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The Rheumatic Heart Disease Healthcare Paradox: Salvador, Brazil.

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The Rheumatic Heart Disease Healthcare Paradox: Salvador, Brazil.

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For my parents

Table of Contents

Paper 1 – Literature Review: Rheumatic Heart Disease, Brazil, slums, and the limits of universal access. 1
Introduction 1
Rheumatic Heart Disease 2
Brazil 5
Economic and Political 5
Health and Healthcare in Brazil 6
Race Relations in Brazil 9
Slums 12
Slum Inequality 12
Slum Definitions 13
Global Slum Demographics 15
Slums in Brazil 16
Conclusion 18

Paper 2 - The RHD Healthcare Paradox: Salvador, Brazil. A provider perspective qualitative study 19
1. Introduction 19
2. Methods 21
Formative Phase 21
Implementation Phase 21
3. Results and Discussion 23
3.1 Slum Risk Factors 25
3.2 Barriers to access/utilization of primary healthcare services 27
3.3 Barriers to treatment in the primary healthcare services 30
3.4 Barriers to access/utilization of specialized healthcare services 32
3.5 Treatment in the specialized healthcare services 35
3.6 Systemic Issues and Neglect 36
Public Health Implications 38

References 41

Appendix 55

Paper 1 – Literature Review: Rheumatic Heart Disease, Brazil, slums, and the limits of universal access.

Introduction

The purpose of this review is to highlight the conundrum of rheumatic heart disease (RHD) in Brazil. RHD is preventable and its incidence in the developed world has sharply declined over the last forty years.[1] While the reason for this decline is unclear, access to healthcare and antibiotics is certainly an important contributor.[2] Brazil has had a universal healthcare system for more than twenty years, yet the disease persists there, with incidences in urban slums widely incommensurate with Brazil's national economic and development status.[3] As such, we can inquire as to why this eliminable disease continues at such rates in a country with universal healthcare access and to what extent the particular nature of slums has stymied eradication. While such a research question necessarily requires an ecological understanding ranging from biological to social factors, this review and subsequent study will be limited to questions of access and utilization of the healthcare system for residents of slums. Such an inquiry requires multiple areas of understanding. First, we will discuss RHD, its epidemiology, diagnosis, and unique trajectory. Second, to appreciate the global context, we will discuss Brazil and the development and implementation of its universal healthcare system. Third, since we are approaching healthcare in the slums of Brazil, we will review what is known about caring for the health of individuals in these particular urban spaces. In covering three topics brevity is required and certain sub-topics will be necessarily brief.

In summary, this review we will present the background information necessary to appreciate the following: What are the barriers to access and utilization of the public healthcare system for slum residents of Salvador, Bahia-Brazil throughout the course of rheumatic heart disease?

Rheumatic Heart Disease

Rheumatic heart disease (RHD) is a chronic heart condition that develops as an autoimmune response to repeated episodes of pharyngitis caused by *Streptococcus pyogenes*, also known as Group A streptococcus (GAS).[4]

RHD may or may not be preceded by acute rheumatic fever (ARF), which results from the body's autoimmune response to GAS.[4] It is believed that this process

occurs through molecular mimicry, in which activated lymphocytes responding to GAS also recognize self-tissues, although many questions of pathogenesis remain unanswered.[5,6] Acute rheumatic carditis is a common manifestation of ARF that can progress over time to RHD, an acute to chronic disease transition that takes years to decades.[4] In a prospective study in Brazil, 72% of ARF affected children ultimately developed chronic valvular disease, with 16% progressing to severe aortic and/or mitral disease.[7] It is the manifestation of either of these two valvular abnormalities in particular that are characteristic of RHD and eventually lead to heart failure and death.[4–6]

Global incidence and prevalence of ARF or RHD are difficult to discern for a number of reasons. Both ARF and RHD are primarily found in low-resource settings and incidences are poorly documented due to both lack of infrastructure for disease surveillance and because patients may simply not be presenting for care, particularly for ARF.[8] This latter reason may be due to individuals choosing to not seek care for ARF or because of inadequate diagnosis. [9] For example, there may be problems with training, lack of access to diagnostic resources, or because ARF may be clinically milder in areas of high endemicity.[9]

Another difficulty is the various ways in which diagnosis has been made. Previously, estimates were made using clinical characteristics and then confirmed by echocardiography.[10] This method shows prevalence rates in developing countries to be approximately 1-5 per 1000 among school-age children. [8] Echocardiographic screening is much more sensitive, however, and is preferred for confirming the rheumatic etiology of the disease before symptom onset as well as for providing quantitative information.[11,12] Because echocardiogphy is more sensitive, estimates based on clinical findings cannot be compared with those using echocardiographic methods; rate comparisons over space and time cannot be made unless the same methodology has been used. Furthermore, even when using echocardiographic methods exclusively, classification systems have not always been standardized. Fortunately, in 2012 the World Heart Federation published evidence-based guidelines for echocardiographic diagnosis that have become the global standard.[13] This definition includes three pathological categories; definite RHD, borderline RHD,

and normal.[13] It is unknown, however, if these criteria capture the most subtle changes of early RHD.[14]

Whatever the screening method, worldwide estimates vary, and prevalence and incidence in Brazilian slum populations in particular have been poorly studied. In a study in the state of Minas Gerais, school children from low socioeconomic status neighborhoods were screened using nonexpert screeners, telemedicine, and handheld and portable echocardiography.[15] In this study RHD prevalence was found to be 42 per 1000 children (37 borderline and 5 definite).[15] This compares to other echocardiograpy-based estimates in Cambodia (21.5), Mozambique (30.4), Nicaragua (48), and Kenya (62), all of which together provide an average point prevalence in developing countries of 40 per 1000.[16–18] RHD prevalence in low SES Brazilian settings is therefore similar to those seen in developing countries and is disparate with Brazil's status as a middle-income country. Although there has yet to be an echocardiographic-based study in the city of Salvador, Brazil's third largest city by population[19], RHD was found to be the primary cause for valvular heart surgery there.[20] This finding is again incongruent with Brazil's economic status. We would expect a preponderance of valvular surgeries would be for degenerative valve diseases based on Brazil's economic indicators, as opposed to RHD,[20] but we see that this is not the case.

Zooming back out, the incidence and mortality rate of RHD and ARF have largely declined in many parts of the world this past century.[21] Improved sanitation, rapid diagnosis, and the treatment of GAS with antibiotics have all contributed,[2] however, there is greater diversity of bacterial serotypes (as defined by differences in the M protein virulence factor coded by the emm gene) in developing nations, which may implicate genetic changes as well.[22] In Salvador, there was even a difference in the diversity of strains isolated in slum clinics versus private clinics, with private clinics showing a diversity more similar to developed countries.[23] Not only does this imply varying degrees of risk in the same city but also has important vaccine implications. If a vaccine were developed by developed countries based on the bacterial strains in their countries, it would prove ineffective for Salvador's slum populations. Human genetic variance may also play a role in who is at highest risk for developing RHD, as a recent genome-wide association study linked an altered common immunoglobulin heavy chain with RHD susceptibility.[24] This, however, has not been linked to any specific population and would not explain change in RHD incidence over time.

RHD is considered relatively rare in wealthy areas[25] and prevalence is heavily affected by socioeconiomic status (SES). For instance, a study in Kinshasa showed clinical exam based prevalence to be 22.2 per thousand among children who lived in slums but only 4 per thousand for children in non-slum city schools.[26] Known social risk factors include both overcrowding and unemployment, and patients from low and middle-income countries have a poorer disease prognosis associated with advanced disease and low education.[27,28] In developing countries and in many densely populated and economically depressed areas, RHD remains an important public health problem. It accounts for fifteen percent of all patients with heart

failure in endemic countries[29,30] and affects upwards of 15 million people globally per the World Heart Federation,[31] an estimate which rises dramatically to 62-78 million worldwide RHD cases when using echocardiogram based data.[16]

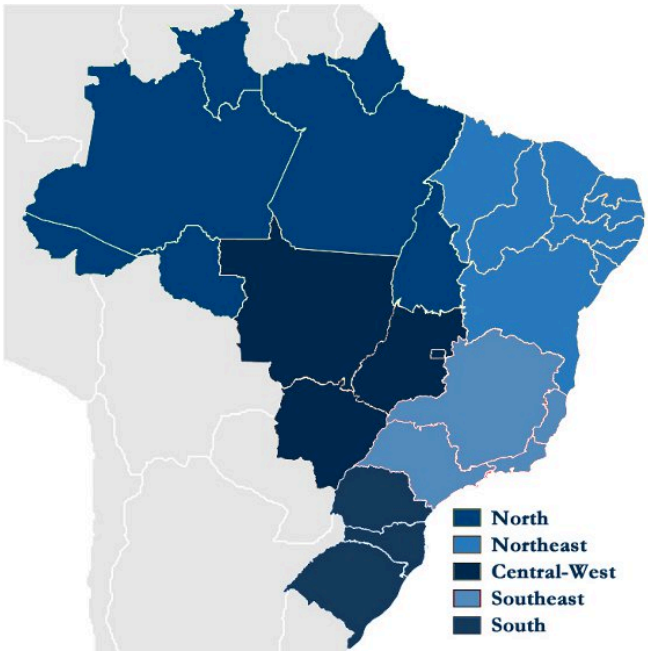
Seeing as the disease starts in adolescence and leads to substantial disability, the true social and economic impact of tens of millions of people with RHD is monumental. Furthermore, since the disease disproportionately affects individuals of lower SES levels and has the ability to lock families into cyclical poverty and therefore, as we will see below, slum residents are at particular risk of detriment from RHD.

Brazil

With a basic understanding of the disease in question, we turn to our current setting of interest in which we will study how the disease is allowed to operate. Although we have acknowledged various biological and social attributes that contribute to disease prevalence, we are interested in slums in Brazil and why people there continue to get sick at current rates. This requires an understanding of the social and political environment. As such, we will discuss Brazil generally through an economic and political lens, look at its healthcare system, and briefly discuss race relations, as all of these affect health.

Economic and Political

Brazil is a large, multiethnic society. It is the fifth largest country in the world both in terms of population size and landmass and is the largest in South America in both respects.[32] In fact, there are more Portuguese speakers in South America than there are speakers of Spanish.[32] An area originally colonized by the Portuguese, Brazil gained its independence in 1822.[33] Between 1920 and 1985, Brazil shifted between populist and military governments until the military regime peacefully ceded power to civilian rulers forming a democratic government.[34]



As a large country, Brazil's landmass is divided into distinctive regions. These five geographical regions include the north, northeast, center-west, southeast, and south, all of which vary in economic, social, cultural, and health conditions. For example, the southeast region (home to Rio de Janeiro and São Paulo) contains only 11% of Brazil's territory, but houses 45% of its population and 56% of its gross domestic product.[35] The northeast, on the other hand, where the state of Bahia and its capital, Salvador, are located, is the nation's poorest region. [36]

Brazil is considered one of the five BRICS nations (the other four being Russia, India, China, and South Africa), middle-income countries grouped together for being rapidly developing and at similar developmental stages. Brazil has well developed industries including automobile, machinery, textiles, cement, computers, aircrafts, and steel, which together compose 26.4% of its GDP.[37] It is also one the world's leading producers of hydroelectric power, has a well developed banking industry, and has an ever expanding services industry.[37] As a positive marker of its economic

development, Brazil's poverty index decreased from 68% to 31% between 1970 and 2008.[35] This remarkable success that has been attributed to various progressive social policies including a robust social security system, the *Bolsa Família* conditional cash transfer program, and increases in the federal minimum wage.[38] Global recognition of these economic and social advancements culminated with Brazil being selected to host both the 2014 FIFA World Cup and 2016 Summer Olympic Games. Alongside this economic development, population characteristics have shifted as well. Between 1970 and 2000 the proportion of the population over 60 years of age doubled and urbanization has increased the percent of those living in cities from 55.9% to 80%.[39]

Despite the economic success of the previous decades, Brazil's economy underwent a sharp recession starting in 2014, its GDP falling by 3.9% in 2015 and 3.6% in 2016.[40] Inflation went as high as 10%[41] and unemployment as high as 8.5% in 2015.[42] These changes have contributed to political instability and a shrinking public confidence in the government, with support for democracy falling in 2016 to 32% from 54% a year earlier.[43] In 2016, President Dilma Roussef was impeached on dubious charges and her vice president, Michel Temer, came into power to serve as president until 2018.[32] Temer, however, has recently undergone his own scandals and there have been fervent calls for his own impeachment amidst widespread unrest.[44]

Despite its economic development and relatively high GDP per capita, Brazil remains one of the world's most unequal in terms of wealth distribution as measured with the Gini coeffiicent. This is a globally used measure of statistical dispersion that is intended to represent economic and wealth distribution in a country. Values range from 0, representing complete equality, to 100, representing complete inequality. Brazil's Gini coefficient was estimated to be 51.5 in 2014 (down from 57.9 in 1981)[45]. As compared to other countries globally, this ranks Brazil amongst the top ten countries with the most *un*equal distribution of resources.

In sum, Brazil is a middle-income country that has until recently experienced a sharply upward trend in growth and development. It is, however, currently in the midst of serious crises both economic and political and remains widely divided between the haves and have-nots.

Health and Healthcare in Brazil

As noted, despite recent tumult, Brazil has undergone substantial economic development in the past few decades. As living conditions improved, so did the health of Brazilians and their health behaviors. However, health habits also began to look increasingly like developed countries with similar associated health detriments.[35] For example, obesity has increased, with the prevalence of obese men in state capitals now at 47.3%,[46] physical activity in state capitals is low,[46] and alcohol abuse is high, with 17% of the population aged 15 years or older reporting

binge drinking.[47] The leading cause of death in Brazil is disease of the circulatory system[48] (followed by cancer and external causes such as homicides and traffic accidents) and rates of disease differ according to both geographic area and social standing. For example, in 2006, the northeast region had an infant mortality rate 2.24 times higher than that of the south region, although this disparity has since moderately decreased.[49]

For our purposes, the healthcare system begins with the inception of the Sistema Única de Saúde (SUS) in the late 1980s. Currently, the Brazilian healthcare system is composed of a network of complementary and competitive service providers and purchasers, which compose three sub-sectors.[35] SUS compromises the public sector, in which services are financed and provided by the government at the federal, state, and municipal level, and includes military health services. [35] Second is the private (for profit and not for profit) subsector where services are financed in a number of ways with both private and public funding.[35] Finally, there is the private health insurance subsector, which consists of multiple health plans with different premiums and tax subsidies. [35]

The Brazilian SUS was formally established by the 1988 Constitution and was based on three overarching principles of 1) universal access to health services (defining health as a citizen's right), 2) equality of access to health care (which included addressing regional inequalities), and 3) comprehensiveness and continuity of care.[50] The founding of SUS arose from a broad-based political movement as well as in response to rising costs and an impending crisis in the Social Security system.[38] One of SUS's successes has been to make healthcare financing more equitable, unifying and integrating what were previously several independent systems of financing and service provision into one comprehensive, publicly funded system that includes the entire population.[38] Towards this end, spending on health increased 224 percent in real terms since the 1980s with a doubling of budget allocations in favor of primary care.[38] A large part of this spending, however, simply reflects economic growth, and government spending on health remains significantly lower that that in most Organization for Economic Co-operation and Development (OECD) countries at just 4 percent of GDP.[51] For comparison, only two OECD countries (Latvia and Turkey) spend less than 6% of GDP on health expenditure.[52]

The establishment of SUS was expected to decrease the importance of the private sub-sector, but this has not happened.[38] In fact, private spending as a share of total health spending has remained stable over the past 15 years, falling only three percent between 1995 and 2009, and spending on private plans has risen to 20 percent.[38] Additionally, direct out-of-pocket spending was unaffected, remaining at 30 percent of total health spending, likely a reflection of the Brazilian government's relatively low amount of total health spending.[53] There has also been relatively little change in the amount individual households spend on health, although there has been a notable reduction in the share of household spending on health among those at the lower end of the income distribution.[38]

The development of SUS led to many changes in the organization of the healthcare system and a boost in the capacity of services. Medical consultations per capita increased 70 percent between 1990 and 2009, with the largest volume increase being in basic care procedures.[38] The number of health care facilities grew more than three fold from 22,000 in 1990 to nearly 75,000 in 2009 and the number of medical consultations per capita in SUS facilities increased 70 percent between 1990 and 2008.[38]

The new facilities are almost entirely outpatient facilities, reflecting the growing emphasis on primary care, and were targeted to address the regional disparities in access to health services.[54] There is now virtually no link between public hospital bed density and average income at the state level and, interestingly, more new public facilities have been constructed in northeastern states (historically poorer with a higher percent of the population being of black or brown skin color), resulting in a higher density of outpatient facilities in states with lower per capita incomes.[38] The average utilization of healthcare services, while improving slightly, remains strongly correlated with average income,[38] and those in the top deciles utilize health services at a rate 50 percent higher those in the bottom two.[38]

This plethora of statistics is intended to provide a brief snapshot of how the Brazilian healthcare system has changed since the development of SUS. How we assess the level to which the implementation of SUS has improved health outcomes is a tricky metric considering that economic success has considerably raised living standards for large parts of the population. For starters, the fact that more people are using the healthcare system and that capacity of the system has increased are positive indicators of success. Brazil has also achieved significant improvements in life expectancy and child/infant mortality over the last twenty years.[51] Furthermore, when looking at coverage of health interventions with a clearly defined group, such as immunizations or prenatal care, Brazil has been a phenomenal success, showing nearly universal coverage with limited geographic disparities.[54] Clearly, successful interventions are possible, and portend to potential amelioration of RHD burden through policy change.

Household surveys performed by the World Bank provide additional data points, finding a reduction in unmet need as well as a decrease in the proportion of households that reported a lack of money as being a reason for not seeking care.[38] As noted earlier, those on the lower end of the income spectrum, in particular, have spent a smaller proportion of their incomes on health.[38] However, spending rates for catastrophic health events are significantly higher for these populations.[55] Despite this, the incidence of catastrophic spending for healthcare overall is low in Brazil and compares well with other South American countries.[55–57]

Despite these successes, there are numerous aspects of the Brazilian healthcare system that need to be improved, particularly surrounding universal coverage and access. For instance, although age-adjusted cardiovascular mortality rates declined 24% from 2000 to 2011, these benefits have not reached every part of the

population.[58] In fact, this decline in age-adjusted cardiovascular mortality differed according to race, sex, neighborhood, and socioeconomic status.[7,58,59] Black individuals and those of lower SES had the smallest decline, especially at younger ages. [53] Access and utilization are likely culprits as they break down along racial and socioeconomic lines. [60] Additionally, the World Bank household surveys found that facility-related reasons for not seeking care have increased, including insufficient numbers of staff, unfriendly staff, difficulty scheduling an appointment, and long waiting times.[38] A cross-sectional study in northeast Brazil found appointment delays and lack of available doctors to be the biggest reasons for not seeking care.[61] Using the same cross-sectional data, but focusing on inequities in the access and utilization of healthcare, researchers found that individuals with higher socioeconomic status had easier access to outpatient secondary care and preventative services.[60]

Importantly, the data are unclear on how well the system actually functions. For chronic conditions, including RHD, people must seek care that requires multiple practitioners (primary care, specialists, surgery) and testing, which involves a complex coordination of care.[62] Effective access, then, not only depends on available services but also on coordination, sharing results, and referral systems, which have been an especially difficult challenge. [62] A study on specialists' perspectives on the referral process in São Paulo found that providers struggle with an inadequate, non-computerized referral-return system that leads to treatment delays and inappropriate use of emergency services.[63]

While it is difficult to develop an exact measure for the functioning of coordination of care, waiting time serves as a helpful proxy. Median waiting times for scheduled appointments in 2010 ranged from 76.3 to 113.4 days depending on the type of treatment sought.[38] A recent study of cancer by the Federal Audit Tribunal found that weakness in primary care and difficulty accessing diagnostic procedures and specialist care led to 60 percent of cancer patients being diagnosed at stage III or IV.[38] Diagnosis this late limits treatment options and survival times. Clearly, diagnosis and difficulties with access are two areas in particular that need improvement, Brazil again comparing very poorly with data from OECD countries.[51]

In sum, the Brazilian healthcare system has undergone major changes over recent decades. Much of this has been positive, with improved capacity and health outcomes, although access to this success appears unevenly distributed and significant problems such as care coordination remain.

Race Relations in Brazil

In 2010 over half of the population self-classified their race or skin color as either black (7.6%) or brown (43.1%), while 47.7% labeled themselves as white.[39,64] The concept of race in the North American context is referred to in Brazil as either "raça" (race) or simply as "cor" (skin color). While these are separate concepts in Brazil,

they are similar enough to be treated as one for our current purposes. Race is an omnipresent topic in Brazilian social and political life.[65] Because lower SES, as well as slum residence, tends to correlate with darker skin tone and health disparities such as hypertension,[66,67] some discussion of race relations is warranted to understand this socially constructed driver of health inequality.

Brazil's racial history is nuanced. It was the last country in the Americas to give up slavery and imported almost 12 times the number of slaves as the United States, at approximately 5.1 million.[68] As scientific racism theories were popularized in the early 20th century it also underwent a concerted effort to counter the number of Afrodescendent individuals by increasing European migration with the intention of "whitening" the population.[69] Between 1884 and 1913, 2.7 million white immigrants came to Brazil induced by subsidized ship passage, land grants, and industrial jobs in the new economic center of the country, São Paulo, creating government-sanctioned economic, social, and health disparities between racial categories.[69]

Economic changes in the 1930s saw the replacement of agrarian elites with leaders from the financial and industrial sectors[69] as well as a public appreciation of the need for social policies aimed at integrating lower SES classes and ameliorating said disparities.[69] This issue was termed "a questão social", or "the social question".

Racial relations continued to change such that, by mid-century, Afrodescendent cultural expression began to be considered an essential element of Brazil's national identity;[69] a stark contrast to the overtly racist attempts at diluting Afro-Brazilian cultural influence. Black cultural expression started to be recognized as itself fundamentally Brazilian and concomitant changes were made in sociopolitical policies.[70] For example, in 1940 the National Penal Code suspended previous restrictions on the popular cultural expressions of samba and capoeira, both of which are related to African traditions.[69] This reconceptualization framed Brazil's racial mixture as an expression of national identity as opposed to a problem that needed solving.[69] This was famously expressed by Gilberto Freyre's presentation of Brazilian history as a "marriage" of three races, indigenous, Portuguese, and African. This contributed to a growing international reputation as a "racial paradise",[69] despite the results of numerous UNESCO studies to the contrary.[71–73]

During the period of military rule between 1964 and 1985 debate in this arena was silenced and no research or organizing was possible,[69] so any progress or lack thereof is difficult to quantify. However, with democratization in the 80s, new black organizations began to emerge and consolidate around various social issues, including health access, all of which challenged the "racial paradise" narrative.[69,70]

Finally, in 2001 the Brazilian government officially recognized, at the United Nations Conference against Racism and Discrimination in South Africa, that Brazil experiences real and ongoing racial discrimination.[74] Various institutional changes were conceived and new policies were instituted to redress these racial inequalities. Among these were land grants to historically disenfranchised groups, instituting

mandatory African history classes in high school classrooms, and the implementation of affirmative action initiatives in the form of racial quotas, which has seen much academic discussion.[74–77]

This history situates us to the modern context in which our analysis will take place. To recap, within the past century Brazil has moved from blatantly racist government policies to cultural validation with minimal political redress to, finally, the abandonment of its overtly positive racial self-image and acknowledgement of racism's existence with attempts to counter it. Modern Brazil is thus undergoing the complicated work of redressing the historical, contemporary, subtle, and explicit exclusion of black and brown skinned citizens in matters social (health included), political, and economic.[78]

Slums

Having reviewed the disease of interest and some economic and sociopolitical aspects of Brazil, we now turn to reviewing slums, the specific types of environment we are interested in. We will review their development as vestiges of colonialism and talk about developmental aspects and consequences on health.

In his novel Oliver Twist, Charles Dickens describes a poor urban area in south London as a place of "crazy wooden galleries… with holes from which to look upon the slime beneath; windows, broken and patched… rooms so small, so filthy, so confined, that the air would seem too tainted even for the dirt and squalor which they shelter… dirt-besmeared walls and decaying foundations."[79] While Dickens wrote works of fiction, his observations are corroborated and nearly identical to a contemporary journalist and campaigner, Henry Mayhew: "The water of the huge ditch in front of the houses is covered with a scum… and prismatic with grease… Along the banks are heaps of indescribable filth… the air has literally the smell of a graveyard."[80]

It is in this later period of Victorian England that the English term "slum" first came into use. Initially, slum was used to describe areas of low-quality housing for the working classes and evolved to include settlements on either cheap or marshy land.[81,82]

In modern times, slums develop as a response to a lack of sufficient housing space. As people come to cities for either work or safety both wages are suppressed (more competition) and housing becomes more expensive (inadequate supply).[83] Addressing the development of slums then requires political work. In Britain, social reformer Sir Ebenezer Howard, who founded the Garden City Movement near end of the 19th century, spearheaded the first response to the development of slums.[84] The "solution" was razing slums, the goal being to remove "unhealthy" urban slums and construct green suburbs in their place.[84] As we will see below, this "solution" was attempted in Brazil as well.

Slum Inequality

From a public health perspective, it has long been well documented that crowded, unsanitary, living conditions lead to poorer health outcomes.[85] From a social perspective, it is an intriguing question of why and how such visible inequality is allowed to manifest amidst areas of opulence in the same city; why the first instinct is to remove rather than treat causes. Inequality, the uneven distribution of power, is ubiquitous globally and is not in itself surprising.[86] In every society we see that misfortune is selective and affects some more than others. [86] We also see that this inequality becomes embodied through different forms of violence, that it has health effects on people's physical bodies through such mechanism as biological

embedding.[87] Bodies, then, can serve as register for, a site of, struggle against forms of domination,[88] a conflict we see played out in slums.

One such manifestation of this struggle is between the health of a slum resident and the ideals of European and North American urban planning. As seen in the Garden City Movement, urban planning was ostensibly aimed at controlling epidemics of urban disease, an ideal that was subsequently exported around the world.[89] British sanitarians were sent to various countries to aid in the control of infectious disease in large colonial cities but in practice they intensely scrutinized indigenous customary practices and responded by razing homes and markets in order to "ventilate" slums of their "unhealthy, dirty, and dark" conditions.[89] This was not just linked to simple medical and health benefits on their own but was justified with scientific racism.[90] In so doing, colonial slum interventions not only caused the indigenous populations to resist the limited interventions offered them,[82] but these policies were also used to justify the physical separation of Europeans from the local population, an early history of racial segregation.[91]

Segregation of urban non-dominant groups, based on color, ethnicity, race, caste, religion etc., is an example of structural racism, the systems-level factors related to, yet distinct from, interpersonal racism.[92] Structural racism, as manifested in the various seemingly neutral political decisions surrounding housing and where in a city someone lives, affects an individual's physical environment, their access to a quality education, employment opportunities, transportation, and access to medical care, all of which affect health.[93] It is these sets of policies that can function in racist ways, disempowering communities of color and reproducing historical conditions.

This geographic isolation also produces and is sustained by symbolic violence, the subtle imposition of systems of meaning that legitimize, and thus solidify, structures of inequality, wherein people who live in slums are seen as not only unhealthy, but deservedly unhealthy.[94] "The most worrying ingredient is most people's use of the word 'slum,' therefore, is the survival of these wholly negative connotations. Slum dwellers are not just people living in poor housing; they are considered by others to be people with personal defects. In Brazil, for example, a *favelado* is not just someone who lives in a favela, he or she is thought to be someone who deserves to live there."[95] With this conception, demolishing a neighborhood is of little consequence; the violence wrought is deserved.

Slum Definitions

What exactly are we talking about when we talk about slums? While areas like slums have existed since the inception of cities, the first modern comprehensive definition didn't emerge until 2003 when the United Nations Expert Group defined slums as human settlements with the following characteristics:[96]

1) Inadequate access to safe water

2) Inadequate access to sanitation and other infrastructure
3) Poor structural quality of housing
4) Overcrowding
5) Insecure residential status

All of these characteristics need further delineation. *Inadequate access to safe water* means less than 50% of households have access to a household water connection, a public standing pipe, or a rainwater collection, and that the source is located at a reasonable distance and can provide at least 20 L/day per person. [96] *Inadequate access to sanitation and other infrastructure* implies that less than 50% of households have a sewer, a septic tank, a pour-flush latrine, or a ventilated improved pit latrine.[96] *Poor structural quality of housing* refers to both the quality of housing location as well as the physical materials involved in its construction.[96] A household is defined to reside in a hazardous location if there is geological risk, meaning it is prone to landslides, earthquakes, or floods, or if the house is exposed to industrial pollution or unprotected hazards such as dumps, railroads, or power lines.[96] *Overcrowding* is simply defined as any household with more than two people per room or a size that is less than five square meters per person.[96] Finally, *insecure residential status* here means that the homeowner lacks formal deeds to the land or residence or any enforceable agreement that can prove their tenure.[96] This is frequent, as slums are often set up on unclaimed or municipal land.[97] Without secure status, people have little incentive to invest in healthier homes.[84,98]

As defined, any one of these characteristics can have adverse consequences on health. There is even criticism that these measurements are undervalued, particularly the parameters for water supply and sanitation, and that they therefore underestimate exposure and health risk.[99] At current measurements, however, the first four increase risk for numerous infectious diseases while an insecure residential status makes accessing healthcare more difficult (low utilization), increases risk of exposure to contamination and pollutants, and exposes residents to the toxic effects of stress associated with constant risk of eviction.[84,100] RHD directly correlates with many of these factors and taken all together, these characteristics make slums unhealthy places to live, affecting health in a myriad number of ways.[101–115] Health outcomes are worse in slums than in neighboring urban areas or rural areas[116–118] and often prevent residents from seeking care before developing end stage disease complications.[84] A concrete way this can happen is by simply being unable to make it to the clinic during operating hours. For example, informal workers, 80% of those employed in low and middle income countries,[119] lose income when absent from work. A worker in the informal sector who is a slum resident with a long and expensive commute is then at particular risk of being unable to access health facilities when they are open if financially insecure.[118,120]

It needs also be noted that living is a slum is different from living in poverty, although the two often co-occur. People who live in slums are subject to the environmental risks as noted above and therefore experience “neighborhood effects”.[120] These refer to factors affecting health at the community level, the spaces

in which people live, that are independent of individual household level factors.[121–123] This also means that while they can collectively benefit from interventions and that some interventions that work in poor non-slum areas, such as pit latrines, may be unsuitable.[100]

So far we have only addressed physical deprivations, which are necessary but not sufficient to understanding health impact. Not only is there detriment to how these physical deprivations affect disease and death but there is also detriment in the economic poverty, social inequalities, and political disenfranchisement that arise from slums and act to disrupt well-being and limit social mobility.[123,124]

Global Slum Demographics

Amidst changing global demographics, slum populations are growing. In 2014, for the first time in the history of humanity, more than half of the world's population lived in cities. This trend is irreversible and is expected to rise to 66% by 2050.[125] In 2014 Brazil, 22.3% of Brazil's urban population lived in slums (down from 36.7% in 1990).[126] By 2030 it is projected that the world will catch up to Brazil, with two of the world's eight billion projected people living in slums, a doubling of the nearly one billion people who live in slums currently.[127] It is, however, notoriously difficult to estimate slum populations. There is more than one definition of slum in use and this definition can change over time (as when the UN-Habitat definition changed the overcrowding parameter).[120] Even if a definition were standardized, many slum communities are not only hard to reach and count but are not officially announced as residential areas and thus get underrepresented in censuses.[128] Also, data regarding them may only be collected only every few years, so annual reporting relies on estimates.[128]

Perfect measurements notwithstanding, as roughly a quarter of the world's population will be living in slums, it is of obvious importance that we have an understanding of how to deliver care to these populations. Our knowledge remains rudimentary, however, and more research has been repeatedly called for in the literature.[84,98,118,120,124,129–131] Indeed, the nature of life in urban slums also creates conditions that can rapidly lead to poor health outcomes for those within slums as well as outside of them. As Farmer notes in Pathologies of Power when discussing tuberculosis in Russian prisons, iron bars may keep in people, but they do not keep in microbes.[132] Likewise, while slum populations may be spatially and socially isolated, the infectious health risk to people living there are not isolated to their inhabitants. For example, the 2010 Haitian cholera epidemic (which killed over 8,000 people in a previously cholera free country),[133] and the 2013-2016 West Africa Ebola epidemic (a historically self-limiting disease that killed over 11,000 people in this outbreak),[134] have an important commonality, they occurred in slums and because of slums. Both outbreaks were exacerbated by the introduction of an infectious agent into a large informal settlement,[91] which allowed for easier spread,

mutation, and propagation.[100] The cholera outbreak occurred in spite of there being available vaccines, effective drugs, and knowledge of how to control the disease. Zika virus is another scourge of urban slums that garnered attention when it spread beyond slum borders.[135] These outbreaks demonstrate both the microbiological virulence and complex community dynamics of disease slum conditions create, both of which make containment and treatment extremely difficult.[91] None of these explosive epidemics can be understood or prevented without understanding the reasons they happen, the existence of slums.[135]

Slums in Brazil

Having discussed slums generally, we turn now to Brazil, where they are termed *favelas* or *comunidades* (communities). Since the late 1800's political changes and economic shifts have caused the population of Brazil to grow and move internally with communities of squatter settlements developing to house migrants and itinerant laborers. One major internal migration was after the abolition of slavery in 1888, which led to a large influx of freed slaves from the countryside and saw the development of large slums.[136] Local governments were not able to meet the needs of these new migrants and residents of the newly formed slums were forced to create their own infrastructures of housing and employment.[34] The Rocinha favela in Rio de Janeiro, for example, developed from a community of wooden shacks and dirt roads to a community with cement and brick houses, paved streets, piped water, and even metered electricity.[129]

Generally, the political establishment ignored favelas until the 1940s when populist politicians ascended to power. In Rio de Janeiro, mayor Henrique Dodsworth (1937-1945) envisioned replacing slums with modern, sanitary, public housing units called "proletarian parks", a similar solution Great Britain attempted fifty years prior.[83] This set a precedent for *favela* removal in Brazil and the subsequent full scale razing of *favelas* that occurred in the 1960s and 70s, which displaced residents and freed up inner city land in Rio's affluent neighborhoods.[34] Since simply razing *favelas* did not address the underlying causes of Rio's housing shortage, however, they continued to grow up until eradication was abandoned as an official policy in the 1970s.[34]

As Brazil transitioned to democracy in the 1980s, Brazilian cities also became important hubs in the international trade of illicit drugs. This forced favela residents to trade the threat of relocation and eviction with drug violence and intense police repression.[137] Fortunately, since 2008 a pacification program has been instituted that urges a less violent approach, instituting community-policing bases directly within *favelas* (including Rocinha mentioned above) combined with urbanization projects.[138] Now, as the recipient of development projects aimed at introducing state law and building community institutions, slum residents are more easily able to participate in civil society.[34] While these new policies have contributed to falling murder rates in Rio de Janeiro (falling 66%) and São Paulo (falling 71%) between

2002 and 2012[139] they have increased elsewhere. Salvador is now considered Brazil's most violent city with nearly 60 homicides per 100,000 people, nearly triple Rio de Janeiro's and quadruple that of São Paulo.[139]

22.3% of Brazil's population continues to live in slums,[126] which are racially segregated from the rest of the city and experience poorer health outcomes.[140] Brazil is thus a nation whose severe income inequality causes a large proportion of its population to live in socially determined areas that affect their health.[141] This matters for health generally and for RHD in particular. The (poor) health determinants of slums contribute to the outsized RHD prevalence in Brazilian slums, which appears unaffected by improved healthcare access.[3] A pubmed search of "Salvador + Brazil + slum" brings up 56 results, none of which address healthcare access or utilization for individuals living in slums. Again, much needs to be addressed for health inequalities to abate, including social circumstances and microbiological ones, but healthcare access for slum residents is an important place to start.

Conclusion

The nation of Brazil has one of the world's highest GINI coefficients and extensive urban slums. Combined with universal healthcare access, which does not imply universal utilization, this provides an interesting and important case study. Even when universal access is made a priority, preventable diseases like RHD are seen to persist in urban slums. Despite the introduction of SUS and consequent reduced household spending on healthcare, increased per capita consultations, and decreased regional disparity,[38] RHD persists.[15] To eliminate the disease we must uncover how the health system fails and consider the difficulties imposed by slums in particular. Why are young, black, low SES men from slums the most at risk for poor cardiovascular health?[7,57,58,91,135,142] Why do lower SES individuals have more difficulty with access?[60,61] What role does poor care coordination within the health system play?[56,62] And, finally, what are the exact ways in which structural[93] and symbolic violence[94] manifest into valvular dysfunction?

Qualitative research methodology provides a way to explore these complex, nuanced causes. By interviewing community health workers, primary care physicians, and cardiologists, an idea of perceived barriers and care coordination issues can be appreciated and community dynamics can be cracked open. In this way, an understanding of the causes of the conundrum of RHD can be unpacked. How Brazil's healthcare system breaks down in its ability to eliminate RHD can provide information to both speed the elimination of RHD as a public health concern in Brazil and contribute to an understanding of healthcare access in slums worldwide. As RHD etiology spans preventative, primary, specialist and surgical care, it also provides a lens through which to view a wide swath of the health system generally. Gaining an insider's perspective on difficulties within this healthcare system regarding patient access, provider referral, testing, and treatment, can provide us with the information necessary to tackle not only RHD for slum populations but other infectious and chronic diseases as well.

If we are to care for what by 2030 will be a quarter of the world's population, we have to understand how to better structure healthcare access so that urban populations in slum environments see the same improvements in health. The results of this study will have implications for the prevention and control of other diseases that tend to proliferate in slum conditions. The recent outbreaks of Ebola in West Africa and cholera in Haiti have shown how infectious diseases can mutate and spread wildly when they surface in slums.[91] The dynamics of healthcare in slums and how we are to treat individuals who live there are thus critically important to understand.

Paper 2 - The RHD Healthcare Paradox: Salvador, Brazil. A provider perspective qualitative study

1. Introduction

As defined by the United Nations Expert Group, a slum is an area having inadequate access to water or sanitation, deficient housing, overcrowding, and residents with insecure residential status.[96] Slums frequently experience increased violence, unemployment, poor social stability, and limited access to social services, producing conditions of social disorganization and poverty that put residents at increased health risk.[137] By 2030 nearly two of the planet's projected eight billion projected inhabitants will reside in slums.[143] Despite this, there is a paucity of health statistics on disease and access to healthcare within slums. As recently noted by a series in the Lancet,[120,131] more research on slums is needed. Urban health statistics exist in aggregate and often mask important intraurban disparities between slums and non-slums and miss unique local environmental and social context surrounding disease. With poor data health officials cannot properly allocate resources or address urgent health needs.[84,129,144]

Rheumatic heart disease (RHD) is one disease frequently recognized in urban slums but its incidence, prevalence, and associated risk factors are not well documented. RHD is caused by group A streptococcal (GAS) infection can cause pharyngitis and acute rheumatic fever, which can lead to the cardiac sequelae of RHD, causing valvular dysfunction and heart failure. RHD is considered relatively rare in wealthy areas[25] and prevalence is heavily affected by socioeconiomic status (SES).[26,145] Known social risk factors include both overcrowding and unemployment, and patients from low and middle-income countries have a poorer disease prognosis associated with advanced disease and low education.[27,28] In developing countries and in many densely populated and economically depressed areas, RHD remains an important public health problem, accounting for 15 percent of all patients with heart failure in endemic countries[29,30] and affecting upwards of 15 million people globally.[31] Of note, this estimate rises dramatically to 62-78 million when echocardiography-based screening is utilized.[16]

Prevalence and incidence of RHD in Brazilian slum populations in particular have been poorly studied. A study in the state of Minas Gerais screened school children from low SES neighborhoods found a prevalence of 42 per 1000 children (37 borderline and 5 definite).[15] This compares to other echocardiography-based estimates in Cambodia (21.5), Mozambique (30.4), Nicaragua (48), and Kenya (62), all of which together provide an average point prevalence in developing countries of 40 per 1000.[16–18] RHD prevalence in low SES Brazilian settings is therefore similar to those seen in developing countries and is disparate with Brazil's status as a middle-income country. Although there has yet to be an echocardiographic-based

study in the city of Salvador, Brazil's third largest city by population,[19] RHD was found to be the primary cause for valvular heart surgery there.[20]

In 1998 Brazil established a universal healthcare system, the *Sistema Único de Saúde (SUS),* which led to many improvements in health outcomes, although these were not evenly spread throughout the population.[7,54,58,59] Brazil also has one of the world's highest GINI coefficients[146] and extensive urban slums. As such, Brazil provides an interesting and important case study in urban slum healthcare access and RHD provides a lens through which to view a wide swath of the health system, spanning from primary care to specialty care.

The aims of this paper are to investigate the barriers faced in navigating prevention and accessing treatment for RHD in the Liberdade neighborhood of Salvador, Brazil. By doing so, we hope to elucidate the dynamics of providing healthcare in slums to both limit RHD and speak more generally to best practices for providing care for individuals in these specific urban environments.

2. Methods

Formative Phase

This study took place in the city of Salvador, Brazil and occurred in two phases. In the formative phase, qualitative data was collected through participant observation and key informant interviews between June 2016 and August 2016. Interviews were performed with three cardiologists at the Hospital Universitário Professor Edgard Santos (HUPES) and three community health researchers at the Federal University of Bahia (UFBA). Participant observation involved accompanying cardiologists on site at HUPES two days per week during valvulopathy and general cardiology clinics. Fieldnotes were taken to record researcher reflections and observations. In addition to a literature review, these transcripts and fieldnotes were thematically analyzed to inform the study design and interview guide of the implementation phase, the results of which are analyzed and presented in this paper.

Implementation Phase

-Study Setting

The implementation phase of the study took place at two referral hospitals in Salvador, HUPES and the Hospital Ana Nery (HAN), as well as a family health post (Unidade de Saúde da Família) in the neighborhood of Liberdade, in Salvador. Both hospitals are urban tertiary hospitals whose catchment area includes the entire state of Bahia. The health post serves a section of the Liberdade neighborhood, a low-income, densely populated neighborhood afflicted with high rates of crime. Of note, Liberdade houses one of the largest populations of Afro-descendent Brazilians in all Brazil.[147]

-Participant Recruitment

Sampling was purposive, intensive, and *a priori*. As RHD begins with streptococcal pharyngitis before progressing to heart disease, the interview subjects ranged from those involved in primary care to specialists in cardiology. Cardiologists were recruited through snowball sampling from initial contacts made during the formative phase. Snowball sampling also yielded a contact with the manager of the family health post, who facilitated contact with the community health workers (CHW) and primary care providers (PCP) there. Community health workers (CHW) were included as they work "on the ground" in the communities of interest, are from those communities themselves, and therefore have a more nuanced understanding of community and social factors that act as barriers to care.

-Data Collection

In this study we used qualitative data collection methods and a semi-structured interview guide to collect data on site from participants in 17 one-on-one interviews and one focus group. We continued to make slight adjustments to the guide during data collection as new themes emerged. The interviews utilized open-ended questions to explore providers' perceptions of barriers and facilitators to healthcare. The focus group was performed first, included five CHWs, and explored similar themes. Interviews and the focus group were performed in Portuguese by local qualitative researchers from UFBA. The authors performed additional training in qualitative interviewing methodology and observed all interviews.

In this study we selected a range of healthcare providers operating at multiple levels in the health system along the spectrum of rheumatic heart disease. At the level of primary care, nine interviews and the five-person focus group were performed with CHWs and individual interviews were performed with a triage nurse and one medical doctor (both of which we refer to as PCPs) at the health post. This comprised 75% of all CHWs and 100% of all full time PCPs at this clinic. An additional six interviews were performed with cardiologists at HUPES (four physicians) and HAN (two physicians). Written informed consent was obtained for all subjects, a written informed consent was provided, and the informed consent was read in Portuguese.

-Data Analysis

Interviews were transcribed into Portuguese and a thematic analysis was performed by the authors using MAXQDA software. Interviews were coded and information was categorized into general themes and subsequent sub-themes upon review. Memos were written about each code/theme to clarify scope, content, and interrelationship. Pertinent quotes were translated for publication.

The University of California, San Francisco ethics committee deemed this research exempt and the research was approved through individual committees at each site that the study was conducted. Funding for this research was provided by the Center for Global Public Health at the University of California, Berkeley.

3. Results and Discussion

This study sought to understand the perspectives of healthcare providers an individual would see along the course of RHD to learn why the disease persists despite access to care. This spectrum of providers, from CHW to specialty cardiologist, often shared similar ideas of what the largest barriers or bottlenecks were, but formulated their reasoning in different ways based on their disparate experiences and life backgrounds.

Our findings revealed six major chronological categories that patients must overcome to avoid developing RHD or have it successfully medically managed. These include the effects of living in a slum (1a and 1b), barriers to access and utilization of primary healthcare services (2), treatment in primary healthcare services (3), access/utilization of specialized healthcare services (4), treatment in specialized healthcare services (5), and systemic issues (6). Note that "health post provider" will be used to refer both to PCPs and CHWs, while "providers in general" refers to health post providers and cardiologists.

Figure 1 – The Referral System and Barriers to Progression (adapted from Meara et al)[148]

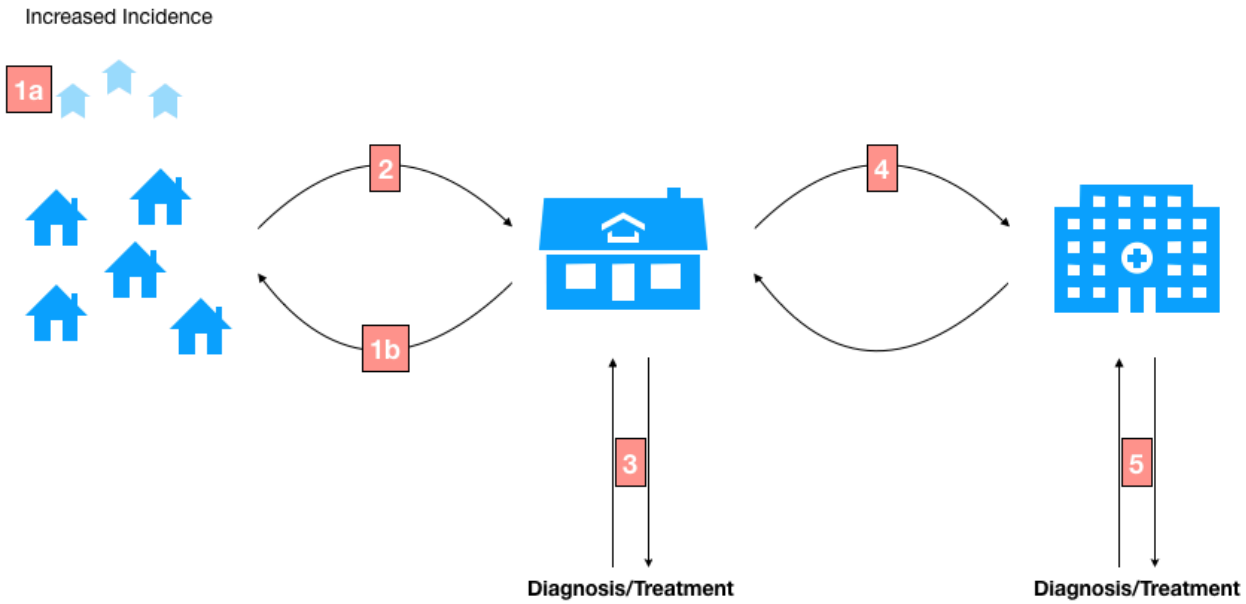


Table 1 – Summary of Findings

1) Slum Risk Factors
- -Overcrowding
- -Poor diet*
- -Inability to exercise+
- -Decreased community outreach+ (1b)

2) Barriers to access/utilization of primary healthcare services
- -Trust and awareness of clinic *not* seen as barrier
- -Resident ambivalence
- -Lack of providers
- -Use of alternative care modalities*

3) Barriers to treatment in the primary healthcare services
- -Health literacy
- -Availability of medication*
- -Lack of diagnostic testing

4) Barriers to access/utilization of specialized healthcare services
- -Insufficient screening/diagnosis by PCP
- -Speed of referral system
- -Inefficiency and lack of triage in referral system
- -Lack of communication between PCP and specialist

5) Barriers to treatment in the specialized healthcare services
- -Health literacy
- -Prophylactic treatment*
- -Lack of diagnostic testing*

6) Systemic Issues
- -Lack of public concern
- -Workforce diversity

*Additionally affected by financial constraints
+Additionally affected by community violence

3.1 Slum Risk Factors

3.1.1 Overcrowding

When asked about what effects living in a slum may have on RHD, all providers pointed to overcrowding and sanitation as being major contributors that lead to enhanced spread of GAS.

> We know that crowded living situations, having few rooms, that this is a factor that promotes the spread of streptococcus. (cardiologist 5)

In addition, CHWs emphasized that resident inability to adequately maintain a healthy living space was due to structural vulnerabilities and resultant poverty.

> The moment you don't have money for adequate nutrition then you don't have proper basic sanitation or you don't have an adequate physical structure that provides decent living conditions. All of these impact health. (CHW – Focus Group)

This is consistent with research that poverty associated risk factors like unhygienic living conditions lead to persistent GAS in the environment and that overcrowding leads to repeated GAS infection.[2,149,150] Thus, physical conditions are reported to facilitate infection and these conditions are constructed and perpetuated by poverty, inhibiting a resident's ability to make their environment healthier.

3.1.2 Diet and Exercise

Insufficient nutrition in children is potentially linked to susceptibility to ARF[151] via a decreased immune response.[152] As noted above, maintaining an adequate diet can be difficult, and despite nutrition recommendations being communicated to patients, providers note that these instructions may be impossible to follow.

> Sometimes… they're very thin… You counsel them about diet, it's just that they won't always manage, but for financial reasons. You'll say "you have to eat every three hours" but sometimes they can only eat twice a day. How are they going to eat more? (PCP 1)

Again we see poverty intervening in an individual's ability to stay healthy. In addition to financial difficulties in procuring a healthy diet, an additional cultural/structural component was identified as well, that patients wanted "strong food" (*comida forte*) in order to feel full.

> They need what they call "strong food," got it? … they have to eat a lot because they'll only be able to eat again at five o'clock in the afternoon… it's no use eating fruit, eating salad, because in the middle of the day they'll feel hungry. (CHW 1)

While this was only stated by one CHW in reference to diet, the authors heard similar sentiments during the formative phase and similar concepts relating economic conditions to a "traditional" Brazilian diet based on beans and rice have been described in the literature.[153–155] When speaking to researchers in the formative phase, slum residents said that they preferred such "strong food" in order to maintain a feeling of fullness for as long as possible. As such, in addition to low SES slum residents not being able to afford sufficient food, food insecurity may affect the food choices they do make in such as way as to cause worse health outcomes.

Another preventative measure of health maintenance is exercise, which is made difficult due to the broader difficulty of violence in the community.

> There is a recreational area… that was recently opened. Some patients use it. But the issue… is… violence. Coming out really early to do physical activity is difficult on account of the violence. (CHW 1)

As noted, there is an outdoor space (although it was also noted that residents may not know how to use the equipment). Past research has shown that exercise improves health outcomes and reduces the risk of both cardiovascular disease[156] and rheumatic fever.[157] However, in this case the space for physical activity is felt to be safe only during inconvenient times, making violence a barrier to its use and therefore increasing resident risk for developing RHD.

3.1.3 Community Outreach

CHWs and PCPs communicate with patients the need for a healthy diet and exercise but lamented that it was difficult to communicate this message to the community due to lack of participation, materials, and physical space.

> There's no equipment to work with, there's no didactic material to work with. (CHW – Focus Group)

In addition to space and material, community violence was seen as hindering education and outreach by the clinic, limiting participation as well as possible educational topics.

> They don't participate much, also… if you prepare some event violence can just put an end to it. (CHW 4)

> We are limited by external violence… There are things that I can't do like give a lecture against drugs or talk about youth and addictions. (PCP 2)

Liberdade is described by residents of Salvador as being one of the most violent neighborhoods in the city. All study participants discussed gang related violence,

specifically in terms of territorial conflicts related to the trafficking of narcotics, as affecting health. For CHWs, the violence not only made outreach more difficult, but they spoke in visceral terms about both the scale of violence and the psychological effects it had on the community and on the CHWs themselves.

> There is always violence… oh is it here. It can explode at any moment, ok? Sometimes we're afraid to enter a community because we don't know what will be there. We're waiting for a bomb to go off. We sometimes get psychological problems because of this. (CHW – Focus Group)

> We work in an area that is super dangerous, crime is high. You have patients who were murdered at the door of the health post, you know? (PCP 1)

Exposure to community violence is known to affect mental health[158] and in Salvador slums it has even been shown to double the prevalence of asthma in children.[159] While it is possible that violence and associated stress affects pathogenic susceptibility, here we see community violence concretely limiting outreach and community contact by CHWs. Presumably, this will affect patient health literacy and lead to poorer health outcomes.

3.2 Barriers to access/utilization of primary healthcare services

In addition to why residents may be more susceptible to disease, healthcare workers at the community clinic pointed to barriers residents faced in accessing and using the clinic's services.

3.2.1 Trust and Awareness

We expected awareness of the clinic and/or a lack of trust in the clinic to be a barrier based on previous research[160] and information from the formative study, but we found that CHW's believed residents to be both informed and trusting of the clinic.

> They're well informed. They have our day-to-day information… and the doctors are really helpful. (CHW 8)

3.2.2 Resident Ambivalence

On the other hand, a major reason CHWs believed residents did not utilize the clinic was that the services did not seem useful. They frequently spoke of community members not having seen successful medical resolution for those who used the health post as a reason to not use it themselves. Once CHW described how this sentiment was expressed in the following way:

> "Boy, did you see that so-and-so did this, that, the other thing and died all the same?" It's neglect. I think that we don't have a lot of fear of death. (CHW 9)

This quote also implies a level of fatalism emerging from the context of the residents' lives, an idea expressed by most CHWs. Individuals in poverty in Brazil have been found to show higher incidences of fatalism and pessimism.[161] In the United States, similar feelings have been shown to undermine a patient's ability to incorporate prevention and disease management into their lives.[162,163] Accordingly, for the segment of the community that is reticent to use the clinic, poverty and associated feelings of fatalism and pessimism may be a major reason why.

The majority of residents were reported to use the clinic, however, it was often stated that their health-seeking behaviors were determined by their symptomology, that they would not come in until overt symptoms were noticed.

> They wait until the moment everything gets worse and then go to the emergency room. (Focus Group - CHW)

In the context of developing RHD, this is a concerning finding, as streptococcal pharyngitis is usually self-limiting, but the lack of treatment allows for the development of post-infectious sequelae.[164]

On the same note, PCPs noted that their process of differential diagnosis often required a child to be brought back by their parents, as a diagnosis was made clinically and without a rapid strep test.

> We ask some children, when we have a presentation that is suggestive of a throat infection or a viral pharyngitis, to be brought back in 48 hours. The responsible parents bring them back. The ones who aren't only bring them back if they get worse. (PCP 2)

Thus, while there are many reasons a child may not be brought back, one may be a lack of overt symptoms, a loss to follow up that can allow for RHD progression.

3.2.3 Lack of Providers

When asked about major barriers to receiving care in the clinic, all providers spoke of the lack of doctors or nurses that could attend to residents.

> Our team went a year without a doctor and only had a nurse, and then we went without the nurse too. (CHW 7)

The lack of primary care physicians in particular has been described in the literature[165,166] and was seen by providers as the major impediment to slum residents getting medical attention. CHWs believed the lack of regular health care providers to be a source of dissatisfaction felt by the community as well.

> People are dissatisfied because of these things. Our team went without a doctor for a year, the nurse moved away. Later they sent two nurses, one stayed for a time, one for another time, but neither came regularly. (CHW 7)

Regardless of how patients behave, treatment is impossible without a provider. It is easy to imagine that years without a provider could make community members feel dissatisfied, distanced from and clinic, and that this could compound feelings of fatalism that affect their health seeking behaviors long into the future.

3.2.4 Alternative Care

The perceptions outlined in the previous section, that going to a clinic is not useful either because the treatment is ineffective or because there is no healthcare provider, are reported to push people towards alternative healthcare modalities.

> So, being without a doctor… they (the residents) will look for other ways. There's no nurse, so they look for other solutions. They'll just go directly to the pharmacy instead. (CHW – Focus Group)

Going directly to a pharmacy for medications is a common practice in Brazil. Availability of over the counter antibiotics decreased in 2010 following new national restrictions, yet the practice is known to persist both anecdotally and from evidence in the literature.[167,168] Additionally, various studies focusing on either antibiotics or pharmacist recommended over-the-counter medications show this practice may indeed be harmful.[169–171] When someone cannot or will not go to a clinic, they do not seem to have good medical alternatives, which would similarly allow for disease progression.

In addition to going to a pharmacy for medication, the use of traditional medicines, usually in the form of teas, was another method residents used to handle their health needs in place of the clinic. This usage has a long history, particularly in Bahia, and is related to the Afro-American religious tradition Candomblé.[172]

> Someone (a patient) comes in and says "look, so-and-so drank a tea or something like that, and it's taking off and they got well. They didn't need to take so much medicine anymore." Then they follow and do the same thing. (CHW 9)

Using traditional mediations was frequently described in terms of adhering to a community health norm, of orienting health behavior around the habits and expectations of one's neighbors. The use of traditional teas was facilitated by a cultural and historical component described as well.

> That culture comes from their ancestors, their parents… And so sometimes they don't want to give it up. Many times they'll even have medication and

> come to the doctor. It's not even because of the lack of medicine but, in this way, they'll forgo the medicine and continue with tea. (CHW 3)

While traditional remedies were seen as an alternative care modality, CHWs saw people who used teas as an exclusive replacement for healthcare as a minority. Instead, they were more concerned with the use of traditional medications as prolonging the time between the appearance of symptoms and seeking medical attention.

> How it generally happens is… they will drink tea, they will use their neighbor's medications, who has the same symptoms, and when they get worse, they'll go to the emergency. (CHW 1)

There may be substantial benefits to using traditional medicines. However, when used as a substitute for seeking medical care in this context, their use likely means a missed opportunity to treat active GAS pharyngitis with antibiotics, which can result in the development of ARF or progression to RHD.

3.3 Barriers to treatment in the primary healthcare services

When a patient notices they are sick and they are willing and able to see a physician at the health post, they still be must be able to follow through with treatment. Two major themes, health literacy and difficulty in accessing medication, worked across multiple categories, but will be addressed here as they were most strongly expressed by health post providers in relation to treatment.

3.3.1 Health Literacy

CHWs universally expressed that patients had a poor understanding of how to take medications, stating that they frequently would use a medication only while experiencing acute symptoms and then stop.

> They come to resolve the problem at that time "Ah, the blood pressure is high, it has to go. I'll measure it, because I'm feeling pain." It's measured, it's high, they take medicine, it's ok, and then they leave the clinic. They think that's it and that they don't have to continue with the medication. (CHW 8)

A similar understanding also led patients to seek medication from a neighbor who had previously had similar symptoms instead of from a clinician. It was frequently presumed by health post providers that when this happened the medications given and taken were not appropriate for the patient's needs and that the giver had a surplus to give because they had not completed their entire course of medication.

> Here's what happens: if they feel well then they discontinue (the medication). When they feel dizzy or something, they'll go to a friend or neighbor and get medicine, and they give them some other pill. (CHW – Focus Group)

This type of medical misuse of medication was often linked to poor health literacy on behalf of the patient, which was linked to educational attainment in general.

> The level of understanding is low. There's the issue of literacy as well. There are a lot of functionally illiterate people, you write things and explain it to them, but when they look at the prescription they don't understand what it is they're holding. (PCP 2)

Overall, low health literacy was seen to necessitate an extended time period with the patient, which was difficult for the PCPs, and required constant follow-up and outreach to ensure proper adherence, stretching the CHWs.

3.3.2 Availability of Medications

Having access to a prescribed medication is by no means a given in Brazil[173] and access to antibiotics in particular is often limited by low socioeconomic status.[174] Similarly, CHWs and PCPs universally identified a lack of basic medications at the health post pharmacy as a barrier for patients and a source of frustration for themselves. The inability to get SUS provided medications at the health post caused patients to seek medications from private pharmacies, resulting in financial pressure that patients often could not surmount.

> I will tell you that this is the greatest difficulty, because people end up not buying the medication and then they get worse. Man, there have been some terrible, terrible throat problems and days where the mom says, "I don't have money, I didn't buy any (medicine)." (CHW 9)

As penicillin is an inexpensive drug to produce this would be a most unfortunate missed prevention opportunity. Finally, the unavailability of medication at the clinic pharmacy and the inability to buy medication in the private sector was pointed to as another factor that led to patients borrowing medications from neighbors.

> They ask their neighbor or go to the pharmacy when they can. These days the pharmacy situation is very difficult, though, and the majority of the time the one who provides most is the neighbor. (PCP 2)

3.3.3 Diagnostic testing

Not only in the medication difficult to obtain, but PCP's reported significant difficulty ordering an antisteptolysin O titer (ASO).

> Access to medication, to complimentary testing. They are not that easy. A simple ASO test through SUS is a very difficult thing to get. (PCP 2)

The inability to access diagnostics such as ASO testing hinders a provider's ability to care for the patient and link symptoms to possible GAS infection. Additionally, it may also contribute to a decreased sense of disease prevalence in the community and in low-resource settings in Brazil generally.[25]

3.4 Barriers to access/utilization of specialized healthcare services

3.4.1 Screening and diagnosis

If a patient makes it through the various barriers to see a PCP and shows evidence of probable RHD then they are referred to specialist cardiology care. In the state of Bahia there is no screening program for RHD and the PCPs at the clinic noted that they would not send a patient for an echocardiogram unless the patient demonstrated symptoms.

> In fact, there's a grading, because we in family medicine think of SUS as an economy. So, it's not use me asking for an echocardiogram if there are no changes to the physical exam or ECG. So, for screening we do cardiac auscultation, a clinical exam, and when there's some alteration suggestive of a morphological change to the heart or valvular change we order an echocardiogram. (PCP 2)

Unfortunately, this method of referral can often miss sub-clinical RHD. Studies comparing auscultation to echocardiography for screening have shown it to be both poorly sensitive and poorly specific and ECG changes will not occur until advanced disease affecting either the mitral or aortic valves develops. [25,175–177]

3.4.2 Referral to Specialists

Referral to cardiology is noted by all parties to be a long and arduous ordeal. Referrals are sent to a central regulation system (*regulação*) that determines where the patient will go for specialty care i.e. one of the various public hospitals in the city of Salvador. Frequently, the amount of time needed to get an appointment, both in terms of the time needed to physically go and get an appointment and the amount of wait time until a cardiologist is seen, is pointed to as a significant barrier to care.

> There was a scheduling day. I arranged everything… then you stay in the regulation the whole time and there's nothing, nothing, nothing. You have to be lucky. Who has the time to spend all day coming to the regulation to see if there's a vacancy? Tell me that. You come every day morning and night. It won't do. (CHW 9)

Heath care providers also pointed to an insufficient number of specialists to meet the necessary demand, making the system fundamentally insufficient to provide for the population it serves.

> First, it's very difficult to even have a specialist, and the few that exist, the few services there are, are overloaded by SUS… the others are private practice. (PCP 2)

This translates into long wait times, which is a known barrier to care in Brazil,[60] and causes frustration for providers. In particular, health workers point to the lack of coordination of referrals within the system itself, and cardiologists especially take issue with there being no system of triage within the regulation. They note that patients are often referred to them inappropriately, adding to their overloaded schedules, and that the sickest patients may end up waiting a long time to see them.

> There are erroneous referrals, overloading the service with patients that don't have a good indication to the detriment of those who need it. So it is necessary to have a triage, who is going to do what, who is going to be seen first or not. (cardiologist 3)

> Triage used to exist… but these days it doesn't. Now, when they enter into the regulation they enter into a blender that mixes everyone up and spits them out randomly. (cardiologist 2)

The concern is that patients languish waiting while the disease may be progressing. Of note, studies have shown this waiting period to be longer for low SES individuals in Brazil,[178] who are much more likely to be living in slums.

This concern is also noted by cardiologists in terms of patients not being appropriately screened and diagnosed at the level of primary care due to a lack of training (although, as noted above, this may also be due to difficulty accessing diagnostics).

> There should be a strong education in primary care, ok? Doctors and nurses need to know where to refer and what the referral criteria are, or do some triage, do some basic exams and then refer. (cardiologist 3)

In addition to a lack of training resulting in incorrect referrals, cardiologists believed that much of the initial workup could be done in primary care but that it does not because of a lack of training.

3.4.3 Communication between physicians

Another issue with the referral system that was noted is that it disconnects the referring physician from the specialist physician, a phenomenon which has been

described in the literature.[63] The majority of cardiologists, but not all, found this detrimental because they did not understand the clinical reasoning that led to the referral and they had no insight into the patient's lived reality.

> We feel rather helpless in relation to these difficulties...There exists a context around the child, around the family. It's that context that we don't have, and we feel rather helpless in how to act on these other factors. (cardiologist 5)

Indeed, a common complaint heard from health post providers was that understanding a patient's context is imperative for understanding how to treat them. CHWs noted that they were the closest to the patient and that they have valuable information.

> I go there to the patient's house, I see how it is and I ask questions. It's because, actually, we live in the area, so we already know more. (CHW 9)

This information was seen by CHWs as being important for understanding a population that they believe is often marginalized and discredited. When asked to describe physician awareness of the lives of community members, one CHW remarked that without being in the community:

> You won't know the reality. You'll just know from high above, you'll understand differently from the community health worker that's there inside… knowing these people. Because not everyone is bad because they want to be…. Many are sex workers. You might go and condemn them, but do you the life she has? Do you know where she came from, what was passed on to her, who her mother and father were? (CHW 3)

One might, it is presumed, not only have more empathy for a patient if one had an idea of their history but make better treatment decisions as well.[179]

We have placed these concerns in this section because CHWs and PCPs often emphasized understanding the context in which a patient lives as a critical part of a patient's care. They described a lack of such knowing as a barrier when the clinician themselves is removed from the patient's lived environment, as cardiologists are. As one CHW described it:

> The physician needs to know the patient in their entirety. The patient is not the disease. The patient… is inserted in a reality, and if you don't perceive this reality and you treat that patient, they'll tell you they're taking the medication and when they get home they won't. (CHW 1)

This reality is harder to see the further removed the clinician, and specialist physicians were reported to be of a different social and economic class as slum residents. It is known that differences in SES affect communication between the

doctor and patient[180,181] and in this case may result in poor adherence, understanding, and therefore poorer outcomes.

3.5 Treatment in the specialized healthcare services

3.5.1 Health Literacy

Health literacy was a topic brought up by each cardiologist interviewed. Similarly to CHWs and PCPs, cardiologists noted patients often had a poor understanding of their condition. This was seen as a major difficulty in terms of understanding the need to see a physician regularly and the need to adhere to medical treatment. In this context, the treatment is prophylactic intramuscular injections of benthazine penicillin G (benzatacil in Brazil) every 21 days.

> What we see most… is the patient not wanting to return. So, sometimes it's because either the family itself doesn't understand, doesn't realize the severity of the disease, or doesn't understand the need for prophylaxis and the importance of taking benzathine every 21 days… It's this question of understanding… that I think is the biggest problem. (cardiologist 4)

A lack of understanding necessitates spending more time with patients to explain the diagnosis and need for treatment, despite the fact that there may not be overt symptoms. As noted earlier, specialty physicians like cardiologists are generally overloaded with public sector patients and sufficient time is likely unavailable.

3.5.2 Prophylaxis

More than half of the cardiologists noted structural barriers that patients can face in adhering to long-term penicillin injections. The first of these being the requirement that the medication be injected in a medical facility:

> The injection should be done by a health professional, if possible within the public network… You need to have access to this location, the benzathine medication needs an antibiotic prescription, and these locations have to have it in stock. (cardiologist 3)

This is ostensibly to prevent complications that can arise from anaphylactic shock; however, cardiologists who spoke of this viewed the risk involved as not worth the resultant limiting of access that occurs with the creation of transport, financial, and logistical barriers.

> The probability of that happening is extremely low. So, even that is a barrier we have to overcome, that's part of our reality here in Salvador. (cardiologist 4)

Another major theme was a lack of penicillin. Cardiologists universally agreed that the lack of mediation constituted a significant barrier to patients as it made prophylactic treatment impossible.

> The main problem is the availability of benzathine penicillin. (cardiologist 1)

Without having access to prophylactic medication, RHD has a higher chance of developing in patients with previous ARF.[25,182–185]

3.5.3 Diagnostic Testing

It is important for clinicians to have access to echocardiography to track valvular damage and disease progression. As echocardiography is an advanced imaging, the system of referral is also run through the central regulation (*regulação*). Echoing similar barriers heard earlier, providers believed that the supply is not enough for the demand, that there should be a triage system, and that the time needed for a patient to get an exam serves as a barrier.

> There is no certain date in the… system for (echocardiogram) vacancies to appear, the vacancies are random. The patient isn't always available to be forever waiting at the desk for the form or vacancy they need. (PCP 2)

This often leads patients to turn to the private sector to get an echocardiogram done, creating a cost barrier. Unfortunately, those coming from the private sector were of dubious quality and were not used for diagnostic purposes. When asked about imaging difficulties, one cardiologist summed up many concerns with the following:

> Many difficulties. The main one being the limits for exam scheduling… And as an echocardiogram is a very examiner dependent test… the quality depends a lot on who does it, so we end up restricting who can do them, so that we principally take the ones done here in the hospital. (cardiologist 1)

3.6 Systemic Issues and Neglect

Speaking more generally, cardiologists in particular were concerned with the lack of public investment and general low government attention to the disease. Indeed, the disease burden in Salvador has never been calculated with an echocardiography-based study. As one cardiologist put it:

> You have to understand that it's a disease that is present and is not eradicated. It may be reduced in the south or southeast regions, where people have better social conditions, but not in the north or here in the northeast. (cardiologist 4)

As illustrated here, the perceived non-acknowledgement of the existence of RHD was often phrased in terms of the economic and political centers of the south ignoring problems in the northeast.

Health post providers did not speak in specific terms about neglect related to RHD, but voiced forceful concerns that their community was indeed ignored, and attributed a large part of this to racial discrimination.

> The whole social structure is set up so that blacks and the poor stay in the same place, and their descendants stay there, not seeing possibilities for getting out. (PCP 2)

Health post providers, when speaking generally, felt as if their community suffered for being on the periphery, for being poor, and for being black. It was interesting, then, that when asked if there was any color or class discrimination between patient and physician, every health post provider emphatically said in their clinic it was not. The reason for this was attributed to the fact that the health post in which we held our interviews was staffed by a black physician who grew up in the area.

> He lives in Liberdade, got it? ... He was born in the ghetto, in the midst of a poor community. So, because of that he has it down pat, got it? A wonderful doctor. (CHW 5)

Having a physician that is from the community and is relatable to the patient would seem to limit likely difficulties in communication and expectation. This is not to say that health literacy concerns are done away with, as all health post providers identified this as an issue regardless, but that the contextual understanding of a patient's lived reality is understood, which improves care. This understanding is likely ultimately necessary to maintain empathy and medically treat patients appropriately. To summarize in the words of the health post physician:

> Sometimes I see this discourse, not here, but in some circles of colleagues, where there is a scapegoating of poverty. As if a person is miserable just because they want to be. I think that without experience of the other class, you won't have an understanding of the other side… how is a physician who never needed SUS, who doesn't know what it is, how it works, who doesn't know what it is to live in a slum, how are they going to be a good family and community physician if that is not their reality? They don't know what is to eat once a day. They don't know what it is to live with police, to have police and criminals taking turns invading your house. Because that's what happens, they don't ask... They don't know what it is to live with the risk of being shot at any moment you're walking because there's a gang war. There is a lack of empathy. (PCP 2)

Public Health Implications

The intent of this study was to investigate health providers' perspective on why RHD might progress in slum areas despite access to care in order to both decrease the burden of RHD and learn about providing healthcare in slums.

Primordial Prevention

In terms of primordial prevention, we recommend continued economic and educational development of slum areas, to both empower residents to better care for their health and productively manage their own homes and neighborhoods to address overcrowding and sanitation.[84] Likewise, understanding that community violence prevents outreach leads us to advocate for measures to decrease levels of community violence in order to enable public health outreach. Finally, further research into what preferences for particular diets in low SES urban neighborhoods exist, how they affect infection susceptibility, and how to stimulate any needed behavior change is needed.

Primary Prevention

What we learned in terms of primary prevention, i.e. preventing the spread of GAS infection via antibiotics, echoes acknowledged barriers in delivering primary care prophylaxis in other low SES settings.[186] These include limited health seeking behaviors for those with sore throats, the inability to maintain an adequate supply of medication, and the ambivalence of residents towards interacting with the medical system. We additionally learned that in such a setting health staff would need to be further trained, diagnostic resources provided, and tracking of a treatment schedule would need to be incorporated. Even perfect execution may not be enough to impact population level ARF,[187] however, and active surveillance of children at risk for GAS pharyngitis is an option that has found success in New Zealand.[188] Given the cost of this approach, however, and the positive benefits that would accrue for other pathologies if primary prevention with antibiotics were successful, the authors support this first approach. It would be necessary, however, to research the viewpoint of residents in Liberdade and other slums to explore what motivations form their health seeking behaviors and why they might choose to not choose not to stay home and/or not adhere to treatment.

Secondary Prevention

For secondary prevention, the irregular supply of benzathine must be addressed[189] and it is likely necessary to ease restrictions on where the injections can be administered in order to facilitate access. To further ease access difficulties, Brazil should consider decreasing injection dosing to once very four weeks instead of three.[190] This is the schedule in New Zealand, and recurrence rates for ARF have remained low.[184,191–193] Further research into improving prophylactic adherence should be performed to identify ideal targets for intervention.[194] According to our

research, however, retention in care is a major issue, as seen elsewhere.[195] To mitigate causative factors, RHD care should be decentralized, as is advocated in Africa.[195,196] Alongside this, we should note, are increased provider training programs regarding the diagnosis and referral necessity of ARF and RHD.[189] In terms of diagnostic echocardiography testing, the irregular quality and various barriers to access for low SES patients may warrant the creation of a RHD specific echocardiography center where patients are triaged in order of medical severity.

Ameliorating Systemic Issues

Moving now to systemic issues, providers generally believed there to be an underinvestment in public healthcare that led to conditions causing both increased prevalence of the disease as well as the inability to counter it. This underinvestment is seen to limit health literacy, extend the time with patients that is necessary for education and contextual insight, limit the number of providers, and limit the diagnostic and treatment options afforded those who rely on the public system. This could be ameliorated by public health campaigns aimed at educating the public about RHD, provision of provider training for RHD, and research to discover the disease burden. An echocardiography-based study should be performed, with the use of telehealth, task-shifting, and/or handheld echocardiography as needed to improve feasibility,[197,198] especially considering recent development of cost-effective models.[199] Finally, medications such as penicillin need to be consistently stocked and available within the public health system.

Finally, it was often communicated that understanding the patient's context was important for their care. To facilitate this, communication between referring physician and specialist should be prioritized. This would likely allow for better treatment for the patient by both physicians, improve adherence, as well as help bridge the cultural and communication divide that exists in a highly economically stratified society.[200,201] Training diverse physicians from slum communities should continue to be prioritized, via quotas or other alternatives,[202] or gaps in the quality of care will likely continue.[203,204] Relatedly, to improve communication between residents of slums that are primarily Afro-descendent and specialist physicians that are primary white and from high SES backgrounds, dialogue between physicians themselves may be enlightening. Developing an understanding of the patient's lived reality is likely to be ultimately necessary to maintain empathy and medially treat patients appropriately.

Conclusion and Future Research

To sufficiently address RHD healthcare in slum environments much more research is needed. At the very least we should know the disease prevalence and must continue to study barriers to care in this and other slum communities in Salvador. Importantly, a further understanding of the etiology of the lapses in the healthcare

system should be investigated. If a quarter of the world will be living in slums in 2030, action should be immediate. Studying RHD in Brazilian slums is an important case study that points out ways in which we can improve the healthcare system to appropriately address healthcare in slums. RHD is preventable and should not exist in a middle-income country with universal healthcare. Learning from Brazil's experience can help us generalize best practices for tackling healthcare in slums globally for afflictions both infectious and chronic.

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Appendix- Interview Guides

General Interview Template
(Final versions edited in field, the following are preliminary guides)

Study Investigator will use this guide to assist with the interview. Investigator will start the interview process by reading the instructions to provider agreeing to participate in study.

Study ID number:_____ **Interview Date**:_____

Instructions:
I want to thank you again for agreeing to participate in this important study. My name is INTERVIEWER NAME and I am working with researchers at UFBA and in the United States Together we are researching the best ways to decrease the burden of rheumatic heart disease in Brazil, particularly in poor urban settings, and are looking at how prevention and treatment can be improved. We want to the experiences you and your patients face in accessing and adhering to treatment. We are hoping to get a better understanding of the difficulties you face in providing treatment. I will be asking some questions but I hope this can be more like a conversation.

Quero agradecer-lhe novamente por ter concordado em participar deste importante estudo. Meu nome é INTERVIEWER NAME e estou trabalhando com pesquisadores na UFBA e nos Estados Unidos. Juntos estamos pesquisando as melhores maneiras de diminuir a carga de cardiopatia reumática no Brasil, particularmente em ambientes urbanos pobres, e estamos analisando como a prevenção e tratamento pode ser melhorado. Queremos as experiências que você e seus pacientes enfrentam no acesso e aderência ao tratamento. Queremos obter uma melhor compreensão das dificuldades que você enfrenta na prestação de tratamento. Vou fazer algumas perguntas, mas espero que isso possa ser mais como uma conversa.

Warm up question (all categories)
Could you please tell me a bit about your work history as a _____, such as when did you start and in what hospitals or clinics you work?

Você poderia me contar um pouco sobre seu histórico de trabalho como _____, como quando você começou e em que hospitais ou clínicas você trabalha?

Final Questions (all categories)
If you could have anything you wanted to help poor people in this/these communities access to care, what would you want?

Se você pudesse ter qualquer coisa que você queria para ajudar as pessoas pobres nestas comunidades ter melhor acesso aos cuidados, o que você quereria?

What are strengths of the favela communities? What is the best part about working/living there? How might these be used to help improve the health of the people who live there?

Quais são os pontos fortes das comunidades carentes? Qual é a melhor parte sobre o trabalho / vida lá? Estas coisas, como poderiam ser usados para melhorar a saúde das pessoas que moram lá?

Probe Questions (all categories)
Why do you think _____? Could you tell me more about _____? Tell me more about that experience. Can you give me an example? Can you walk me through what happened? Can you tell me the story of a patient that exemplifies this point?

Por que você pensa _____? Você poderia me dizer mais sobre _____? Conte-me mais sobre essa experiência. Você pode me dar um exemplo? Você pode me explicar o que aconteceu? Você pode me contar a história de um paciente que exemplifica esse ponto?

Categories below:

Primary Care Providers

Cardiologists

Community health workers

GROUP 1- DIAGNOSIS AND TREATMENT LOGISTICAL DIFFICULTIES

Lead 1:
What is the process for someone getting to your clinic? Can you walk me through the process step by step?

Qual é o processo para alguém chegar à sua clínica? Você pode me descrever passo a passo o processo?

Follow up:
What might be some reasons they would wait before coming in to be seen? (Delays in seeking care)
Please describe any barriers that people may experience coming in.

Quais seriam algumas das razões que eles esperariam antes de serem atendidos? (Atrasos na procura de cuidados)
Por favor, descreva quaisquer barreiras que as pessoas possam enfrentar.

Lead 2:
Let's say a parent bring in a child that has a sore throat that may be due to streptococcus pyogenes. What would be your usual process for working up and treating streptococcal pharyngitis?

Digamos que os pais tragam uma criança que tem infeccão na garganta, que pode ser por causa de Streptococcus pyogenes. Qual seria o processo usual para fazer o diagnóstico diferencial e tratar a faringite estreptocócica?

Follow up:
Does the treatment process usually go as planned?
How might you improve this process?
What difficulties do you think this child and their parent might face in adhering to this treatment program?
Are any of these difficulties specific to people who live in slums?

O processo de tratamento geralmente sai como planejado?
Como você poderia melhorar esse processo?
Que dificuldades você acha que essa criança e seus pais podem enfrentar ao aderir a este programa de tratamento?
Alguma dessas dificuldades é específica para pessoas que moram nas comunidades (pobres)?

Lead 3:
Now let's say this same parent brings their other child in with a classic presentation of rheumatic fever (things like migrating polyarthritis, pancarditis, subcutaneous nodules, erythema marginatum, syndenham corea). They say he has had these symptoms many times, but it has never been diagnosed as rheumatic fever before. What are the challenges physicians face when making this diagnosis?

Agora vamos dizer que estes mesmos pais tragam o seu outro filho com uma apresentação clássica de febre reumática (coisas como poliartrite, pancardite, nódulos subcutâneos, eritema marginado, syndenham corea). Eles dizem que o filho teve esses sintomas muitas vezes, mas nunca foi diagnosticado como febre reumática. Quais são os desafios que você ou outros médicos encontram para fazer o diagnóstico correto de febre reumática?

Follow up:
How can this be a difficult diagnosis to make?
How might you treat this patient now?
What difficulties do you think this child and their parent might face in adhering to this treatment program?
Are any of these difficulties specific to people who live in slums?

Porque você pensa que a febre reumática é difícil diagnosticar?
Como você trataria esse paciente agora, depois de diagnosticado?
Que dificuldades você acha que essa criança e seus pais podem enfrentar na aderencia a este programa de tratamento?
Algumas dessas dificuldades são específicas para pessoas que moram nas favelas?

Lead 4:
Imagine this same child starts to display cardiac symptoms. What next steps might you take?

Imagine que esta mesma criança comece a apresentar sintomas cardíacos. Quais são os próximos passos que você tomaria?

Follow up:
Have you had difficulty referring to specialists in the past?
In what ways was this difficult?
Why do you think that is?
How might the parent and child themselves have difficulty in following up with a cardiologist?

No passado você teve algum tipo de dificuldade em indicar especialistas para tratar pacientes ?
Você poderia explicar quais foram as dificuldades?
Por que você acha que estas dificuldades existem?
Quais são as dificuldades que os pais e a criança enfrentariam ao tentar ir ao cardiologista?

Lead 5 (if not addressed by Lead 4):
What does it take to order an echocardiogram?

O que é necessário para ordenar um ecocardiograma?

Follow up:
How might the parent and child themselves have difficulty in following up with a cardiologist?

Como os pais e a criança podem ter dificuldade em contactar o cardiologista para fazer o ecocardriograma?

GROUP 2 –PUBLIC SECTOR DIFFICULTIES

Lead I
What do providers find most difficult about treating patients that have very few resources/live in poor communities?

Em relação aos doentes que tem poucos recursos e moram nas comunidades mais pobres, o que os trabalhadores da área da saúde acham mais difícil de tratar?

Follow up:
Is that how you feel too?

Isso é o que você pensa também?

Lead II:
What are some difficulties you face working in this health post that your colleagues in private settings don't?

Quais são as dificuldades que você encontra trabalhando nesse posto de saúde que os seus colegas do setor privado não encontram?

Follow up:
Are there things about working in that health post that you appreciate over working in a private setting?
How does insurance factor in?

Há coisas sobre o trabalho nesse posto de saúde que você prefere se comparado com o trabalho no setor privado?
Você acha que os planos de saúde afetam o seu trabalho na assistência dos doentes?

Lead III:

From your experience in treating patients living in slums, what do you think makes it difficult for them to come to your clinic when they are sick? (Delays in reaching/receiving care)

Da sua experiência no tratamento de pacientes que moram nas favelas, qual a dificuldade que você acha que eles têm em procurarem a clínica quando estão doentes? (Atrasos na obtenção / recepção de cuidados)

Lead IV:
What are the challenging factors you've faced in getting patients to adhere to medical instructions? Getting medications, testing, and following up on referrals etc.

Quais são os desafios que você enfrenta para os doentes aderirem às instruções médicas? Obter medicação, testes, e acompanhamento de especialistas, etc.

Follow up:
Can you think of any particular instances of this that you've experienced?

Você pode descrever um caso recente?

GROUP 3 – INSIDE THE CLINICAL SPACE

Lead One:
What information do you ask from patients to make decisions about diagnoses and referrals?

Que informações você pede aos pacientes para tomar decisões sobre diagnósticos e indicação de especialistas?

Follow up:
Is it difficult to get the information you need from patients for making diagnoses, referrals?
Can you talk about the process of getting a good history?
Are there particular things you can point to that make communication difficult?

Você pode falar sobre o processo de obter um bom histórico clínico?
É difícil obter as informações que você precisa de pacientes para fazer diagnósticos, indicar especialistas?
Quais são os fatores que tornam a comunicação com os pacientes difícil?
[follow up: pergunte sobre o nível socioeconômico, raça, etc.]

Lead Two:
What are the common attitudes medical providers have towards patients who live in slums?

1) *Quais são as atitudes que os trabalhadores da área da saúde têm em relação às pessoas que moram nas comunidades ?*

Como é que os provedores respondem as dificuldades? [probe on that] have you already identified what you do to make improvements?

Lead Three:
What expectations do you have for following up on treatment and adherence for patients who seek medical care?

Quais as suas expectativas em acompanhar o tratamento e adesão de pacientes que procuram atendimento médico?

Follow up:
What expectations do you have in the interaction with a patient? What would model an "ideal interaction" for you?

Quais as suas expectativas em relação à interação com um paciente? O que seria um modelo ideal de interação para você?

Lead Four:
How would you describe what a "healthy lifestyle" is to your patient?

Como você descreveria um "estilo de vida saudável" para o seu paciente?

Follow up:
How do patients achieve a healthy lifestyle?
What actions do you expect them to take to make this a reality?

Como os pacientes conseguem um estilo de vida saudável? Que ações você espera que eles tomem para tornar isso uma realidade?

GROUP 1- DIAGNOSIS AND TREATMENT LOGISTICAL DIFFICULTIES

Lead 1:
What is the process for someone getting referred to your clinic? Can you walk me through the process step by step?

Qual é o processo para alguém ser encaminhado à sua clínica? Você pode me descrever o processo passo a passo?

> Follow up:
> *What makes it difficult for someone referred from a primary care physician to get into your clinic?*
> *Describe any barriers people may experience coming in.*

O que torna difícil para alguém que foi encaminhado por um médico de cuidados primários vir à sua clínica?
Por favor, descreva quaisquer barreiras que as pessoas possam enfrentar.

Lead 2:
Do you feel that people who are referred to you from health posts or government hospitals have been referred correctly? Why or why not?

Você acha que as pessoas que são encaminhadas para você de postos de saúde ou hospitais públicos foram encaminhadas corretamente? Por que ou por que não?

> Follow up:
> *If a patient has rheumatic fever and there is risk it will develop into rheumatic heart disease, who is responsible for prescribing preventative treatments and coordinating testing?*

Se um paciente tem febre reumática e há risco de que isso se torne uma cardiopatia reumática, quem é responsável pela prescrição de tratamentos preventivos e coordenação de testes?

Lead 3:
What are the challenges in coordinating cardiology care with the referring physician?

Quais são os desafios na coordenação dos cuidados de cardiologia com o médico que encaminhou o paciente?

> Follow up:
> *What makes the process difficult?*

O que torna o processo difícil?

Lead 4:
Let's say a parent who recently moved do your area comes in to your clinic with a child that has been referred for possible valvular dysfunction secondary to rheumatic fever. What

would be your usual process for working up possible rheumatic heart disease? Can you take me through this step-by-step?

Digamos que um pai que se mudou recentemente para a sua região chega à sua clínica com uma criança que foi reportada com uma possível disfunção valvular secundária (que pode ser por causa de febre reumática). Qual seria o processo usual para fazer o diagnóstico diferencial e tratar o cardiopatia reumática? Você pode me descrever passo a passo o processo?

> Follow up:
> *What does it take to order an echocardiogram?*
> *How might someone have difficulty in getting an echocardiogram?*
> *Would anything about this be more difficult for someone living in a slum?*
>
> *O que é necessário para pedir um ecocardiograma?*
> *Como alguém pode ter dificuldade em fazer um ecocardiograma?*
> *Seria mais difícil para alguém que mora numa favela?*

Lead 5:
How often are you able to see your patients with rheumatic heart disease?

Quantas vezes você é capaz de ver seus pacientes com doença cardíaca reumática?

> Follow up:
> *How does this affect managing their care?*
>
> *Como isso afeta o seus cuidados?*

Lead 6:
Now let's say this patient returns with an echocardiogram that indicated rheumatic heart disease. What will their care involve form this point forward and what treatments will be involved?

Agora vamos dizer que este paciente retorne com um ecocardiograma que indicou doença cardíaca reumática. Quais serão os cuidados com o paciente desse ponto em diante e quais tratamentos serão envolvidos?

> Follow up:
> *What difficulties do you think this patient might face in adhering to this treatment program?*
> *Are any of these difficulties specific to people who live in poor communities? Which?*
>
> *Que dificuldades você acha que esse paciente pode enfrentar ao aderir a este programa de tratamento?*
> *Algumas dessas dificuldades são específicas para pessoas que moram nas favelas? Quais?*

Lead 7:
Imagine this patient's cardiac symptoms progress rapidly. What next steps might you take?

Imagine que os sintomas cardíacos desse paciente progridam rapidamente. Quais são os próximos passos que você pode tomar?

Follow up:
Does the treatment usually go as planned?
Have you had difficulty referring to surgery in the past? In what ways was this difficult?
Who provides anticoagulant therapy? What difficulties arise with this?
Can you reflect on the process of choosing either a mechanical or prosthetic valve?
How might patient themselves have difficulty in following up with a surgeon?

O tratamento geralmente vai como planejado?
Você já teve dificuldade em encaminhar o paciente a uma cirurgia no passado?
De que maneira isso foi difícil?
Quem provê a terapia anticoagulante? Que dificuldades surgem com isso?
Você pode refletir sobre o processo de escolher uma válvula mecânica ou protética?
Como o paciente pode ter dificuldade em ter acompanhamento de um cirurgião?

GROUP 2 –PUBLIC SECTOR DIFFICULTIES

Lead I
What do providers find most difficult about treating patients that have very few resources/live in slums?

O que os provedores acham mais difícil sobre o tratamento de pacientes que têm poucos recursos / vivem em favelas?

Follow up:
Is that how you feel too?

Isso é o que você também pensa?

Lead II:
What are some difficulties you face working in this public hospital that your colleagues in private settings don't?

Quais são as dificuldades que você enfrenta trabalhando neste hospital público que seus colegas em hospitais privados não enfrentam?

Follow up:
Are there things about working in a public hospital that you appreciate over working in a private setting?

How does insurance factor in?

Há coisas sobre trabalhar em um hospital público que você prefere comparado com o trabalho no setor privado?
Você acha que o sistema de seguro afeta o seu trabalho na assistência dos doentes?

Lead III:
From your experience in treating patients living in slums, what do you think makes it difficult for them to come to your clinic?

De sua experiência no tratamento de pacientes que vivem em favelas, o que você acha que torna difícil para eles virem para a sua clínica?

Follow up:
Do you think transportation is an issue?
What about cost barriers?
Is there any fear of institutions/doctors?
What about cultural/religious factors?
Any social dynamics you can think of?

Você acha que o transporte é um problema?
Existe barreiras de custo?
Existe algum medo de instituições / médicos? E quanto a fatores culturais / religiosos?
Alguma dinâmica social que você possa pensar?

Lead IV:
What are the challenging factors you've faced in getting patients to adhere to medical instructions? Getting medications, testing, or following up on referrals etc.

Quais são os fatores desafiadores que você enfrentou para os pacientes seguirem as instruções médicas? Obtenção de medicamentos, testes ou acompanhamento com especialistas, etc.

Follow up:
Can you think of any particular instances of this that you've experienced?

Você consegue pensar em algum caso particular que você presenciou?

GROUP 3 – INSIDE THE CLINICAL SPACE

Lead One:
What are the common attitudes medical providers have towards patients who live in slums?

Quais são as atitudes que os trabalhadores na área da saúde têm em relação aos pacientes que vivem em favelas?

Lead Two:
What information do you ask from patients to make decisions about diagnoses and referrals?

Que informações você pede aos pacientes para tomar decisões sobre diagnósticos e indicar especialistas?

Follow up:
Is it difficult to get the information you need from patients for making diagnoses, referrals?
Can you talk about the process of getting a good history?
Are there particular things you can point to that make communication difficult?

É difícil obter as informações que você precisa de pacientes para fazer diagnósticos, indicar especialistas?
Você pode falar sobre o processo de obter um bom histórico clínico?
Quais são os fatores que tornam a comunicação com os pacientes difícil?
[follow up: pergunte sobre o nível socioeconômico, raça, etc.]

Leads Three:
What expectations do you have for following up on treatment and adherence for patients who seek medical care?

Quais as suas expectativas em acompanhar o tratamento e adesão de pacientes que procuram atendimento médico?

Follow up:
What expectations do you have in the interaction with a patient? What would model an "ideal interaction" for you?

Quais as suas expectativas em relação à interação com um paciente? O que seria um modelo ideal de interação para você?

GROUP 1- DIAGNOSIS AND TREATMENT LOGISTICAL DIFFICULTIES

Lead 1:
Let's say a parent who recently moved do your area and would like their child to see a physician for a sore throat. What is the usual process for seeing a physician? Can you take me through this step-by-step?

Digamos que um pai se mudou recentemente para a sua região e gostaria de trazer seu filho para ver um médico devido a uma dor de garganta. Qual é o processo usual para consultar um médico? Você pode me descrever passo a passo o processo?

Follow up:
What is your role in helping to facilitate this care?

Qual é o seu papel em ajudar a facilitar este cuidado?

Lead 2:
In your experience, what are some reasons that patients wait to seek medical care?

Em sua experiência, quais são algumas das razões que os pacientes esperam para procurar atendimento médico?

Follow up:
Do you think financial reasons are important?
What about distance to the clinic?
Is there some history of being disconnected from the clinic?
Do people have confidence in these medical services?
Are they aware of these local clinics?

Você acha que razões financeiras são importantes?
E a distância até a clínica?
Existe algum histórico de estar desconectado da clínica?
As pessoas têm confiança nestes serviços médicos?
Eles estão cientes dessas clínicas locais?

Lead 3:
What makes the process of a slum resident seeing a PCP difficult? What are barriers that people face? (Delay in reaching care)

O que torna o processo de um morador de favela ver um PCP difícil? Por favor, descreva quaisquer barreiras que as pessoas possam enfrentar.

Follow up:
What are important factors that make health posts inaccessible?
(If not addressed specifically, ask about community violence, poverty, race, geographical location of clinic, cost, availability of appts.)

Quais são os fatores importantes que tornam os postos de saúde inacessíveis?
(Se não abordado especificamente, pergunte sobre violência comunitária,

pobreza, raça, localização geográfica da clínica, custo, disponibilidade das consultas.)

Lead 4:
If a patient is having difficulty getting to a PCP, what other methods do they have for managing their health?

Se um paciente está tendo dificuldade em obter cuidados primários, que outros métodos têm para controlar sua saúde?

Lead 5:
Now let's say a parent takes their child to a clinic for a sore throat and they are prescribed antibiotics. In your experience, what are the challenges people face in getting these treatments?

Agora vamos dizer que um pai leva seu filho para uma clínica devido a uma dor de garganta e são prescritos antibióticos. Em sua experiência, que dificuldades você acha que esse paciente pode enfrentar em obter os medicamentos?

Follow up:
Is cost an issue? How about access to a pharmacy?

O custo é um problema? O acesso a uma farmácia é uma problema?

Lead 6:
Imagine this patient develops heart symptoms and they need to be on long-term antibiotics and have ultrasounds taken of their heart. In your experience, what are some barriers that make following through on these difficult?

Imagine que este paciente desenvolva sintomas cardíacos e precise usar antibióticos a longo prazo e ter ultrassom tirados de seu coração. Em sua experiência, quais são as barreiras que tornam o acompanhamento difícil?

Lead 7:
Assuming they need to see a specialist, what makes the process of seeing a specialist (a cardiologist) difficult for someone living in a poor neighborhood?

Supondo que eles precisem ver um especialista, o que torna o processo de ver um especialista (como um cardiologista) difícil para alguém que mora numa favela?

Lead 8 (if not addressed already):
What does it take to get an echocardiogram (ultrasound of the heart)? Can you take me through this process?

O que é preciso para obter um ecocardiograma (ultrassom do coração)? Você pode me descrever passo a passo o processo?

GROUP 2 –PUBLIC SECTOR DIFFICULTIES

Lead I
What do community health workers find most difficult about helping coordinate care for patients that have very few resources/live in slums?

O que os profissionais de saúde acham mais difícil em ajudar a coordenar os cuidados com pacientes que têm muito poucos recursos / vivem em favelas?

Follow up:
Is that how you feel too?

O que é que você pensa desta situacão?

Lead II:
From your experience in working with patients living in slums and providers at health posts, what understanding do you think providers have of the lives of these patients and their abilities to adhere to medical treatment?

De sua experiência em trabalhar com pacientes que vivem em favelas e provedores em postos de saúde, que compreensão você acha que os provedores têm da vida desses pacientes e suas habilidades para aderir ao tratamento médico?

Lead III:
What do you think are difficult factors for patients in following through on provider instructions? Getting medications, testing, following up on referrals etc.

Quais são os fatores mais difíceis para os pacientes seguirem as instruções médicas? Obter medicação, testes, e acompanhamento de especialistas, etc.

Follow up:
Can you think of any particular instances of this that you've experienced?

Você pode descrever um caso recente?

GROUP 3 – INSIDE THE CLINICAL SPACE

Lead One:
What information about patients do you wish doctors had when making treatment plans for patients?

Que informações sobre os pacientes você gostaria que os médicos tivessem para tomar decisões sobre os planos de tratamento para os pacientes?

Follow up:
Are there particular things you can point to that make communication between patients and providers difficult?

Existem coisas específicas que você pode apontar que tornam a comunicação entre pacientes e provedores difícil?

Are there any difference in background providers (race/socioeconomic status) have with slum residents that may help explain this?

Existem diferenças entre os provedores (raça/ status socioeconômico) e os moradores da comunidade que possam explicar isso?

Lead Two:
What are the common attitudes medical providers have toward patients who live in slums?

Quais são as atitudes que os trabalhadores da área da saúde têm em relação aos pacientes que moram nas comunidades ?

Lead Three:
What expectations do you have for following up on treatment and adherence for patients who seek medical care?

Quais as suas expectativas em acompanhar o tratamento e adesão de pacientes que procuram atendimento médico?

Follow up:
What expectations do you have in the interaction with a patient? What would model an "ideal interaction" for you?

Quais as suas expectativas em relação à interação com um paciente? O que seria um modelo ideal de interação para você?

Lead Four:
How would you describe what a "healthy lifestyle" is to your patient?

Como você descreveria um "estilo de vida saudável" para seu paciente?

Follow up:
How do patients achieve a healthy lifestyle?
What actions do you expect them to take to make this a reality?

Como os pacientes conseguem um estilo de vida saudável? Que ações você espera que eles tomem para tornar isso uma realidade?