>- food services<br>- pharmacy<br>- community health workers | - primary care clinics<br>- on-site laboratories<br>- food services<br>- pharmacy<br>- community health workers |

*Study Setting*

The present study of heart failure was conducted in rural Haiti, based at University Hospital Mirebalais (HUM). The author (DMS) travelled to HUM and affiliated hospital sites 6 times between August 2013 and January 2015 and stayed in this region of Haiti for a cumulative duration of approximately 7 months, including a 14-week stay from late January to late April 2014. During this timeframe, the author worked alongside HUM NCD clinic physicians as a medical student observer. Activities included observation of NCD clinic visits, discussion of NCD clinic priorities with providers, and travel with clinical care teams to “mobile clinic” patient home-visits and ZL satellite clinics. In this capacity, the author gained a uniquely contextualized purview on patient help-seeking and care delivery considerations for heart failure in the rural Haitian setting. Throughout this time, the author kept a personal field journal in which he described his experiences, recorded his reflections on conversations with care providers, and noted observations about care delivery and barriers to care amongst patients in rural Haiti. In the context of observing and assisting local clinicians as they provided care for

patients facing extraordinary challenges, the author's observations were foundational for generating this study's research framework.

HUM is a 300-bed national public academic referral hospital operated in partnership between the Haitian Ministry of Public and Population Health, the Haitian-based non-governmental organization *Zanmi Lasante* (ZL), and the Boston-based non-governmental organization Partners In Health (PIH). The hospital was built to expand Haiti's training capacity, healthcare workforce, and medical infrastructure after the 2010 earthquake took an enormous toll on both the living and built healthcare infrastructure of Haiti. HUM opened for inpatient services in October of 2013. It is located in the predominantly rural Central Plateau region of Haiti serving a primary catchment area of approximately 300,000 patients and total referral area of 3 million patients, though open to all presenting patients (see Figure 3 below). The population of urban Mirebalais is approximately 17,000 and is located 56 kilometers outside of Port au Prince, approximately 90 minutes by car (85). The hospital is a tertiary care facility providing emergency, internal medicine, obstetric, oncologic, orthopedic, ophthalmologic, and pediatric services, seeing approximately 500 outpatients per day. In HUM's first twenty months of operation, approximately 151,000 patients had registered for a total of 240,000 patient consultations (G. Kwan, personal communication, April 28, 2015). Besides particularly vulnerable patients who qualify for a national ministry of health fee waiver, patients pay a one-time registration fee of US\$1.20 (50 Haitian Gourdes), which—as described further below—accounts for a full day's income for most Haitians. A survey from one subset of patients revealed that nearly 50% of patients had sold personal belongings to pay for healthcare (67). All subsequent clinic visits, diagnostic tests, and medications are provided for free to lower barriers to care access (67, 68).



The HUM hospital is the newest and largest facility within the PIH/ZL network of healthcare facilities in rural Haiti. The PIH and ZL sister organizations were founded in the mid-1980s in the nearby village of Cange. Here, their organizational values and priorities for healthcare delivery grew from delivering care to a population comprised almost entirely by impoverished farmers who had recently been displaced from their homes and consequently lacked access to even basic sanitation and healthcare infrastructure. In this setting, PIH/ZL found that medical outcomes improved dramatically when offering not only a so-called “cost-effective” regimen of medications but also integrating comprehensive socioeconomic support into this provision of medications, such that patients were able to consistently access medical care in spite of their overwhelming socioeconomic obstacles. A centerpiece of their delivery approach is a community-based team of lay health workers (“*accompagnateurs*”) delivering medication as well as psychosocial, financial, and nutritional support to patients and their families—effectively serving as a bridge to overcome the barriers these patients alone could not surmount given their medical and socioeconomic hardships. This “*accompagnement model*” remains the guiding principle of the ZL/PIH organization and the new HUM facility.

Of note, this ZL/PIH *accompagnement model* has become increasingly influential in global health delivery designs, as it has demonstrated an ability to improve medical outcomes in low-resource settings of both social and medical complexity (63). For example, at multiple international PIH sites, this *accompagnement model* has improved outcomes for patients on complex regimens for HIV and TB, at times to levels comparable to those at premier US teaching hospitals (51, 52, 58, 59). Furthermore, this model resonates with a growing recognition in global health of the importance of “*task sharing*” in settings of resource scarcity (60, 61, 62).

The particular setting for this study on heart failure is the non-communicable disease (NCD) clinic at HUM. NCD clinic is staffed by a generalist physician, nurse, and forthcoming community health worker team. Most commonly seen conditions are hypertension, diabetes, heart failure, stroke, and various respiratory diseases (e.g. asthma and COPD). The NCD clinic has developed a protocol-driven approach for the diagnosis and management of these conditions based on the experience of a similar NCD clinic operated by PIH in rural Rwanda (24). The available clinic diagnostics include blood pressure, basic chemistries, lipid panel, complete blood count, EKG, x-ray, CT, and echocardiography. Formulary medications for these conditions include beta-blockers (carvedilol, metoprolol, atenolol), ACE inhibitors (lisinopril, captopril, enalapril), furosemide, hydralazine, isosorbide, spironolactone, hydrochlorothiazide, amlodipine, and nifedipine. Since opening in October 2013, NCD clinic has served approximately 2,000 patients. As noted above, NCD clinic is open to any patient in Haiti though primarily serves patients from its three catchment zones (see Figure 3 below).

Currently, there are no published contemporary reports on general heart failure in rural Haiti. Given regional similarities between SSA and Haiti in terms of socioeconomic status, a predominantly rural population distribution, and shared ethnic genetic profiles, SSA likely represents the best proxy estimates for heart failure in Haiti (14, 22, 57). Existing data from SSA, as described above—in addition to the data presented in this paper—suggest heart failure is likely a significant cause of morbidity and mortality in Haiti, with RHD, hypertensive heart disease, peripartum cardiomyopathy, and the various nutritional and infective cardiomyopathies representing the predominant etiologies.

However, a detailed description of the unique historic, economic, and political context of Haiti—and the eventual development of HUM—is warranted to deter a reflexive assumption that

heart failure in Haiti uniformly reflects the epidemiologic and healthcare delivery considerations of SSA.

The biosocial health care delivery context of present-day Haiti owes in a uniquely path-dependent manner to its history of colonial and post-colonial exploitation. Initially the most valuable slave labor agricultural export machine of the French after receiving the western third of Hispanola from the Spanish in 1697, Haiti won its independence in 1804 after the first successful slave uprising in colonial history (69). The foundation of modern Haiti's rural agriculture economy and population distribution developed at this point, when the nation of former slaves turned toward an economy of rural, self-sufficient agriculture over the large, export-oriented plantations of colonial rule. However, further development was promptly stifled—as it has remained to the present day—by an 1820 embargo by the French for war reparations totaling the modern equivalent of 40 billion dollars (31). Even after this indemnity was lifted in 1920, Haiti has suffered continued external and internal oppression of economic, health, and educational infrastructure development. From a US military invasion in 1915, the US-supported brutal and repressive Duvalier dictatorship of 1957 to 1986, and continued destabilization of Haiti's democratic process into the end of the 20<sup>th</sup> century, Haiti continues to suffer from economic underdevelopment and, accordingly, widespread disease and malnutrition in the absence of decent healthcare infrastructure (47, 48, 69). Even as a tenuous democracy began to take hold in the 2000s, Haiti was struck by a major earthquake in 2010, centered in Port-au-Prince and resulting in the costliest disaster in terms of both life and dollars the world has seen in over forty years (31).

Haiti's present day healthcare delivery context is thus a direct reflection of these two hundred years of struggle. Today, the country of nearly 10 million remains largely rural, with

only approximately 36% of the population living in an urban setting (of which 70% live in slums) (32). The average income in Haiti is roughly 600 USD per year, or 1.60 USD per day, although this value is inflated by the wealthiest 10% in Haiti earning 70% of the country's total income (34, 35). Even among those who can afford access to healthcare services, the basic and healthcare infrastructure remains largely absent. In 2010, average life expectancy was 61 years, maternal mortality 350 out of 100,000 live births, and neonatal mortality 25 out of 1,000 live births. Only 51% of rural Haitians have access to improved drinking water sources, and only 10% have accessed to improved sanitation facilities (32). 44% of Haitians are “undernourished” (34). Only 15% of births in rural Haiti were attended by a trained health professional, and per the most recent estimate (1998), there are only 25 physicians per 100,000 people—of which most are likely located in urban Port-au-Prince despite a predominantly rural population (32, 33).

### *Study Objectives*

It is thus within this context of extreme poverty in rural Haiti that this study has developed the following goals, research question, and specific aims:

The overall study goal is to inform and eventually improve the heart failure care delivery model in rural Haiti through an analysis of clinical heart failure outcomes and subsequent analysis of patients' heart failure illness experience. The research agenda has thus been driven by the following research question,

*“After discharge from an initial presentation for heart failure, are patients able to maintain appropriate follow-up care, and what individual and socio-structural factors influence these follow-up characteristics?”*

The specific aims of this study are thus,

1) to describe patient characteristics of heart failure follow-up care after initial presentation to

HUM

2) to identify possible causes for the observed departures from optimal heart failure follow-up

care

3) to propose further investigative approaches to understanding barriers and facilitators to heart

failure diagnosis and management

## **METHODS**

### *Study Population*

This study is a retrospective cohort analysis. Adults ( $\geq 18$  years old) of all sexes who were admitted to the internal medicine ward of HUM for at least twelve hours with any diagnosis of heart failure from October 2013 through September 2014 were included. A patient's first hospitalization during this study period was considered the initial admission, and any subsequent admissions were considered readmissions. Physicians assigned diagnoses of heart failure at any time during the hospital stay based on a combination of clinical signs and symptoms and available diagnostics. Diagnoses were coded using ICD-10. The primary ethical approval for data presented in this study was obtained from the ethical review board of *Zanmi Lasante*, Haiti and Boston University Medical Center, Boston, MA and the study conformed to the principles outlined in the Declaration of Helsinki. All data presented in this study represent a secondary analysis of collected data. This secondary analysis was deemed non-human subjects research by the Partners Health System ethical review board, Boston, MA, on April 21, 2015 and the Harvard Medical School ethical review board, Boston, MA, on May 20, 2015 and thus did not require further IRB review and approval.

### *Data Collection*

A list of subjects meeting the inclusion criteria, as well as demographic and care utilization data, were exported from the HUM electronic medical record (EMR) (OpenMRS Limited, Grandville, MI). Routinely collected clinical data were extracted from admission and discharge documents, including vital signs, comorbidities, discharge medications, and heart failure symptom severity (using the New York Heart Association classification system [27]) and

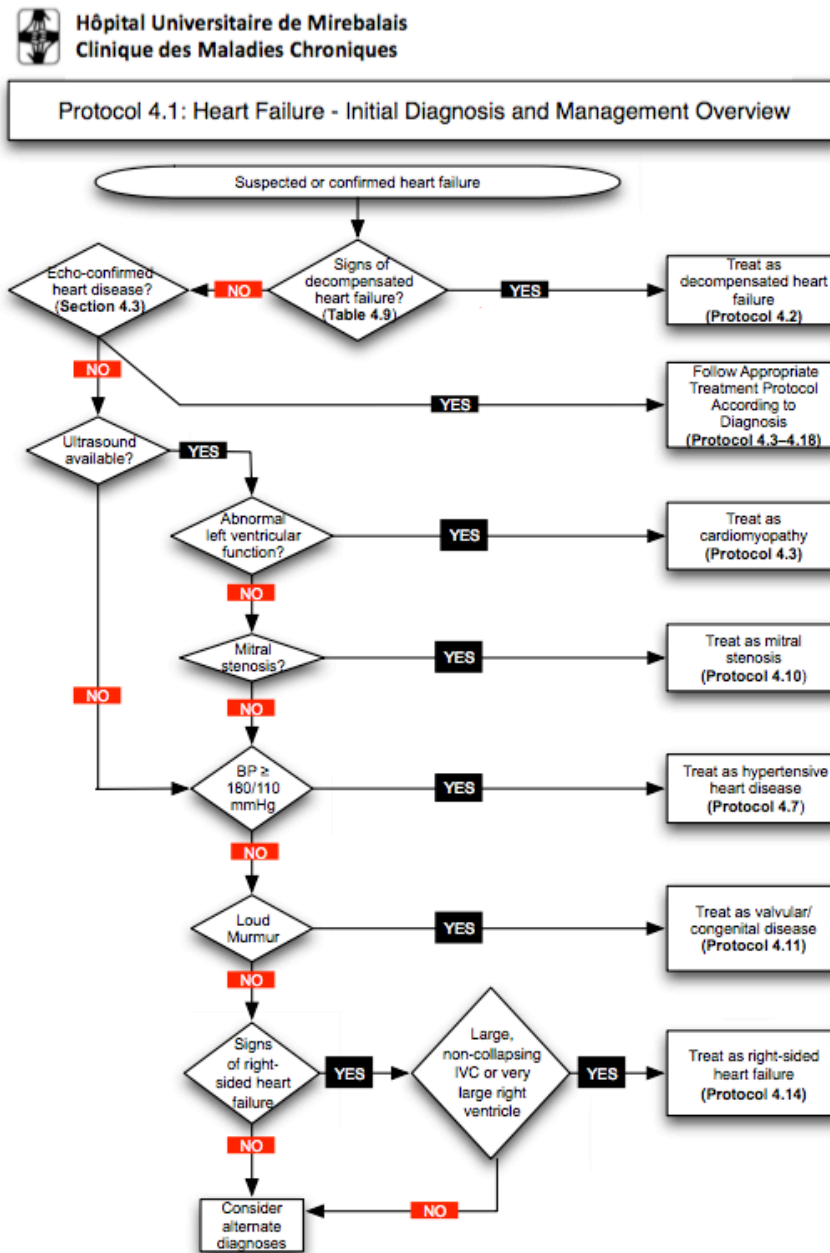
entered into a database. Comorbidities such as history of hypertension and diabetes were recorded based on patient self-report and were not systematically confirmed by clinical staff. Demographic data included age, sex, and address (to level of Communal Section). Clinic visit data from an affiliated health center using the same EMR (Lacolline health center, Lascohabas) was also evaluated for patients who may present to this clinical site for follow-up after discharge from HUM, rather than follow-up to the HUM NCD clinic.

All data collection was conducted by another investigator (GFK) under the IRB approval process described above. The data were exported into a de-identified Microsoft Excel file and securely transferred to this study's investigator (DMS).

### *Heart Failure Diagnosis*

Most patients admitted to HUM internal medicine ward are given a diagnosis of heart failure on the basis of a standardized clinical protocol developed in a similar low-resource setting (see Figure 2) without defining an underlying etiologic cause.

Figure 2



When echocardiography was available, etiology was identified by the echocardiographic interpretation of a visiting cardiologist (GFK) trained in echocardiography (25). GFK performed formal echocardiograms on admitted patients with heart failure throughout the course of the study period during 6 visits lasting 3-4 weeks each. Echocardiograms were performed using



SonoSite MicroMaxx (SonoSite, Inc., Bothell, Washington) portable ultrasound machines with 5-1 MHz probes. Two-dimensional chamber dimensions and calculated left ventricular mass (by the cube formula) are reported (28).

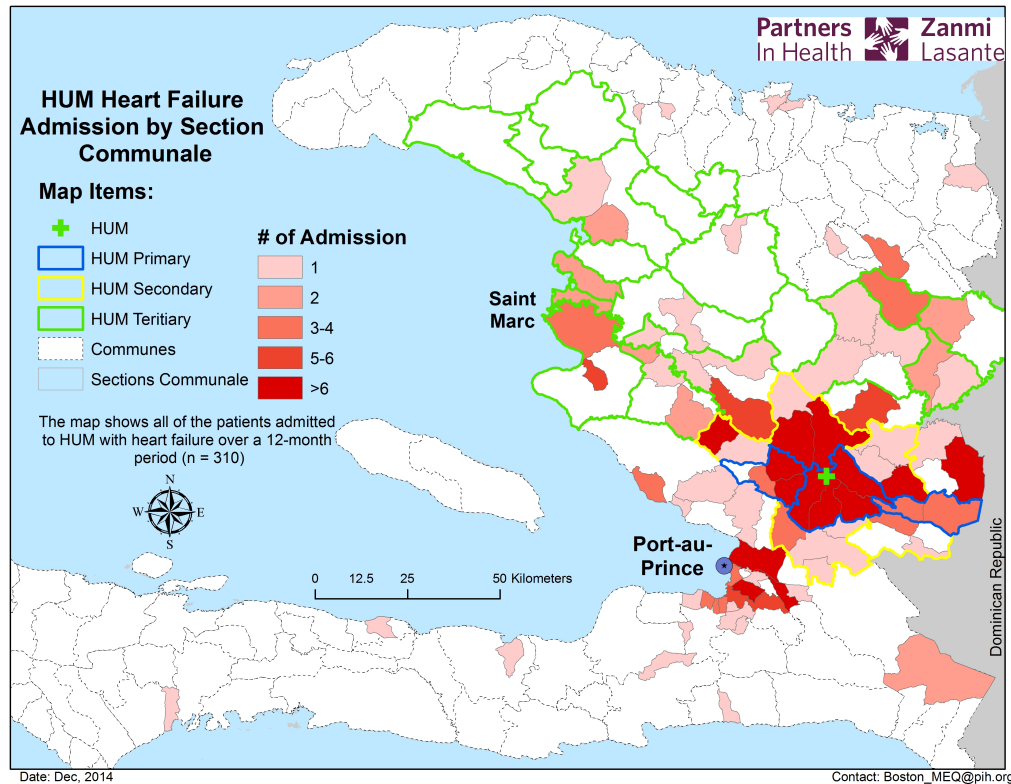
The echocardiographic criteria for diagnosis of a single primary cause of heart failure were based on similar criteria as the Heart of Soweto study (17). Cardiomyopathy was diagnosed in patients with left ventricular ejection fraction  $\leq 50\%$  (28). A diagnosis of hypertensive heart disease was assigned to patients with clinical heart failure, preserved left ventricle systolic function, and a history of hypertension (17). Peripartum cardiomyopathy was diagnosed in women who had cardiomyopathy on echocardiography and the onset of heart failure symptoms “towards the end of pregnancy or in the months following delivery” as described by a working group of the European Society of Cardiology (29). Rheumatic heart disease was diagnosed based on the combination of functional and morphological abnormalities of the mitral and aortic valve as outlined by the World Heart Federation criteria (30). Ischemic heart failure was diagnosed with the visualization of regional left ventricular wall motion abnormalities.

### *Geographic Data*

The communal section in which a patient lives is recorded at the time of hospital registration. Patients in this study were grouped into geographic zones corresponding to distance from HUM (see Figure 3 below). Patients in Zone 1 reflect the primary catchment area of HUM and generally are intended to receive all primary care through HUM based on HUM’s regional referral structure. Patients in Zone 2 form a secondary catchment area in which patients are to receive primary care from another facility though present to HUM for inpatient care, as it is the closest regional hospital. Patients in Zone 3 may present to any regional hospital in closer

proximity to their home but may be referred to HUM for specialty care. Patients in Zone 4 live outside of the HUM primary and referral catchment areas.

**Figure 3**



### *Clinical Care and Outcomes Data*

The following outcomes were ascertained from the HUM data set as described above:

- 1) in-hospital death
- 2) linkage to outpatient care, defined as any outpatient visit to HUM within 30 days of initial admission
- 3) retention in outpatient care, defined as a second outpatient visit to HUM within 30 days of the initial outpatient visit (above)
- 4) all-cause readmission to HUM within 30 days\* of discharge from initial admission

\*30 days was chosen as the timeframe unit because patients are provided a 30-day supply of medication and instructed to return within this timeframe for outpatient visit and medication refill. Patients who did not return to HUM for outpatient care were not contacted.

### *Data Analysis*

The numbers of patients with available data are shown in the tables and figures. Continuous data are summarized as means with standard deviations or medians with interquartile ranges. Differences in means were tested using the two-sample t-test and Cochran-Armitage trend test. Categorical data were summarized as proportions with differences tested using the difference of proportions test (Pearson chi-square). There was no specific target sample size. Analyses were performed using SAS 9.3 (SAS Institute Inc., Cary, NC).

## RESULTS

The demographic characteristics of patients admitted to HUM’s internal medicine ward during this study period are presented in Table 2. A total of 311 patients met eligibility criteria with an average age of presentation of 53 years. Women were admitted (n=186; 59.8%) for heart failure more often than men (n=125; 40.2%), and the average age of women admitted with heart failure was younger than men (mean age 48.3 versus 58.8 years old; p<0.01). Nearly one-third of all patients presenting with heart failure were under 40 years old (n=91; 29.3%), of which 40.9% are women (p<0.01).

Table 2 also shows the catchment areas (see Figure 3 above) from which patients presented. Most patients came from within the primary catchment area (Zone 1, n=100; 32.2%). Zone 3 represented the next greatest number of heart failure admissions (n=99; 31.8%), followed by Zone 4 (outside the designated ZL catchment area) (n=63; 20.3%), and Zone 2 (n=49; 15.8%). The populations of each zone are shown in Table 1 of the Supplementary Appendix.

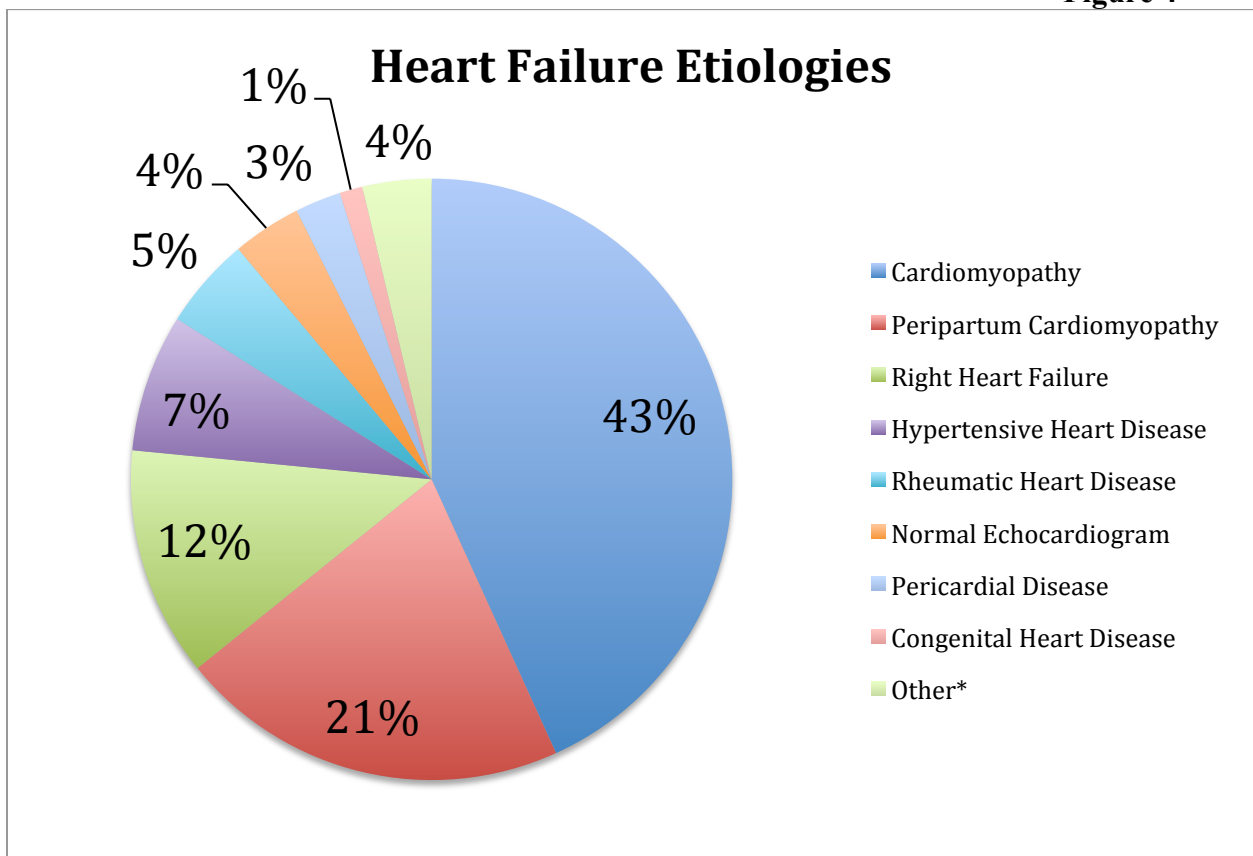
**Table 2**

| Characteristic                  | Total patients | SD or % | Women | SD or % | Men  | SD or % | p value |
|---------------------------------|----------------|---------|-------|---------|------|---------|---------|
| N                               | 311            |         | 186   | 59.8    | 125  | 40.2    |         |
| Age at admission (years)        |                |         |       |         |      |         |         |
| Mean (sd)                       | 52.5           | (18.5)  | 48.3  | 18.8    | 58.8 | 16.2    | <0.01   |
| ≤ 40 years                      | 91             | (29.3%) | 76    | 40.9%   | 15   | 12.0%   | <0.01   |
| Catchment area                  |                |         |       |         |      |         | 0.12    |
| Zone 1 (Primary)                | 100            | (32.2%) | 68    | 36.6%   | 32   | 25.6%   |         |
| Zone 2 (Secondary)              | 49             | (15.8%) | 28    | 15.5%   | 21   | 16.8%   |         |
| Zone 3 (Tertiary)               | 99             | (31.8%) | 59    | 31.7%   | 41   | 32.0%   |         |
| Zone 4 (Outside referral zones) | 63             | (20.3%) | 31    | 16.7%   | 32   | 25.6%   |         |

The clinical etiologies of all heart failure admissions receiving diagnosis by echocardiography and/or clinical history (n=81; 26% of total heart failure admissions) are shown in Figure 4. Among both men and women, the leading cause of heart failure was cardiomyopathy, accounting for 43% (n=35) of total diagnoses (36% of women, n=18; 55% of

men, n=17). Among women, the second leading cause was peripartum cardiomyopathy (n=17; 21%). Right heart failure was the next most common cause in both genders, representing 12% (n=10) of total admissions. The remaining causes, in descending order, include hypertensive heart disease (n=6; 7%), rheumatic heart disease (n=4; 5%), pericardial disease (n=2; 3%), and congenital heart disease (n=1; 1%). Of note, only one patient was diagnosed with ischemic cardiomyopathy.

**Figure 4**



In-hospital and “linkage” to care (defined as return for HUM outpatient care within 30 days of discharge) outcomes are shown in Table 3 below. Of the 311 patients admitted with heart failure, 37 (12%) died during the initial admission. Of those discharged (n=274), 101 (37%) were linked to care. Among these patients linked to care, only 48 of the initial 274 (18%) returned or were “retained” for their second NCD clinic follow-up appointment within 30 days from their initial, post-discharge follow-up appointment.

**Table 3**

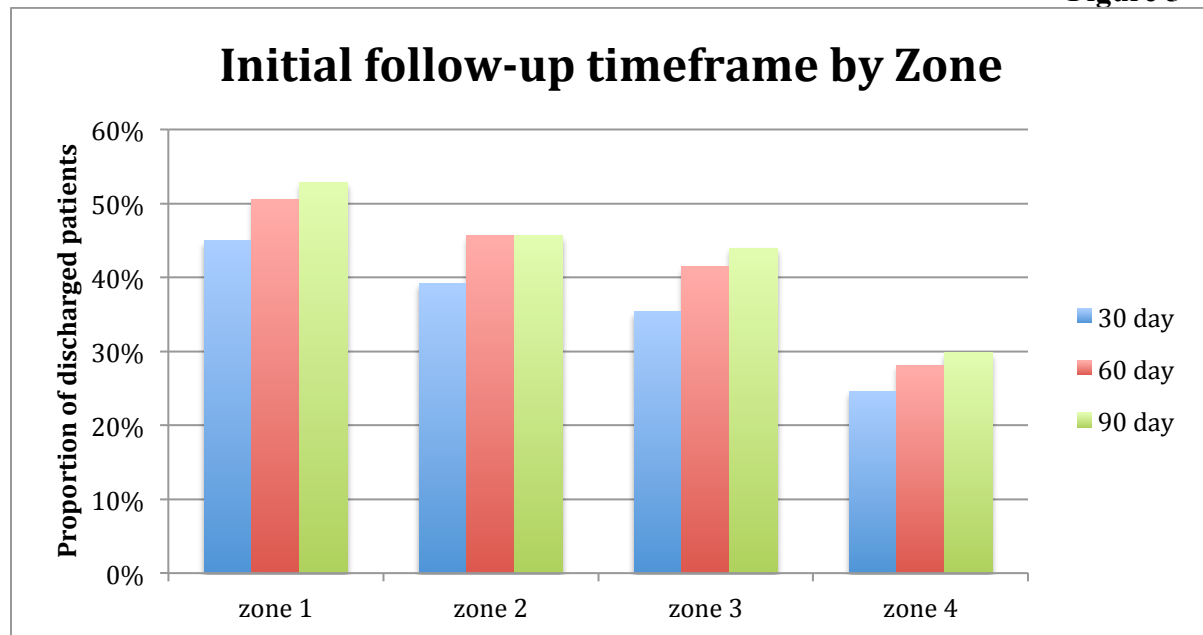
| Short-term outcomes by catchment area                         |                  |                 |                |                |                |         |
|---|------------------|-----------------|----------------|----------------|----------------|---------|
|   | Total            | Zone 1          | Zone 2         | Zone 3         | Zone 4         | p value |
| <b>All patients, n=311</b>                                    |                  |                 |                |                |                |         |
| In-hospital mortality, n (%)                                  | 37/311<br>(12%)  | 11/100<br>(11%) | 3/49<br>(6%)   | 17/99<br>(17%) | 6/63<br>(10%)  | 0.63    |
| <b>Discharged patients, n=274</b>                             |                  |                 |                |                |                |         |
| Linkage: 30-day clinic visit, n (%)                           | 101/274<br>(37%) | 40/89<br>(45%)  | 18/46<br>(39%) | 29/82<br>(35%) | 14/57<br>(25%) | 0.08    |
| Retention: 2 <sup>nd</sup> clinic visit within 30 days, n (%) | 48/99<br>(49%)   | 20/40<br>(50%)  | 9/18<br>(50%)  | 11/27<br>(41%) | 8/14<br>(57%)  | 0.96    |
| Readmission within 30 days, n (%)                             | 18/274<br>(6.6%) | 9/89<br>(10.1%) | 4/46<br>(8.7%) | 4/82<br>(4.9%) | 1/57<br>(1.8%) | .03     |

Among the 101 total patients linked to care, patients from HUM’s primary catchment area (Zone 1) demonstrated the highest linkage to care rates (n=40/89; 45%). Linkage declined in descending order with distance from HUM, with 39% (n=18/46) linked from Zone 2, 35% (n=29/82) linked from Zone 3, and 25% linked from Zone 4. These 30-day linkage rates by zone reached statistical significance (p=0.014).

The relationships between catchment zones and 30-, 60-, and 90-day post-discharge follow-up rates are shown in Table 4 and Figure 5 below. As noted above, a total of 37% of patients from all zones were linked to care within 30 days post-discharge. Of those not linked to care within 30 days, only 15 patients returned for care between 31 and 60 days post-discharge and 5 returned between 61 and 90 days post-discharge. Additional breakdown of which zones these additional patients presented from is listed below.

**Table 4**

| Post-discharge time to initial follow-up by catchment area |               |             |             |             |             |         |
|--|---------------|-------------|-------------|-------------|-------------|---------|
|  | Total         | Zone 1      | Zone 2      | Zone 3      | Zone 4      | P-value |
| Follow-up within 30 days, n (%)                            | 101/274 (37%) | 40/89 (45%) | 18/46 (39%) | 29/82 (35%) | 14/57 (25%) | 0.014   |
| Follow-up within 60 days, n (%)                            | 116/274 (42%) | 45/89 (51%) | 21/46 (46%) | 34/82 (41%) | 16/57 (28%) | 0.009   |
| Follow-up within 90 days, n (%)                            | 121/274 (44%) | 47/89 (53%) | 21/46 (46%) | 36/82 (44%) | 17/57 (30%) | 0.010   |

**Figure 5**

## **DISCUSSION**

The rationale for study aims centered on post-discharge outcomes for heart failure patients stemmed from the author's (DMS) observations of general NCD care delivery at HUM, as described above. Insight into the importance and challenges of NCD follow-up care in rural Haiti was generated by local experts—medical providers who care for heart failure patients on a daily basis—and the experience of the investigator as a medical student observer from both clinician and patient perspectives.

In these discussions with providers about management of NCDs, and cardiovascular diseases in particular, it became clear that outpatient follow-up rates were sub-optimal at HUM's NCD clinic. Two key domains emerged in these discussions as to why patients struggle with returning consistently for outpatient follow-up. First, providers noted that some patients take medications only when feeling symptomatic instead of daily and thus are not prompted to return for appointments and refills in the recommended 30-day intervals. Also, multiple providers cited a common belief among patients that medication cannot be taken without food causing many of the patients in this study population with food insecurity to skip doses. Uniformly, providers implicated a lack of time to provide this information during clinical visits as a result of the NCD clinic's high volume of patients and accordingly hurried clinical visits time, as most patients lacked other available means of learning about these diseases without clinical-based education. As a possible solution, one physician meets with his daily patient panel to provide a group education session before beginning individual clinical visits.

Providers often couched the inaccessibility of health literacy education within a broader discussion of structural barriers to care in rural Haiti that prevent heart failure patients from



adhering to routine 30-day clinical follow-up visits. Primarily, providers cited the multiple obstacles patients face when travelling to HUM from their rural homes. As one physician noted, *“Haiti is not the urban areas, the real Haiti is the rural areas...it is difficult to have access, to give them what we’re supposed to give them...people have to walk for 2 or 3 hour [sic] before finding a medical center...especially in the Central Plateau during rainy season it is quite hard to cross rivers to go to seek medical care.”* (M. Louine, personal communication, December 18, 2014)

In addition to significant distances and logistical challenges, providers also often cited the cost of transportation as potentially prohibitive to repeat follow-up visits to HUM NCD clinic as the cost of transportation may often come at the expense of other necessities. For example, one physician estimated that as many as forty percent of his patients can only afford only one meal a day. Thus, paying for transportation to a follow-up visit could force a patient to go a full day without food, or worse, withhold food from family members. Because of barriers such as these to frequent follow-up care, providers often pointed to the importance of chronic care delivery models that bring medical providers closer to patients’ daily lives rather than relying on patients to traverse their many socioeconomic obstacles in order to manage chronic conditions like heart failure. One provider pointed to the importance of decentralizing primary care follow-up visits from HUM in the form of nurse-staffed primary care outposts where patients could travel for far less logistical and financial cost. Providers were generally even more enthusiastic about the utility of community health workers, or “*accompagnateurs*,” in their ability to ensure that patients have access to daily medication therapy and monitoring of disease progression through regular home-visits:

*“we were using accompagnateurs to give pills to patients every morning...but we didn’t have money to pay accompagnateurs for this category of patients (NCD clinic patients), so what we*

*do (sic), we use family members, we educated them, and we use them as accompagnateurs and it was a success.*” (M. Louine, personal communication, December 18, 2014)

These provider observations were reinforced by the investigator’s observations in NCD outpatient clinic and on various clinical and non-clinical visits to patient homes. Regarding patient knowledge of heart failure and its treatment, few patients appeared to have access to educational resources given the scarcity of televisions, internet, and literature on medical subjects in rural Haiti. However, one NCD clinic provider has started a local radio show to raise awareness for NCD care as a means to overcome this paucity of accessible health information. Additionally, providers often have a large volume of patients to see on a daily basis, leaving only enough time to perform a focused history, physical exam, and write prescriptions in order to see the day’s full panel—thus time for sufficient patient education is often not possible.

Most striking to the investigator, though, were the enormous logistical obstacles facing patients in rural Haiti seeking care at HUM. One mobile clinic visit to provide follow-up care in patient homes in nearby Cange illustrates the difficulties patients must overcome to travel from home to clinic and back, especially among patients struggling with heart failure symptoms who often struggle to breathe after minimal exertion or even at rest. Cange is separated from HUM by 20 kilometers of paved highway. Most patients travel in “tap-taps,” which are often weathered, aged pick-up trucks modified with bench seating in the truck bed for passengers (intrepid enough to squeeze in) (see Figure 6 below).

**Figure 6: truck bed tap-tap**



A round trip tap-tap ride from Cange to HUM and back costs roughly 200 Haitian Gourdes, or 4 USD equivalent, which represents at least two day's wages for an average Haitian (34). Patients can also ride on the back of motorcycles for a slightly higher cost. In both cases, a patient must possess enough exertional capacity and mobility to mount a truck bed or ride on a motorcycle, which many patients with heart failure may lack. Even more difficult though, especially for patients with heart failure symptoms, is the terrain that must be traversed to and from most patients' homes to Cange's main road. Most homes in Cange, like the majority of Haiti, are not adjacent to a main road but instead sit deeper into the countryside. These homes, usually erected from scrap metal or wood, connect to one another via narrow dirt footpaths (see Figure 7 below). These paths follow the natural contour of the land, which in Cange and many other locations, can become steep gradients, often rocky and unstable, that require both hands and feet to scale. Also, during the rainy season (lasting from April to June and September to November), these paths can

become thick with mud or washed away by flashfloods—a byproduct of Haiti’s history of massive deforestation.

**Figure 7: Rural Haitian Terrain**



Even for patients who can manage the journey from home to HUM, the trip often presents financial challenges in addition to logistical ones. For example, our team made a follow-up visit to a patient with HIV requiring daily medication treatment in rural Hinche. Her home is a one-room dwelling made of clay, sitting precariously on a dusty dirt hillside, miles from the nearest paved road (see Figure 8 below). During our visit, she spoke mostly of her new roof, which was made possible by months of saving what little money she could in addition to financial support provided by PIH/ZL. Previously, her roof was made of rusting corrugated steel that leaked extensively during rainy season, which would soak her family’s clothes, bed, and living supplies. With her savings, she was recently able to purchase caulking and a new section of non-rusted corrugated steel that she had patched together to form a roof that no longer leaked. Later, her accompagnateur told us that her story is emblematic of the harsh competing priorities of many patients in the area, especially given that most patients live on less than 2 USD per day

(34, 35). In this case, saving money to buy scrap metal so that a patient's family and belongings aren't soaked with rain can preclude patients from paying for transportation for follow-up care and medication refills, especially if their symptoms are not actively worsening.

**Figure 8: Rural Haitian Home**



### *Quantitative Description of Heart Failure in rural Haiti*

Before discussing how this study's quantitative results demonstrate patients' barriers to regular NCD clinic follow-up, it is worth noting how some general characteristics of heart failure in rural Haiti share some commonalities with existing literature on heart failure in LMICs, while also offering some potentially unique exceptions. First, the mean age of heart failure presentation (see Table 2) accords with data from other LMICs showing a mean age of onset significantly younger (57) (and thus significantly more burdensome to socioeconomic productivity) than HICs, where average heart failure onset is greater than 70 (26, 57). Even when stratifying by gender to remove the possibility of a high peripartum cardiomyopathy prevalence distorting the average age of other heart failure etiologies, the average age of male presentation is 59 years of age (see Table 2).

As with other LMICs, this lower average age of heart failure onset is in large part attributable to non-ischemic etiologies. From this study, almost none of the patients diagnosed by echocardiography (only participants diagnosed by echocardiography received an etiologic diagnosis to heart failure) demonstrated an ischemic pattern of cardiomyopathy (see Figure 4). However, if the existing categories of echocardiography-diagnosed heart failure reach statistical significance, the etiologies observed in this cohort demonstrate some features unique from its most comparable heart failure cohort studies in SSA. Most strikingly, hypertensive heart failure is consistently the leading category in SSA heart failure studies (at minimum 33% in studies reaching statistical significance), whereas far fewer in this cohort were categorized as hypertensive heart failure (see Figure 4) (4, 11, 14, 16, 57). One possibility for this difference may be risk factors among Haiti's rural population distinct from those in SSA studies, which are formed almost entirely of urban study participants. Another possibility for hypertensive heart failure being underreported in this study is misclassification, as idiopathic cardiomyopathy can result from "burnt-out," untreated hypertension that causes a patient's long-standing hypertension to subside due to hemodynamic changes secondary to heart failure (43, 44). Also unique from SSA studies—and a possible rationale for the relatively lower proportion of hypertensive heart disease—is the predominance of cardiomyopathy. Cardiomyopathy has a number of possible underlying etiologies, including nutritional deficiencies and a variety of infectious causes, all of which point toward an environment deprived of basic health infrastructure. Haiti's particular predominance of cardiomyopathy relative to existing studies in SSA may be due to Haiti's relatively worse poverty and health systems infrastructure compared with the settings of SSA studies. From these SSA studies, which include eleven nations, only two rank worse than Haiti on the UN Human Development Index (36).

While the clinical heart failure characteristics of this cohort offer a picture of heart failure in Haiti and suggest possible future intervention targets, the particular focus of this study is describing and interpreting characteristics of patient heart failure outcomes regardless of specific heart failure etiology. In this study, overall in-hospital mortality for heart failure (see Table 3) was similar to the in-hospital mortality rates observed in a large review of heart failure in HICs (ranging from 4-30% in-hospital mortality), thus suggesting a reasonable quality of inpatient care at HUM, especially when considering that 98% of patients who presented to HUM had NYHA class III or above heart failure symptoms (64, 70). Another noteworthy outcome in this study is HUM's relatively low 30-day all-cause readmission rate (see Table 3). In the largest multinational trial among patients with heart failure (in North America, South America, Europe and Asia; predominantly in HICs), the average 30-day readmission rate was 11.4% (5.4% for heart failure) (71). 30-day readmission rates for heart failure are considered an indicator of inpatient care quality, which may further indicate high-quality inpatient care at HUM. However, as will be explored further below in regard to follow-up care, HUM readmission rates may be misleadingly low due to the logistical and financial challenges of seeking hospital care—as well as the high threshold for patient seeking treatment demonstrated by the high NYHA class admission average.

It is worth noting that 40% of all admissions to HUM's internal medicine ward during the study period were for a primary diagnosis of heart failure (64). While no data exist to compare this metric to other LMICs, this proportion is staggeringly high compared to the United States, in which approximately 3% of hospital admissions are the result of heart failure—and heart failure represents one of the most common hospital admission diagnoses in the country (37). This HUM statistic may, surprisingly, be an underrepresentation when considering that the key feature of

heart failure is discomfort with activity, thus making care-seeking particularly difficult as described in more detail above, in addition to the significant economic and logistical burdens of seeking care in rural Haiti generally. Currently there is insufficient data to reasonably estimate the prevalence of heart failure within the Mirebalais commune or beyond; however, the internal medicine admission prevalence of heart failure alone provides significant supportive evidence of the extensive burden of heart failure in Haiti (as well as indicative of improvements in HIV/TB care over the past decade given that HIV and TB were the previously the predominant causes of hospital admission) (50).

Because heart failure is a chronic, progressive disease requiring daily medication, regular follow-up and medication management by a physician is the centerpiece of effective disease management. Following discharge from HUM, heart failure patients receive a 30-day supply of medication with instruction to return within 30 days to HUM NCD clinic for follow-up care and medication refill. However, these data indicate that of all patients discharged from HUM with a diagnosis of heart failure during this study, a minority returned to clinic or were “linked to care” within 30 days as advised, and of those, even fewer returned within the following 30 days for their next appointment and medication refill at HUM (see Table 3). Thus, it is likely that many patients were not on an appropriate heart failure regimen within 60 days of discharge from the hospital (unless they were receiving follow-up care from another non-HUM clinic, which is unlikely given the scarcity of physicians and health centers in rural Haiti).

To understand whether distance travelled to HUM affected these outpatient follow-up rates of care after hospital discharge, patients were stratified into four geographic zones of increasing distance from HUM (see Figure 2). This stratification revealed better 30-day rates of follow-up care in order of proximity to HUM (see Figure 4).



The average age at heart failure admission may suggest another factor influencing the poor outpatient follow-up rates observed in this study. As noted above, the average age of patients admitted for heart failure in this study was 53. Among women presenting with heart failure, nearly 1 out of 3 are younger than 40 years of age. Thus, a majority of patients presenting with heart failure are of a productive, working age. Especially in Haiti where even a day's income is significant, taking time away from work to travel for follow-up care may not be economically feasible.

Considering this significant burden of travel, it is possible that a 30-day follow-up timeframe is too frequent for most patients. To evaluate this, we examined if patients return to clinic within 60 and 90 days post discharge at significantly higher rates. In both cases, patients did not return for follow-up at significantly higher rates, thus indicating that if a patient does not return for follow-up within 30 days, s/he is unlikely to do so at all.

While distance from HUM offers the only quantitative data from within this study for explaining the observed poor linkage to care rates, another possible explanation is a high outpatient mortality rate before 30 days from inpatient discharge. In a US study among patients with significantly superior access to health infrastructure (Medicare recipients), 1 out of 10 patients with heart failure died within 30 days after hospital discharge (notably this US population differs from this study cohort both in average age and heart failure etiology, which may weaken this comparison) (1). However, inpatient medication data collected from HUM suggest that a majority of heart failure patients are not prescribed an appropriate heart failure medication regimen upon discharge (which likely reflects the lack of training and continuing medical education opportunities in Haiti prior to the establishment of HUM, which is actively providing training on quality metrics such as these). These findings, described elsewhere (64),

could impact outpatient follow-up rates in multiple ways. A sub-optimal discharge regimen could cause rapid deterioration of heart failure symptoms, thus prompting patients to return to clinic more frequently. Alternatively, inferior regimens may result in a significant number of deaths from heart failure as an outpatient before returning for their 30-day follow-up, thereby falsely lowering observed follow-up rates. This information remains speculative though, as cause of death is rarely determined in LMICs, and when it is, the precision of official death registries notoriously unreliable (10).

Study findings support a few key likely causes for the poor follow-up rates observed in this cohort. First, the distance required to travel for regular follow-up appointments at 30-day intervals may be too difficult for many patients living in rural Haiti. In addition to time costs, such travel also presents many potential logistical obstacles for patients, especially those whose mobility is limited by heart failure symptoms. Also, for the average Haitian patient, transportation to and from HUM can present a significant financial burden that may be irreconcilable with other competing financial priorities, including basic necessities like food and shelter. Finally, access to reliable information on both risk factors and appropriate treatment for heart failure appear to be constrained by limited public availability of medical information, as well as a patient volume at HUM that precludes the physician from having time to provide this information.

#### *Lessons from other Chronic Diseases in rural Haiti*

The conclusions generated from this study's data are further validated by similar conclusions drawn by previous investigators working in rural Haiti on diseases (TB and HIV, in particular) requiring similar treatments of daily, chronic medication therapy. As with this heart

failure cohort, TB and HIV treatment outcomes—in Haiti and globally—have been frequently characterized by a “cascade of care” or “treatment cascade,” in which the number of patients achieving regular follow-up and daily medication adherence progressively declines with time (77, 83, 84). A large body of literature has explored reasons and potential targets for improving sub-optimal “adherence” or “compliance” in the realm of TB, HIV and many other chronic diseases (45, 51, 59). The various claims of causality within this body of literature have been noted to comprise a spectrum from individual, patient-level, “cognitivist” factors to extrapersonal, sociostructural level factors that transcend the agency of individual patient-actors (46). And while the merits of these various models for patient adherence is beyond the scope of this paper, what is salient to this discussion is the preponderance of research on chronic disease management in Haiti demonstrating sociostructural factors similar to those identified in this study as key causes of sub-optimal adherence and linkage to consistent outpatient follow-up. For example, the most in-depth explorations of access to chronic disease management in rural Haiti point to “structural violence” as the central, organizing root cause of Haiti’s poor health outcomes. In this extensively described historical, political, and economic process, structural violence in Haiti manifests in individual lives as a profound scarcity of socioeconomic capital that precludes patients from affording basic necessities and dilapidates healthcare infrastructure such that few patients are geographically situated for regular access (47, 48). Further validation for this structural violence model is provided by the significant improvements in TB and HIV outcomes in rural Haiti observed after the implementation of medical interventions that incorporate comprehensive social support packages specifically designed to bridge the structural barriers patients in rural Haiti face (49, 50, 51).

### *Implications for Heart Failure Delivery Designs*

The observations generated by this study and supporting evidence from similar, more well-described chronic disease delivery models in rural Haiti suggest a few key targets for improving the poor linkage to care rates observed in this cohort of heart failure patients. First, mechanisms to decrease the logistical, financial, and time costs associated with regular 30-day clinical visits to HUM could yield improved linkage and retention rates. Providing 60- instead of 30-day prescriptions may prolong the timeframe before a patient's heart failure decompensates. Also, extending post-discharge follow-up intervals to 60 days would theoretically reduce financial and time cost burdens. However, data from this study did not show patients returning to clinic more frequently after 60 or 90 days post-discharge compared to 30 days. Thus, these interventions are unlikely to improve patient linkage and retention rates and may only marginally prolong a patient's timeframe before decompensating due to required medication refill. Instead, increasing the number of decentralized primary care outposts across the HUM catchment area could significantly decrease travel costs for many patients, thereby resulting in easier access to follow-up appointments for disease monitoring and regular medication refills. However, even decentralized outposts such as these are unlikely to bridge the many barriers patients in rural Haiti face. Community health workers trained to monitor disease progression and dispense medications on daily, weekly, or monthly visits to patient homes represent one step further in overcoming the barriers patients face to receiving adequate follow-up care. Furthermore, these community health workers have been trained in other settings to identify social support needs and to follow-up to patient homes with educational, financial, and nutritional support, thereby bridging any of the structural barriers to follow-up care identified above that preclude patients from regular follow-up and medication adherence (52).

Of note, the intervention targets for improving heart failure management in LMICs proposed by other groups and influential organizations share little in common with interventions proposed above for rural Haiti, thus raising the possibility that these recommendations may not be valid in this context—if not other similar contexts similar globally. For example, the WHO, Global Cardiovascular Task Force, and the World Heart Federation recently endorsed ten core “Best Buy” interventions for LMICs for the prevention and treatment of CVDs. These interventions were explicitly formulated in consideration of the “epidemiological transition occurring” in LMICs, and accordingly, eight of ten of these interventions are designed to reduce risk factors specific to ischemic heart disease (42). The remaining two interventions promote the availability of essential medications for disease treatment, with a particular emphasis on medications for reduction of ischemic heart disease and stroke. The influence of the epidemiologic transition in LMICs towards prevention of ischemic heart disease on global policy prescriptions is widespread, as evidenced by the ubiquity of references to the “epidemiologic transition theory” in LMIC heart failure literature (4, 8, 11, 14, 16, 17, 42, 53). In a majority of these articles, preparatory investment in a theoretical but yet unrealized burden of ischemic heart disease take importance over delivery strategies to address the current disease burden, as embodied by recommendations such as the following, which are worth quoting at length:

*“CVD is a major global health problem, with the majority of the burden occurring in developing countries. Most of our knowledge about prevention and treatment derives from studies conducted in developed countries and predominantly among white populations. Therefore, there is an urgent need to establish appropriate research studies, increase awareness of the CVD burden, and develop preventive strategies in developing countries. In the meantime, as it is likely that most risk factors will be of some importance in all ethnic populations in the world, prevention and treatment strategies that have been proven to be effective in developed countries should be adapted for developing countries. These strategies should include approaches to prevent the development of risk factors in the population as a whole by changes in social and governmental policy as well as approaches that can be applied to high risk individuals. Some approaches are relatively low cost and readily applicable (e.g., promoting physical activity, use of aspirin, or angiotensin-converting enzyme inhibitors in high risk subjects and controlling blood pressure*

*using thiazides or beta-blockers), whereas others may only be applicable to relatively affluent sections of some societies (e.g., statins or coronary artery bypass graft surgery).” (23)*

*“Despite some important limitations, our data provide preliminary evidence to show the effect of epidemiological transition in this population who face many threats to their present and future cardiac health, including a high prevalence of modifiable risk factors for atherosclerotic disease, a combination of infectious and non-communicable forms of heart disease, and late clinical presentations. The combination of common preventable risk factors and late clinical presentations (especially heart failure) represents a particular challenge to improve primary and secondary prevention strategies to not only reduce the number of new cases of cardiovascular disease” (81)*

*“The high burdens of CVD in the developing countries are attributable to the increasing incidence of atherosclerotic diseases, perhaps due to urbanization and higher risk factor levels (such as obesity, diabetes, dyslipidemia, hypertension, etc.), the relatively early age at which they manifest, the large sizes of the population, and the high proportion of individuals who are young adults or middle-aged in these countries” (22)*

*“CVD remains the No. 1 global cause of death, accounting for 17.3 million deaths per year, a number that is expected to grow to >23.6 million by 2030. Increasingly, the populations affected are those in low- and middle-income countries, where 80% of these deaths occur, usually at younger ages than in higher-income countries, and where the human and financial resources to address them are most limited [1]. The epidemiological transition occurring is exacerbated by the lack of vital investment in sustainable health policies to address and curtail the risk factors associated with CVD and NCDs.” (42)*

However, ischemia appears to be a relatively infrequent cause of heart failure in this study population—as well as the preponderance of similar cohort studies in other LMICs. And while these strategies offer a possible approach for the reduction of ischemic heart failure, stroke and myocardial infarction, 40% of all internal medicine admissions to HUM result from predominantly non-ischemic heart failure. Therefore, it appears that adopting CVD intervention targets in rural Haiti based on the “epidemiologic transition” model would be premature in Haiti. Or, as noted about the importance of the epidemiologic transition on SSA populations more generally,

*“The landmark global burden of disease report in 1996 drew attention to the importance of degenerative cardiovascular diseases as causes of present and future morbidity and mortality in developing countries. It alerted the global community to the fact that atherosclerotic vascular disease, previously considered important only in the developed world, was increasing in*

*importance as a cause of death and disability in developing nations. Importantly, the report predicted that degenerative cardiovascular disease would become a major issue in those countries over the next decades, which would warrant urgent preventive measures. Several publications address these issues, and the matter is sometimes an undisputed topic of discussion and presentations at national and international meetings. The anticipated epidemic of atherosclerotic cardiac disease has, however, not yet manifested in most of the population of sub-Saharan Africa.” (73)*

Also, as has been offered in critiques of the epidemiologic transition theory, even if settings such as rural Haiti evolve toward increasing ischemic etiologies—as has been observed in industrializing nations like South African and Mexico—a “double burden” of disease emerges wherein the poorest populations remain vulnerable to “pre-transitional” diseases even as prevalence of atherosclerotic ischemic diseases increases. Thus, shifting emphasis in these settings to prevention and treatment of ischemic diseases potentially leaves an “unfinished agenda” of disease among the poor (54, 55).

Furthermore, the observations of the inherently structural patient barriers to heart failure management raise the question of whether isolating risk factors as primary intervention targets over other intervention approaches is warranted in settings such as rural Haiti. While risk factor reduction is an important component of prevention and treatment of ischemic heart disease, as noted above, this approach has been touted as a “Best Buy” across LMIC settings despite conflicting data on the importance of ischemic heart failure in these settings (42). This risk-factor-oriented approach has two important negative implications for the design of appropriate heart failure management interventions in settings like Haiti. First, making risk factors into targets without acknowledging the sociostructural barriers to risk reduction can imply that patients alone possess the individual agency to overcome any given risk factor. However, as noted by above, many patients in rural Haiti are only able to secure one meal per day and therefore likely lack control over the how much salt goes into its preparation. Second, promoting risk factor prevention with minimal emphasis on treatment interventions for the existing burden

of heart failure ignores a growing recognition of the synergy between prevention and treatment in the form of health systems strengthening investment in low-resource settings (54, 61, 78). This approach, sometimes referred to as “diagonal” investment, is especially important in settings with heart failure etiologies like rural Haiti. For example, among the predominant etiologies observed in this cohort—including viral/nutritional cardiomyopathies, rheumatic heart disease, hypertensive heart disease, and peripartum cardiomyopathy—improving access to existing health systems infrastructure functions as both prevention and treatment. For example, in the case of hypertensive heart disease, prevention requires early diagnosis of hypertension and regular treatment with anti-hypertensive medication. Yet, the same investment to increase access to hypertension treatment, perhaps in the form of decentralized primary care outposts or community health worker training, in turn improves the access infrastructure for patients requiring treatment for existing heart failure of any etiology. The same holds true for the prevention of rheumatic heart disease, in which any investment to increase patient access to antibiotic treatment for pharyngitis concurrently builds access for patients across the primary-level health system, such as heart failure patients seeking routine follow-up care and medication management from primary NCD providers.

### *Future Directions*

This study offers an initial quantitative and informal qualitative picture of heart failure in rural Haiti that—when considered alongside lessons from diseases requiring similar chronic management approaches like HIV and TB—can offer insight into possible interventions for improving the poor linkage to heart failure care observed. However, these extrapolations do not



provide as precise an understanding of the particular illness experience of heart failure—and its unique obstacles to care—as can be provided by those who live with heart failure in the context of rural Haiti. As described in great detail elsewhere, qualitative research can provide unique and often essential granularity for the particular individual-level and sociostructural barriers and facilitators to care for a given disease (46, 79, 80). The themes generated by these studies can offer unique and nuanced information to inform the development of healthcare delivery interventions specific to the particular obstacles presented by a given disease in its specific biosocial context.

For this reason, we propose a forthcoming mixed-methods study into both the individual and sociostructural barriers and facilitators facing patients with, or at risk, for developing heart failure in order to elaborate possible intervention targets unique from those extrapolated in this discussion.

Because the heart failure syndrome has a variety of underlying etiologies, we will focus our investigation on a single etiology that can serve as a model disease until the nuances between heart failure etiologies can be investigated, if deemed necessary. Hypertension has been selected as the heart failure etiology of focus for this qualitative inquiry for multiple reasons. First, hypertension is useful as both an upstream risk factor for the development of heart failure and a target of heart failure treatment in patients with existing heart failure. Thus, our qualitative inquiry may yield valuable information into both the management of active heart failure, as well as possible intervention targets for the prevention of the development of heart failure. Second, hypertension in the absence of heart failure syndrome is most commonly asymptomatic, and as a result, will offer a picture of how patients conceptualize the importance of regular access to the health system in the absence of symptoms—yet again adding insight into possible prevention

methods. Third, hypertension may yet prove to be a leading cause of heart failure in rural Haiti, as it has been shown to be in SSA (56) and perhaps globally (57), despite the non-statistically significant data shown in this study.

A protocol and study materials for this proposed study have been created and can be found in this supplementary appendix section (see *Proposed Study Protocol; Proposed Study Materials*).

## LIMITATIONS

The primary limitation of this study is its relatively small sample size, resulting in a statistical power that may not be capable of detecting significance among many variables presented. In this study, mean patient age, 30-day readmission rates, and time to initial post-discharge follow-up by zone all reached statistical significance. However, all other conclusions about heart failure etiologies, in-hospital mortality, and linkage and retention rates all fail to reach statistical significance, possibly as a result of insufficient sample size. Thus, any conclusions about the poor follow-up rates resulting from structural barriers to care may not be founded on an accurate statistical description of these variables.

Furthermore, this study design lacked sufficient resolution to differentiate the relative importance of various barriers to follow-up care. Additional qualitative and quantitative methodologies could elaborate the significance of distance, logistics, time cost, and financial cost on patient ability to return for follow-up care.

Another limitation of this study is an inability to determine what percentage of patients who did not return for follow-up visits were lost to follow up as a result of death. If the true value is higher than assumed, then the conclusions about poor linkage and retention may be overstated.

Also, there are two notable confounders for the proposed correlation between distance from HUM, as approximated by stratifying into Zones 1-4, and follow-up rates of care. First, patients who present from Port-au-Prince qualify as Zone 4, despite Port-au-Prince's closer proximity to HUM than many communes in Zone 3. Thus, variables in addition to distance may be reflected in patients' follow-up rates from Zone 4. If most patients from Zone 4 successfully linked to care travel from Port-au-Prince, this would underestimate the true effect of distance on

follow-up for patients presenting from communes in Zone 4 outside Port-au-Prince.

Alternatively, patients in Port-au-Prince live nearer to a higher density of healthcare facilities and may return for follow-up care to providers within the city, thereby overestimated the effect of distance from Zone 4 participants outside Port-au-Prince. Also, distance from HUM does not adequately account for the travel burden caused by poor road quality or even absence of passable roads, especially in the rainy seasons. Patients who live in particularly isolated areas, even if only a few miles from HUM, may face more time, cost, and logistical difficulty than patients living in more distant zones with unimpeded access to paved roads.

## **CONCLUSIONS**

Heart failure is the most common cause of hospital internal medicine ward admission in the Central Plateau region of rural Haiti. Of the patients admitted for heart failure management, roughly 80% are not receiving appropriate heart failure follow-up care within 60 days of discharge. Of many possible reasons for these poor retention rates observed in this study, this study demonstrates that distance from clinic may be one substantial barrier. This observation accords with a large body of literature on chronic diseases in rural Haiti that demonstrate logistical, financial, and other structural barriers to care as essential intervention targets for improving patient retention in chronic disease management.

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## APPENDIX

Table 1

| List of communes within the Primary, Secondary, and Tertiary zones of University Hospital Mirebalais. All other Communes in Haiti are considered outside of the referral area and are grouped into Zone 4. Population per 2012 estimates (85) |                                |
|---|--------------------------------|
| <i>Department</i>   | <i>Commune</i>                 |
| <b>Zone 1: Primary HUM Catchment Area, Population = 165,118</b>   |                                |
| Centre  | Mirebalais                     |
| Centre  | Saut d'Eau                     |
| Centre  | Savanette                      |
| <b>Zone 2: Secondary catchment, population = 184,291</b>  |                                |
| Artibonite  | La Chapelle                    |
| Centre  | Boucan Carré                   |
| Centre  | Lascahobas                     |
| Ouest   | Cornillon                      |
| <b>Zone 3: Tertiary catchment, population = 2,189,873</b>   |                                |
| Artibonite  | Desdunes                       |
| Artibonite  | Dessalines                     |
| Artibonite  | Gonaïves                       |
| Artibonite  | Grande Saline                  |
| Artibonite  | Petite Rivière de L'Artibonite |
| Artibonite  | Saint-Marc                     |
| Artibonite  | Saint-Michel de L'Attalaye     |
| Artibonite  | Verrettes                      |
| Centre  | Belladères                     |
| Centre  | Cerca Cavajal                  |
| Centre  | Cerca La Source                |
| Centre  | Hinche                         |
| Centre  | Thomassique                    |
| Centre  | Thomonde                       |
| Ouest   | Arcahaie                       |
| Ouest   | Cabaret                        |
| Ouest   | Croix-des-Bouquets             |
| Ouest   | Fonds Verettes                 |
| Ouest   | Thomazeau                      |

## **I. BACKGROUND AND SIGNIFICANCE**

The burden of hypertension in Haiti is unquestionably high despite few reliable estimates of its prevalence. Globally, hypertension is estimated to be present in 33% of adults.<sup>1</sup> Of the handful of epidemiologic studies published on hypertension in Haiti, one estimates over 66% of Port-au-Prince adults over forty years old to be affected with another estimating 60% to be previously unaware of their hypertension.<sup>2,3</sup>

Hypertension is a proximal, upstream cause of stroke, ischemic and hypertensive heart disease, as well as some forms of kidney disease. Ischemic heart disease and stroke are the two leading causes of death worldwide, respectively<sup>4</sup>. As a result, hypertension ranks atop all worldwide risk factors for disability adjusted life-years (DALYs), disproportionately affecting low- and middle-income countries. Thus, hypertension is among, if not the, most burdensome disease in Haiti.<sup>5</sup>

Optimizing diagnosis and treatment of hypertension is a top priority for Mirebalais University Hospital's (HUM) newly opened non-communicable disease (NCD) clinic. HUM is one of Haiti's few teaching hospitals, serving a population of approximately 300,000 in the predominantly rural Central Plateau of Haiti. In our current NCD clinic model, hypertension patients are seen by a physician and nurse approximately once per month, with additional support through group education sessions and community-based *agents de santé* home visits. This model was adopted from a similar NCD clinic approach at PIH-supported hospitals in rural Rwanda with intention to adapt our delivery model to meet the specific needs of Haiti's local context. To do so, our team is currently tracking many important clinical indicators, adherence metrics, and patient demographics. However, our delivery design will further benefit from a qualitative understanding of hypertension from both patient and provider perspectives, as demonstrated by the valuable delivery model insights generated by prior qualitative studies of TB and HIV in rural Haiti.<sup>6</sup>

## **II. SPECIFIC AIMS**

The overall objective of our study is to expand understanding of the individual and social structural factors influencing treatment-seeking and management of hypertension among both current and potential NCD clinic patients in order to improve our design of hypertension care delivery. We will achieve this through the following specific aims:

- 1) to elucidate patient and provider explanatory models of hypertension—in particular, understandings of pathophysiology, characteristics, and management expectations
- 2) to elucidate patient and provider perspectives on barriers and facilitators to hypertension diagnosis and treatment
- 3) to quantitatively evaluate patient hypertension knowledge both as a means to inform future HUM NCD clinic educational interventions and add a quantitative dimension to the qualitative aims listed above

### III. SUBJECT SELECTION

#### *iii(a) List inclusion/exclusion criteria*

Inclusion criteria for patients:

- (1) Residence in Haiti;
- (2) Primary ethnicity self-identified as Haitian;
- (3) Minimum age of 21 years old;
- (4) Must be able to give informed consent;
- (5) Must have hypertension as diagnosed by AMA guidelines<sup>7</sup> or the following risk factors, as self-identified by the patient or medical record: diabetes, overweight/obesity, tobacco use.
- (6) Must be Zanmi Lasante patient

Exclusion criteria for patients:

- (1) Have any impairment to any extent that would be likely to impair ability to understand and respond to survey or interpersonal questions (as assessed by trained study personnel during the recruitment or informed consent process);

Inclusion criteria for providers:

- (1) Resident of Haiti;
- (2) Primary ethnicity self-identified as Haitian;
- (3) Minimum age of 21 years old;
- (4) Must be able to give informed consent;
- (5) Directly provide medical care to patients with hypertension or at risk for it.

Exclusion criteria for providers:

- (1) Have any impairment to any extent that would be likely to impair ability to understand and respond to survey or interpersonal questions (as assessed by trained study personnel during the recruitment or informed consent process);
- (2) Directly supervised by this study's investigators.

#### *iii(b) Source of subjects and recruitment methods*

Subjects will be either:

- (1) patients at Zanmi Lasante with a diagnosis of hypertension or associated risk factors;  
or
- (2) medical staff employed by Zanmi Lasante who directly provide care for patients with hypertension.

All subjects will be recruited through in-person dissemination of a recruitment letter in Haitian Creole (*see attached "Recruitment Letter" documents*), which may be read by the subject or recited orally to the subject by Zanmi Lasante-affiliated staff who speak Haitian Creole and will therefore be capable of answering any questions.

### IV. SUBJECT ENROLLMENT

As outlined in section *iii(b)* above, subjects will come from two source: patients and medical providers.

Study personnel (identified in Section IV below) will recruit prospective medical provider participants from across Zanmi Lasante medical facilities. Study personnel will work with knowledgeable Zanmi Lasante staff to generate a list of medical providers who are key informants (that is, likely to possess a deep, experienced knowledge of local diagnostic and treatment approaches to hypertension as well as the experiences of patients with hypertension or associated risk factors). These medical providers will most likely be Zanmi Lasante's community health workers or *agents de santé*, although other providers may also be recruited. Once identified, medical staff will be contacted by study personnel (NCD clinic physician, nurse, or nurse-supervisor) either in-person or by phone who will then present an introduction to the study and offer an invitation to participate. Recruitment forms have been created to guide study personnel and participants in this process, including determination of eligibility criteria (*see attached "Recruitment Screening" documents*). If medical staff members decide to participate, study personnel will proceed with obtaining verbal informed consent (*see attached "Consent Form" documents*). Verbal consent was suggested over written consent by the initial Partners IRB Committee review because of the relatively low risk of this study to participants as well as the potential for difficulty with written consent given the possibility for illiteracy among prospective participants. If medical staff are interested in participating though need more time to decide or need to provide informed consent at a later time, study personnel will collect the participant name and phone number to follow-up at a later date to proceed with enrollment and informed consent processes, if applicable. This documentation will be stored confidentially as outlined at the bottom of this section. All documents will be in Haitian Creole, and all study personnel enrolling patients will be fluent in Haitian Creole. Of note, Mr. Stephen does not fluently speak Haitian Creole. Recruitment will not take place among medical providers who are directly supervised by the investigators. Prospective participants will be reminded that neither their decision to participate or not participate will have no effect their employment.

Study personnel will also recruit prospective participants from Zanmi Lasante's patient population. Patients will be recruited in order to form the following three groups:

- (1) patients without hypertension but with associated risk factors (diabetes, overweight/obesity, tobacco use)
- (2) patients with previously diagnosed hypertension, previously enrolled in hypertension treatment at Zanmi Lasante, unsuccessfully controlling their hypertension on current regimen
- (3) patients with previously diagnosed hypertension, previously enrolled in hypertension treatment at Zanmi Lasante, successfully controlling their hypertension on current regimen

Patient participants from groups 1-3 will be identified as they present to NCD clinic at Zanmi Lasante's hospital, University Hospital Mirebalais. Medical records will be analyzed for prior blood pressure values, blood pressure treatment history, and any risk factors associated with hypertension. Once patients are identified, they will undergo the same enrollment and consent procedures as described above with recruitment and consent

forms adapted for these participants (*see attached*). Prospective patient participants will be reminded that participation will have no effect on their medical care.

For all participants, individual enrollment and consent forms, an enrollment log (with participant name, phone number and/or housing location), and participant ID log will be used for administrative purposes and kept in a locked, secure location within a Zanmi Lasante facility (HUM administrative office) and/or password-protected computer of Zanmi Lasante-approved study personnel. Subject identifiers will be kept separated from collected data.

## V. STUDY PROCEDURES

For this study we propose a convergent mixed-methods study design employing semi-structured, open-ended, individual interviews; focus group discussions (FGD); and a quantitative knowledge survey.

For both patient and medical provider participants, interviews, FGDs, and quantitative surveys will be conducted over the course of approximately 6 months. Study personnel who will recruit, consent, enroll, and conduct data collection/analysis may include all or a subset of the following: NCD clinic physicians, NCD clinic nurses, HUM research assistants, HUM NEC community educators, HUM *agents de santé* and faculty/students from the HMS Dept. of Global Health and Social Medicine (i.e. Dr. Becker, Dr. Kwan, and Mr. Stephen). All study personnel have been or will be trained in the responsible conduct of human subjects research prior to participation.

For patient participants, approximately 6 to 15 will be recruited to participate in semi-structured, open-ended individual interviews to discuss their views of hypertension pathophysiology, treatment, and associated barriers and facilitators to receiving care. These participants will be recruited from across each of the 3 subgroups described in section IV above. Convenience sampling will be used to identify participants for each subgroup. HUM's NCD clinic uses an online patient data system called "RedCap" to log patient demographic information and medical history. Using this software, we can identify patients who meet general study eligibility criteria (listed above in section III) as well as criteria specific for subgroups 1-3 (listed above in section IV) prior to their upcoming appointments. Patients meeting these criteria can then be flagged in RedCap so that our study staff can provide them with recruitment and, if interested, consent information at the conclusion of a routine clinical visit to HUM NCD clinic. The interview guide has been attached in this application. Interviews will be audiorecorded and notes will be taken during the FGD. Each FGD will last approximately thirty to sixty minutes and will be co-facilitated by a local Zanmi Lasante medical provider fluent in Haitian Creole.

Additionally, approximately 36 to 45 participants will be recruited to participate in focus group discussions (FGD) to provide their views of hypertension pathophysiology, treatment, and associated barriers and facilitators to receiving care. These participants will be recruited from across each of the 3 subgroups described in section IV above with approximately 3 to 8 participants per focus group session, for a target of 5 to 12 FGD



sessions. Convenience sampling will be used to identify participants for each subgroup. These participants will be provided recruitment and, if applicable, consent for participation through the same process described above for interview participant recruitment and consent. These FGD will take place at the HUM hospital facility in a private setting. The FGD guide has been attached in this application. FGD will be audiorecorded and notes will be taken during the interview. FGD will last approximately 30-60 minutes.

For medical provider participants, approximately 12 to 15 will be recruited to participate in FGD to discuss their views of how patients conceptualize hypertension pathophysiology and treatment as well as provider-perceived barriers and facilitators to patients receiving appropriate care. Purposive sampling methodology will be utilized to identify these provider participants, with a target of 2 to 4 FGD sessions each comprised of 3 to 8 participants. Our aim is to recruit medical providers at Zanmi Lasante facilities who are likely to possess a deep, experienced knowledge of how hypertension is diagnosed and managed within the Zanmi Lasante catchment area. The FGD guide has been attached in this application. FGD will be audiorecorded and notes will be taken during the interview. Each FGD will last approximately thirty to sixty minutes and will be co-facilitated by a local Zanmi Lasante medical provider fluent in Haitian Creole.

Each patient study participant will also respond to a quantitative hypertension knowledge survey, which has been included in this application. This short survey is intended to be read aloud to participants and has objective scoring criteria on the basis of their verbal responses; however, the participants may complete the survey independently if they prefer, as there is space to write answers. Participants will be invited to complete the survey after they have provided verbal consent to participate in this study (*see attached recruitment and consent forms*). For patient participants in subgroups 1-3, verbal consent will be offered at either HUM NCD clinic during the course of their clinical visit or following a routine home visit by the patient's *agent de santé*, thus providing a convenient opportunity to complete this survey without requiring additional travel by participant or study personnel.

Once eligibility criteria for enrollment are confirmed and informed consent has been obtained, each study participant will be assigned an identification code at the time of enrollment. Only this code will appear on data collection forms (i.e., interview, focus group, and knowledge survey response and note-taking forms).

A key linking subject ID codes to participants and a copy will be created. The original and any copies will be kept separate from any study data and stored as detailed in section IX below. Consent and screening documents containing identifiable information will also be kept separately from the study data.

A record of each study participant's enrollment eligibility will be filed.

## **VI. ANALYSES**

Audiorecorded interviews will be transcribed verbatim and then translated into English for analysis. Once translated, transcripts will undergo a coding process as follows. First, all interviews will be read in their entirety to identify themes relevant to research questions that emerge during the process. Transcripts will then be coded according to these themes, in addition to coding of key information elicited in the interview process and intended to address key study questions. Comments illuminating key findings will be excerpted and collated. Various dimensions of these coded data will be analyzed, including frequency and associations with the various provider and patient strata.

Additionally, study personnel from focus group discussions and interviews will take notes on non-verbal data generated during each session which may provide additional data for theme generation in addition to transcript analysis. An example of this note taking form has been attached.

Quantitative data will be analyzed by first objectively scoring answers. Mean overall scores with standard deviations will be calculated. Also, questions will be individually analyzed for the proportion of respondents answering correctly to establish content areas of strength and weakness.

Following independent analysis of quantitative and qualitative data, the two modes of data will be compared in a convergent mixed-methods analytic approach. In this approach, quantitative and qualitative data will be compared side-by-side to assess for areas of convergence and/or divergence, thus generating new data to support or contradict each independently collected data modality and potentially creating future research questions.

## **VII. RISKS AND DISCOMFORTS**

This study presents no clear medical risks to participants.

Interview and focus group participants may feel uncomfortable when asked sensitive questions about personal behaviors, emotions, and experiences. All participants will be instructed that they can decline to answer any question or withdraw from the survey or interview at any time. Participants will also be instructed not to share information about their participation or the participation of others in the focus group discussions with anyone; however, nothing guarantees that participants will follow these instructions and, as such, breach of confidentiality is another risk. To further minimize risk of confidentiality breach, study names will not be placed on interview forms, focus group forms, or other data collection forms. Participant names will only be linked to study data through a code. Also, if a participant says something during the interview that he or she would prefer not be included, it will be permanently removed from the official record and will not be used in any resulting publications.

## **VIII. POTENTIAL BENEFITS**

There are no direct benefits in participating in this study.

However, the objective of this project is to gather data which can be utilized to improve Zanmi Lasante's approach to delivering hypertension care in Haiti. As such, this study offers potential benefit to the patient participants as well as the general population of Haitians with or at risk for hypertension.

## **IX. MONITORING AND QUALITY ASSURANCE**

*Data and safety monitoring:* The focus group and interview content includes sensitive questions related to personal health and self-care as well the social perceptions of Zanmi Lasante, a prominent social institution in Haiti. It is possible that participants will find these topics uncomfortable to discuss. To minimize this risk, the following measures will be implemented:

(1) Study staff who are facilitating focus group discussions and interviews will remind participants that they are not required to answer any questions and that all answers will remain confidential, including any subsequent reports and publications.

(2) At the end of all focus group discussions and interviews, participants will be asked "Do you have any questions or concerns about your participation in the study today?"

### *Data Confidentiality*

For all participants, individual enrollment and consent forms, an enrollment log (with participant name, phone number and/or housing location), and participant ID log will be used for administrative purposes and kept in a locked, secure location within an administrative office at HUM and/or encrypted, password-protected computer of Zanmi Lasante-approved study personnel. All paper documents (consent and enrollment forms plus study personnel notes from interviews, FGD, and knowledge surveys) will only be transported from the site of collection to the secure Zanmi Lasante storage site.

*Adverse event reporting:* The Co-Investigators (Davis Stephen and/or Dr. Gene Kwan) will monitor data collection and results regularly by attending most interviews and focus group discussions, as well as through regular meetings (in person or by telephone or by skype) with the data collection team on an approximately weekly basis in order to identify any other adverse events. The PI (Anne Becker) will meet at least once every two weeks with Co-Investigators by phone, Skype, or in-person throughout the data collection phase. Study staff will also be instructed to follow a structured protocol on identifying and reporting any adverse events within a 24-hour period to Dr. Kwan or Mr. Stephen, who will then notify Dr. Becker. Dr. Becker will notify the Partners IRB of any Reportable New Information within 24 hours of becoming aware.

Additionally, Zanmi Lasante in Haiti has its own institutionally based IRB which has reviewed a previous iteration of this proposal and submitted their full approval to begin it (see attached). An amendment reflecting the changes proposed herein has also been submitted to the local IRB for review concurrent to this Partners amendment review. Dr. Waking Jean-Baptiste, NCD Clinic Manager who is cited as a study co-director multiple times in this IRB, will be covered under the Zanmi Lasante IRB. Recruitment of study participants will not begin until we have received both Partners and local ZL IRB approval. The confidentiality of personal health information is protected by Haitian law but may be disclosed with patient permission.

## X. REFERENCES

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## *Proposed Study Materials*

### Patient Interview Question Guide

#### **[explanatory models of hypertension pathophysiology, symptoms, tx, etc.]**

1. For this interview, we would like to learn about your thoughts on the disease called hypertension. I would like to start by asking, have you heard about hypertension? [if no, skip to question #6]

- a) What can you tell me about what hypertension is?
- b) How does it work?
- c) What causes a person to get hypertension?

2. What does hypertension feel like?

- a) How does a person know if he or she has hypertension?
- b) Can a person feel if he or she has hypertension?
- c) If yes, what does hypertension feel like?

3. Is hypertension a problem that needs to be treated? Why or why not?

- a) What problems can hypertension cause?
- b) What health problems can happen to a person who has hypertension?
- c) Can hypertension affect your ability to work or do other things?
- d) How serious of a problem can hypertension be? And why?

4. Is hypertension a problem that can be treated? If yes, how?

- a) What is the best way to treat hypertension?
- b) How do you or others you know treat it?
- c) What are other ways people in your community treat it? (i.e.: family remedies, traditional healers, herbal medications, CHWs, clinic, hospital)
- d) Can hypertension be cured and go away for good?
- e) Can hypertension be prevented?
- f) When does a person know that it needs to be treated?

5. For people who do not have hypertension, is it possible to reduce their risk of getting hypertension? If yes, how?

- a) What specific things can be done to reduce someone's risk of getting hypertension?

#### **[patient-level barriers and facilitators to care]**

6. Do you see a doctor or nurse regularly?

- a) If no, why not?
- b) Do you find it difficult to go see a nurse or doctor? If yes, why?
- c) Is transportation to your nurse or doctor difficult? If yes, why?
- d) Do you struggle paying for other things if you go see your nurse or doctor?
- e) Do you have to give up other things to see your nurse or doctor?

7. Describe when you found out you had hypertension?

- a) What did you think when you found out?

8. How does having hypertension affect your life?
  - a) Is your life any different now that you have hypertension? If yes, how?
  - b) Do you take medication every day? Is this difficult for you? Why?
  - c) Give an example of a time you needed to refill a medication? What did you have to do to get a refill? Was it difficult?
  
- 9\*. Think of the last time you were sick. Describe what you did to receive care?
  - a) Was it difficult? Why or why not?
  - b) Did you find it difficult to go see your nurse or doctor? If yes, why?
  - c) Was transportation to your nurse or doctor difficult? If yes, why?
  - d) Did you struggle paying for other things to see your nurse or doctor?
  - e) Did you have to give up other things to see your nurse or doctor?
  
10. Think of the last time you needed to refill a medication. Describe how you got your refill?
  - a) Was it difficult? Why or why not?
  
- 11\*. Do you know anyone who struggles treating his/her hypertension? If yes, why do you think this is?
  
- 12\*. Do you know anyone who successfully controls their hypertension? If yes, why do you think this is?
  
13. Are there risks or side effects to treatment?
  - a) Are there unpleasant things about treatment (i.e. taste, hard to remember, hard to do)
  - b) Is treatment hard to get or find?
  - c) Is treatment hard to learn?
  - d) Is treatment harder when you start and then gets easier, or is treatment hard after starting too?
  - e) Is treatment expensive?

**[social-level barriers and facilitators to care]**

14. Is hypertension a rare or common problem?
15. Hypertension is a common disease in adults in Haiti; why do you think so many people in Haiti have hypertension?
16. What makes hypertension so hard to treat in Haiti?
  - a) Do you think some believe treatment is not necessary?
  - b) Do you think some people want treatment but are not able to get it? If yes, why?
  - c) Is treatment hard to get or find?
  - d) There are many risks for developing hypertension, including stress, high salt diet, smoking, and inactivity. Which of these do you think are most important?
17. What could be done to make hypertension easier to diagnose and treat?
18. What advice do you have for clinics, doctors, nurses, and CHWs about how to be more effective in treating hypertension?

**[wrap-up]**

19. Do you have any questions or concerns about your participation in the study today?

Thanks for participation. And reminder that all information discussed today will remain confidential.

\*Starred questions will be substituted for the subgroup of patients without hypertension but at risk for it

## Patient FGD Question Guide

### **[explanatory models of hypertension pathophysiology and treatment]**

1. As you all know, we are here to discuss hypertension and its risk factors. I would like to start by asking, have you heard of hypertension? What can you tell us about what hypertension is?
  - a) What causes a person to get hypertension?
  - b) How does a person know if he or she has hypertension?
  - c) What does hypertension feel like?
  - d) Is it a rare or common problem?
  
2. What problems can hypertension cause?
  - a) What health problems can happen to a person who has hypertension?
  - b) Can hypertension affect your ability to work or do other things?
  - c) How serious of a problem can hypertension be? And why?
  
3. Is hypertension a problem that can be treated?
  - a) Can hypertension be cured and go away for good? If so, how?
  - b) Can hypertension be prevented? If so, how?
  
4. Is hypertension a problem that needs to be treated?
  - a) When does a person know that it needs to be treated?
  - b) Are there things a person can do to take care of the problem by himself/herself?
  - c) What are some things that can be done about hypertension?
  - d) What are some of the ways that people treat hypertension? (i.e.: family remedies, traditional healers, herbal medications, CHWs, clinic, hospital)
  
5. How should hypertension be treated?
  - a) How do you or others you know treat it?
  - b) What are the best ways to treat it?
  - c) What are other ways people in the community treat it?
  
6. Do you think that some people don't believe treatment is not necessary?
  - a) Do you think some people believe treatment is not worthwhile?
  
7. Are there risks or side effects to treatment?
  - f) Are there unpleasant things about treatment (i.e. taste, hard to remember, hard to do)
  - g) Is treatment hard to get or find?
  - h) Is treatment hard to learn?
  - i) Is treatment harder when you start and then gets easier, or is treatment hard after starting too?
  - j) Is treatment expensive?
  
8. How would you compare treatment for another health problem (choose one chronic and one acute treatment regimen)



- a) Without saying names, how do you or others you know treat it?
- b) What are the best ways to treat it?
- c) What are other ways people in the community treat it?
- d) Is it possible to reduce your risk of getting hypertension? If yes, how?
- e) What specific things can be done to reduce your risk?
- f) Can hypertension be cured and go away for good?
- g) When does a person know that hypertension needs to be treated?
- h) Are there things a person can do to take care of the problem himself/herself?
- i) Do you think that some people don't believe treatment is necessary?
- j) Are there risks or side effects to treatment? Unpleasant things about treatment?
- k) Is treatment hard to get or find? Is treatment expensive?

9. What are other important things about hypertension we have not discussed?

**[patient-level barriers and facilitators to care]**

10. We find that hypertension is difficult to treat, even when patients regularly see their doctor or community health worker. Think of yourself or others you know who struggle with hypertension. Without saying their names, why do you think they have this difficulty with hypertension?

- a) What makes hypertension difficult to control for patients?
- b) Do you think the treatment is not effective enough?
- c) Do you think the doctor gave them the wrong treatment?
- d) Do you think the doctor gave them the wrong dose?
- e) Do you think it is difficult to follow treatment directions?
- f) Do you think people in their family interfere with treatment?
- e) Do other priorities interfere with the treatment? If so, what?

11. Think of yourself or others you know who successfully control their hypertension. Without saying their names, what do you think makes these patients able to get treatment and successfully stay on it?

- a) Are there any specific people who help make hypertension easier to control?

**[social-level barriers and facilitators to care]**

12. In general, why do you think so many people in Haiti have hypertension?

13. Diet is important for treating hypertension, so doctors encourage patients to reduce salt and increase vegetables. Are you or others able to do this easily? If not, why?

14. What makes hypertension so hard to treat in Haiti?

15. What could be done to make hypertension easier to diagnose and treat?

16. What advice do you have for clinics, doctors, nurses, and CHWs about how to be more effective in treating hypertension?

**[wrap-up]**

17. Do you have any questions or concerns about your participation in the study today?

Thanks for your participation. And reminder that all information discussed today must remain confidential.

## Hypertension Knowledge Survey

1            2            3            4            5  
 Strongly    Disagree    Don't      Agree      Strongly  
 disagree                    know                                    agree

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| <i>Definitions</i>  |   |   |   |   |   |
| 1. 150/90 is considered a “normal” or “healthy” value for blood pressure?                   | 1 | 2 | 3 | 4 | 5 |
| <i>Risk Factors</i>   |   |   |   |   |   |
| 2. For each of the following, indicate which can lower your blood pressure:                 |   |   |   |   |   |
| a. Reducing salt intake   | 1 | 2 | 3 | 4 | 5 |
| b. Reducing “maggi” intake  | 1 | 2 | 3 | 4 | 5 |
| c. Herbal medication  | 1 | 2 | 3 | 4 | 5 |
| d. Local healers / voodoo / witchcraft  | 1 | 2 | 3 | 4 | 5 |
| e. Reducing water intake  | 1 | 2 | 3 | 4 | 5 |
| f. Reducing stress  | 1 | 2 | 3 | 4 | 5 |
| g. Reducing alcoholic beverages   | 1 | 2 | 3 | 4 | 5 |
| h. Reducing tobacco   | 1 | 2 | 3 | 4 | 5 |
| i. Regular physical activity  | 1 | 2 | 3 | 4 | 5 |
| j. Taking vitamins  | 1 | 2 | 3 | 4 | 5 |
| <i>Treatment &amp; Lifestyle Modifications</i>  |   |   |   |   |   |
| 3. Hypertension is a treatable condition  | 1 | 2 | 3 | 4 | 5 |
| 4. It is necessary to take medication for hypertension everyday, even without symptoms      | 1 | 2 | 3 | 4 | 5 |
| 5. For each of the following, indicate which may be side-effects of hypertension treatment: |   |   |   |   |   |
| a. Increased urination  | 1 | 2 | 3 | 4 | 5 |
| b. Anxiety  | 1 | 2 | 3 | 4 | 5 |
| c. Dizziness  | 1 | 2 | 3 | 4 | 5 |
| d. Sexual side effects  | 1 | 2 | 3 | 4 | 5 |
| 6. It is necessary to take hypertension medication with food                                | 1 | 2 | 3 | 4 | 5 |
| <i>Symptoms &amp; Sequelae</i>  |   |   |   |   |   |
| 7. Having hypertension is a problem   | 1 | 2 | 3 | 4 | 5 |
| 8. “Uncontrolled” hypertension is dangerous or life-threatening                             | 1 | 2 | 3 | 4 | 5 |
| 9. I can feel when my blood pressure is   |   |   |   |   |   |

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| high  | 1 | 2 | 3 | 4 | 5 |
| 10. I believe that [blank] can be caused by untreated hypertension:   |   |   |   |   |   |
| a. Stroke   | 1 | 2 | 3 | 4 | 5 |
| b. Diabetes   | 1 | 2 | 3 | 4 | 5 |
| c. Heart disease  | 1 | 2 | 3 | 4 | 5 |
| d. Kidney disease   | 1 | 2 | 3 | 4 | 5 |
| e. Lung cancer  | 1 | 2 | 3 | 4 | 5 |
| 11. Hypertension always has symptoms  | 1 | 2 | 3 | 4 | 5 |
| 12. Hypertension can be a threat to your health even if you are not feeling sick                                | 1 | 2 | 3 | 4 | 5 |
| 13. [Blank] can be caused by untreated hypertension:  |   |   |   |   |   |
| a. Headache   | 1 | 2 | 3 | 4 | 5 |
| b. Diarrhea   | 1 | 2 | 3 | 4 | 5 |
| c. Blurry vision  | 1 | 2 | 3 | 4 | 5 |
| d. No symptom   | 1 | 2 | 3 | 4 | 5 |
|   |   |   |   |   |   |
| <i>Social Aspects of Hypertension</i>   |   |   |   |   |   |
| 14. Having hypertension is a common problem in Haiti.   | 1 | 2 | 3 | 4 | 5 |
| 15. I know friends or family with hypertension.   | 1 | 2 | 3 | 4 | 5 |
| 16. I know friends or family who have had complications due to untreated hypertension.                          | 1 | 2 | 3 | 4 | 5 |
| 17. I would not want others in my community to know if I had hypertension.                                      | 1 | 2 | 3 | 4 | 5 |
| 18. Hypertension affects my daily life.   | 1 | 2 | 3 | 4 | 5 |
|   |   |   |   |   |   |
| <i>Self-Assessment</i>  |   |   |   |   |   |
| 19. My health is important to me.   | 1 | 2 | 3 | 4 | 5 |
| 20. I eat a healthy diet.   | 1 | 2 | 3 | 4 | 5 |
| 21. My diet has too much salt.  | 1 | 2 | 3 | 4 | 5 |
| 22. I am physically active.   | 1 | 2 | 3 | 4 | 5 |
| 23. I can afford the medicines I need.  | 1 | 2 | 3 | 4 | 5 |
| 24. The hospital pharmacy always has the medications I need   |   |   |   |   |   |
| 25. If the hospital pharmacy does not have the medications I need, I can find them in a private pharmacy        |   |   |   |   |   |
| 26. If the hospital did not cover the cost of medications, I would be able to afford them in a private pharmacy |   |   |   |   |   |

|  |   |   |   |   |   |
|--|---|---|---|---|---|
| 27. Other important things interfere with taking care of my health.  | 1 | 2 | 3 | 4 | 5 |
| 28. It is important to me to avoid having a stroke.  | 1 | 2 | 3 | 4 | 5 |
| 29. It is important to me to avoid having a heart attack.  | 1 | 2 | 3 | 4 | 5 |
| 30. I understand what I can do to avoid having a stroke.   | 1 | 2 | 3 | 4 | 5 |
| 31. I understand what I can do to avoid having a heart attack.   | 1 | 2 | 3 | 4 | 5 |
| 32. I would like to do more to treat my hypertension but do not have enough information.                                     | 1 | 2 | 3 | 4 | 5 |
| 33. I would like to do more to treat my hypertension but do not have enough money.   | 1 | 2 | 3 | 4 | 5 |
| 34. I would like to do more to treat my hypertension but do not have enough support from doctors, nurses or agents de santé. | 1 | 2 | 3 | 4 | 5 |
| 35. I would like to do more to treat my hypertension but find it difficult to remember to take my medicines.                 | 1 | 2 | 3 | 4 | 5 |
| 36. I would like to do more to treat my hypertension but find the instructions for my medicine too hard to follow.           | 1 | 2 | 3 | 4 | 5 |
|  |   |   |   |   |   |
| <i>HUM Clinic Questions</i>  |   |   |   |   |   |
| 37. I am supposed to attend one clinic session per month   |   |   |   |   |   |
| 38. It takes me too long to get to clinic  |   |   |   |   |   |
| 39. I have to wait too long at the clinic  |   |   |   |   |   |
| 40. I understand everything the doctor tells me at the clinic  |   |   |   |   |   |
| 41. I would feel comfortable having a trained nurse help me take care of my blood pressure                                   |   |   |   |   |   |
| 42. I would like to have a periodic reminder to take my medication sent to me by SMS/text                                    |   |   |   |   |   |
| 43. I would like to have a periodic reminder about upcoming clinic visits sent to me by SMS/text                             |   |   |   |   |   |
| 44. If a text is sent to me, I will receive it   |   |   |   |   |   |
| 45. My cell phone is always charged  |   |   |   |   |   |

|   |  |
|---|--|
| 46. I would like to have a community health worker visit me at home to remind me to take my medications       |  |
| 47. I would like to have a community health worker visit me at home to remind me about upcoming clinic visits |  |
|   |  |
| <i>Demographics</i>   |  |
| 48. Age   |  |
| 49. Gender  |  |
| 50. Schooling   |  |
| 51. Income / job  |  |
| 52. Source of HTN knowledge (school, media, medical, friends/family)  |  |

## Provider FGD Question Guide

\*Starred questions are only for *agents de santé*, nurses, NEC community educators

### **[explanatory models of hypertension pathophysiology and treatment]**

1. As you all know, we are here to discuss patients' hypertension and its risk factors. I would like to start by asking, how well do you think your patients understand hypertension what can you tell us about what hypertension is?\*

  - a) What causes a person to get hypertension?
  - b) How does a person know if he or she has hypertension?
  - c) What does hypertension feel like?
  - d) Is hypertension a rare or common problem?

2. Without saying names, how well do your patients understand hypertension?
  - a) Do they understand what causes it?
  - b) Do they understand it is possible to reduce their risk? If so, how?
  - c) Do patients recognize the problems hypertension causes? If so, what problems do they believe hypertension causes?
  - d) How serious of a problem do your patients believe hypertension is? Why?
3. How well do patients understand the treatment of hypertension?
  - a) What options do they feel they have for treatment?
  - a) Do they recognize the importance of taking medication daily? If not, why?
  - c) What are other ways people in the community treat it?

### **[patient-level barriers and facilitators to care]**

4. As you all know, we find that hypertension is difficult to treat, even when patients regularly see their doctor or community health worker. Think of your patients who struggle controlling their hypertension. Why do you think this is?
  - a) What makes hypertension difficult to control for patients?
  - b) What other priorities interfere with treatment?
5. Think of patients who succeed in controlling their hypertension. Why do you think they succeed?
  - a) What specific things do they do that others struggle with?
6. What could we, Zanmi Lasante, offer that would make hypertension easier to control for our patients?

### **[social-level barriers and facilitators to care]**

7. In general, why do you think so many people in Haiti have hypertension?
8. What makes hypertension so hard to treat in Haiti?
9. What could be done to make hypertension easier to diagnose and treat?

### **[wrap-up]**

10. Do you have any questions or concerns about your participation in the study today?

Thanks for participation. And reminder that all information discussed today must remain confidential.