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Primary Care and the Reproduction of Health Inequity in a Central São Paulo Neighborhood

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Primary Care and the Reproduction of Health Inequity in a Central São Paulo Neighborhood

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M.P.H., University of Michigan School of Public Health, 2009

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An abstract of  
A dissertation submitted to the Faculty of the  
James T. Laney School of Graduate Studies of Emory University  
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## Abstract

### Primary Care and the Reproduction of Health Inequity in a Central São Paulo Neighborhood

By Emily Sweetnam Pingel

This dissertation bridges public health scholarship on health disparities with a medical sociology focus on culture and history, investigating relationships within a neighborhood primary care clinic in São Paulo, Brazil. I argue that the health of neighborhood residents is contingent upon the material configurations of the neighborhood and the cultural imaginaries at hand among neighborhood residents and health professionals. Relying upon fifteen months of ethnographic fieldwork, including 450 hours of participant observation and 58 in-depth interviews, I seek to expand a body of work theorizing race, racism, and health within spatial context. I offer three innovative contributions in service of this goal: 1) I center my analysis on multi-professional health service teams, moving the sociology of health professions beyond examining the role of a singular group (i.e., physicians), and 2) I reinvigorate the sociological perspective on culture and community health and 3) I incorporate digital communications into the study of patient-provider interactions.

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## Chapter 1: Introduction

While he did not reference health specifically, Max Weber offered the first sociological glimpse into what we now describe as health inequity. His concept of “life chances” points to the outcomes one has in life as a result of one’s social situation. Today the influence of social inequalities on health outcomes is fundamental to a social determinants of health perspective (Link and Phelan 1995). Social inequalities influence health through the mechanisms of money, status, and power, as these elements are differentially distributed along the divisions of race, ethnicity, class, and gender (Caldwell 2017; Shim 2010; Spencer and Grace 2016; Telles 2006; Williams and Sternthal 2010). Many medical sociologists have taken up these concerns, while other scholars have questioned whether “inequity” has become something of a black box, deserving of ethnographic scrutiny (Adams et al. 2019).

This dissertation seeks to investigate how culture shapes racial inequalities through a focus on: 1) micro-level interactions between patients and providers, mediated by primary care as an institution; 2) the material configurations of public *and* private neighborhood spaces such as homes, sweatshops, churches and schools; and 3) the cultural imaginaries at hand among neighborhood residents and health professionals. I offer three innovative contributions in service of this goal: 1) I center my analysis on multi-professional health service teams, moving the sociology of health professions beyond examining the role of a singular group (i.e., physicians); 2) I reinvigorate the culture concept, as an essential piece to understanding neighborhood health, and 3) I present a portrait of neighborhood health *outside* of the United States, emphasizing how local sociocultural processes are coequal with global health policy in determining health outcomes. With support from a Fulbright

Research Award and Boren Fellowship, I conducted over 400 hours of participant observation and 58 in-depth semi-structured interviews with health providers and patients. In the course of my research, I identified multiple processes that illuminate how status inequalities translate into uneven health service provision and how digital technologies become a vehicle for communicating aspirations for health. Furthermore, sociospatial configurations – where and in what conditions individuals live and work – provide crucial information about patterns of social cohesion and isolation.

Bom Retiro (“good retreat”) is a neighborhood of approximately 37,000 people in the central region of São Paulo, Brazil. Since the early twentieth century, Bom Retiro has been home to immigrants from multiple countries, many of whom arrived to seek work in the textile industry or to join family members already established in the neighborhood (Lesser 1999). While the origins of immigrant residents have changed over the past century, the presence of garment manufacturing and wholesale/retail sales continues to define the neighborhood economy. My interviews with patients (N=24) and health professionals (N=34) allowed me to compare how local actors articulate their vision for health with my own observations of how health is enacted through day-to-day routines and communication. In addition, I augment these observations and interviews with textual sources (Smith 2005), namely institutional documents (e.g., employee productivity forms) and WhatsApp threads between providers and within patient groups. Throughout data collection and analyses, I move between my observations and social theory, in an abductive process that expands theoretical possibilities while remaining firmly attached to empirical data (Swedberg 2014; Tavory and Timmermans 2014).

## **Health Equity in Brazil**

The Sistema Único de Saúde (SUS), Brazil's national healthcare system, holds enormous potential to address issues of health equity. Health inequity remains a persistent global public health concern that is both avoidable and unjust (Braveman 2006). In response to the United Nations' 2030 Sustainable Development Goal of achieving universal access to health services, global health experts advocate for the expansion of community-based primary health care (DeMaeseneer et al. 2007; Starfield, Shi, and Macinko 2005). In service of these goals, the architects of SUS devised the 1994 Family Health Strategy (FHS) to improve the quality of and access to primary care throughout Brazil. By 2015, the FHS covered almost 123 million individuals in the country, comprising 63% of the population (Andrade et al. 2018). Brazil's constitution proclaims that each citizen has a right to "equality before the law, without distinction of any nature." This principle extends to the national health system, making equity a primary aim of Brazilian healthcare (Paim et al. 2011). For its part, the FHS aims to integrate neighborhood health clinics into the communities using mobile primary care teams (Wadge 2016).

In theory, if not always in practice, all Brazilian citizens have access to basic primary care services. Non-Brazilians residing in Brazil are often able to access these services as well. Many immigrants in the neighborhood of Bom Retiro are enrolled and seen at the neighborhood clinic. Given these circumstances, Bom Retiro was an ideal setting in which to investigate how social inequalities shape health *beyond* the issue of access. I approach the issue of health equity from the perspective of examining sociocultural and linguistic challenges among community health workers, clinical providers, and non-Brazilian immigrant residents.

Through this three-paper dissertation, I explore how the very systems put in place to reduce inequity in healthcare end up reproducing it through everyday

interactions between healthcare professionals and patients. I demonstrate how these interactions are embedded within cultural narratives of race and labor that permeate professional communications and expectations. Finally, I offer glimpses into how some individuals contest or resist these narratives, while others use them to inform their healthcare decision-making.

### **The Neighborhood of Bom Retiro and the Bom Retiro Public Health Clinic (BRPHC)**

Bom Retiro is a neighborhood in north central São Paulo. It has been home to various waves of immigrants since the late 19<sup>th</sup> century. Today, Bolivians, Paraguayans, Koreans, and Chinese represent the largest immigrant populations. Known as one of the garment districts of the city, Bom Retiro's streets are lined with tri-level tenements. The first floor is often a retail space, showcasing clothing or wholesale fabric. In many Brazilian urban areas, dozens of businesses selling variations on the same product (e.g., wedding dresses, jewelry, electronics) are concentrated in a single commercial area. In the case of Bom Retiro, the primary goods are clothing and fabric. People will travel across the city to shop for deals in the district. The second floor of the tenement may comprise a workshop, replete with sewing machines for making the clothes on sale downstairs. In some cases, the employees that sew in these shops – many of whom are Bolivian, Paraguayan and Korean immigrants - live behind or above the workshop floor.

Given its immigrant populations, Bom Retiro is simultaneously a unique study location and a neighborhood that in many ways reflects the socioeconomic and racial diversity of Brazil as a whole. Nearly half of Bom Retiro's residents identify as non-white. 53% of residents belong to the middle class (Classe C), mirroring the portion



of middle-class Brazilians across the country (DNA Paulistano 2014). The remaining residents are working class or poor.

The primary care clinic can be found at the end of the main retail street running through the neighborhood. It is in a small one-story building resembling a house with an accessibility ramp in front. To the left is a window where a pharmacist sits, filling prescriptions. Inside the building is a single hallway, lined with benches, on which patients are seated when waiting to be seen. There are about five exam rooms, a meeting room (which also doubles as storage for medical files), and the reception area at the front. The clinic – known as the UBS for Unidade Básica de Saúde (Basic Health Unit) - has the feeling of a destination, as it sits somewhat awkwardly at the convergence of four streets. During clinic hours, people mill about the front of the building or sit on outdoor benches.

## **Research Questions**

This qualitative dissertation employs ethnographic data collected through 452 hours of participant observation, 58 in-depth semi-structured interviews with patients and healthcare professionals, and WhatsApp group text threads. I analyze these data to explore how culture shapes primary care provision. Three sets of research questions guide my analysis:

1. How do racialized geographies (the ways that individuals organize the neighborhood around them in ethnoracial terms) shape the provision of primary care? What are the material configurations and cultural imaginaries informing these geographies?
2. How do community health workers (CHWs) navigate relationships with patients across axes of similarity and difference? How can we interpret CHWs

identification of favorite patients as mostly older adults and difficult patients as immigrants? How do stigma and recognition shape these processes?

3. How do the inspirational messages and crime alerts that women share via WhatsApp reproduce cultural imaginaries linking whiteness and safety? How can we understand the urge to share these messages? What are the simultaneous points of resistance to these imaginaries?

## **Theoretical Background**

In the following section, I outline the theoretical background that informed this dissertation as I entered the field. I used this background as a starting point to think through my empirical observations in the field. Where these theories fell short, I conducted further reading and analysis, which I have then incorporated into each paper.

### **Inequalities and Health**

In Latin America, sanitation reforms were intertwined with dreams for the nation-state. Public health programs in Brazil were often a reflection of elite anxieties about the ethnoracial and class makeup of the nation (Cueto 2015). Furthermore, Brazil's public health system has a long history of managing the fallout from ethnoracial and class-based health disparities (Lesser and Kitron 2016). As Brazil rapidly industrialized throughout the twentieth century and a majority of the nation came to reside in urban centers (Fontes 2016), health inequities were magnified.

Today, the influence of social inequalities on health outcomes is fundamental to a social determinants of health perspective (Link and Phelan 1995). Social inequalities influence health through the mechanisms of money, status and power, as

these elements are differentially distributed along the divisions of race, ethnicity, class, gender, sexuality, nationality, and so on.

### ***How do resource inequalities shape health?***

As I will discuss in the penultimate section, in everyday life there are rarely sharp dividing lines between the processes by which resources, status and power shape health; rather these processes are nearly always interdependent. Often in the public health literature, socioeconomic status is portrayed as a unitary construct (Herd, Goesling, and House 2007) whereas in sociology, it is broken down into its various components, e.g., income, wealth, education, occupational prestige (Krieger, Williams, and Moss 1997). All this is to say that the concept of socioeconomic status (SES) is not stand-in for either “resources” or “status” alone. Furthermore, economic measures such as income and wealth are inflected by social statuses, such as gender and race (Braveman et al. 2005; Krieger et al. 1997). As an example, researchers do not often examine the effect of income on health independent of other variables under the SES umbrella; to do so would be to ignore the myriad ways in which the components of SES enable one another. Researchers have, however, compared various components of SES in their effects on health outcomes. For example, Herd, Goesling & House (2007) found that whereas education predicted the *onset* of functional limitations and chronic illness, income had a greater effect on the *progression* of each condition.

Link and Phelan first coined the term “fundamental causes” in their 1995 paper, in which they theorized that socioeconomic status was a fundamental cause of inequalities in mortality. By fundamental, they wished to convey the idea that despite changes over time in proximal causes of disease, certain distal elements remain

stubbornly steadfast in determining mortality rates (Link and Phelan 1995). In a later paper in which they tested this theory, they found that it is specifically greater access to resources that explains lower rates of highly preventable deaths (Phelan et al. 2004). Economic capital is beneficial in an array of health-related scenarios, e.g., paying for medical insurance, paying for care at point-of-service (whether out-of-pocket or as a co-pay), and spending money on transportation to and from healthcare visits. Furthermore, when wages stagnate and the distribution of income becomes more unequal, societies face the specter of rising income inequality (Harrison and Bluestone 1988; Morris and Western 1999) Scholars have pointed to greater levels of income inequality as a culprit in the higher rates of chronic illness in the United States compared to other similarly wealthy, industrialized nations (Banks et al. 2006).

In addition to economic capital, a major line of research into inequality's effects on health has been through social capital and social networks, which has its roots in Durkheim's study of suicide (Durkheim 2006). Berkman and Syme's landmark study (Berkman and Syme 1979) on the residents of Alameda County brought forth the idea of social connection as a protective factor in health. Overall, the more social ties of different types participants reported (marriage, family and friends, religious, and civic groups), the lower their mortality rates. The inverse of social ties – isolation – has been repeatedly been shown to result in higher mortality and disability (Cornwell and Waite 2009; House, Landis, and Umberson 1988). Kawachi et al. posit that income inequality results in higher all-cause mortality through the mechanism of reduced social capital (Kawachi et al. 1997). Specifically, they propose that rising income inequality in a society engenders higher levels of social mistrust and lower rates of participation in civic life, which in turn leads to higher mortality rates.

A lesser studied resource that likely shapes health outcomes is that of cultural capital. Cultural capital is on display in patient-provider interactions (Lareau 2002). Indeed, the cultural capital a patient demonstrates has the potential to shape physician perceptions and in turn service provision, including recommended treatments (Shim 2010).

Finally, education, much like SES, is a construct that straddles the already fuzzy borders between resources, status, and position. Education-as-resource acts as a source of knowledge, from which individuals may draw to enhance their outcomes. Health literacy is an obvious example; the more easily one can seek and digest health information, the better the chances of maintaining or improving one's health status. Yet education can also be conceived of as achieved status, in terms of one's possessing a credential indicating membership in a high-status group (Collins 1971)—a sign that one's habitus is of the dominant status group (Bourdieu 1977). Moreover, others have argued that the educational system is a means of reproducing one's position in the social hierarchy (Bowles and Gintis 2011) such that working-class children are prepared for working class jobs (or more contemporarily, the service economy), and wealthier children are groomed for white-collar professions. Much like education, SES can also be conceived of in terms of prestige. I will turn now to how status and prestige have been theorized in regard to health outcomes.

### ***How do status inequalities shape health?***

**Socioeconomic Status.** Discussions of the social gradient dominate how SES and education have been conceptualized as shaping health outcomes. In many cases, education is measured as educational status (highest degree conferred) or number of years of education; it is sometimes one of several composite variables within the SES

construct. Either way, researchers have demonstrated that health outcomes are distributed on a social gradient: across populations, as SES increases, all-cause and specific mortality rates decline. The existence of the social gradient has been explained from an ecological, life-course perspective - the idea that over the course of people's lives, they accumulate forms of (dis)advantage. (Dis)advantage in one sphere of life (e.g., in housing) is often correlated with disadvantage in others (e.g., at work), such that it has a compounding effect (Blane, 2006; Banks et al. 2006).

Epidemiologist Michael Marmot attributes the relationship between sustained disadvantage and poor health to "the psychological experience of inequality." In other words, the experience of inequality is internalized and becomes manifest through greater susceptibility to illness, both chronic and infectious (Marmot 2004). Recent research on deaths of despair (e.g., from suicide, and alcohol- and drug-related conditions), which appear to be driving declining life expectancy in the United States, particularly among White men, suggest that perceived loss of status may have similarly deleterious effects (Case and Deaton 2015).

**Race.** The processes described above are concerned with explaining the effects of socioeconomic inequality. I focus now on how sociologists and other scholars have theorized that ethnoracial and gender inequalities experienced at all societal levels are responsible for disparate health outcomes. Understanding health inequity necessitates attention to the independent effects of systems of race and gender; the two cannot be reduced to socioeconomic differences (Williams and Sternthal 2010). Similar to the artificial disentangling of resources, status, and power in this essay, I acknowledge here that I am highlighting the health effects of racism and sexism, while acknowledging that race, ethnicity, class, gender, and nation constitute interlocking systems of oppression (Collins 2002).

W.E.B. Du Bois, in his account of Black Americans living in Philadelphia at the turn of the century, identified the primary determinant of health as “the peculiar attitude of the nation towards the well-being of the race” which he goes on to characterize as indifference (1899). While he devotes a single section specifically to health, his comprehensive portrayal makes it obvious to the reader how racial discrimination constrains nearly every aspect of social life. Du Bois provided the template for a wealth of sociological research on how racism results in health disparities. Evidence of such disparities is widespread. For example, scholars note that differences in rates of all-cause mortality between Blacks and Whites are at roughly the same level as they were in 1950 (Smedley, Stith, and Nelson 2003; Williams and Collins 2001).

While discrimination may originate at the level of interpersonal interaction and group positioning (Blumer 1958; Bobo 2002), its effects are inscribed upon and reproduced by institutions and social structures (Bonilla-Silva 1997). The “criminal justice” system, encompassing police and prosecutors, has been identified by multiple scholars as a prime site for the perpetuation of racial social control (Alexander 2012; Gonzalez Van Cleve 2016; Krieger 2012). A new generation of sociologists have begun linking the effects of this system to racial health disparities (Sewell and Jefferson 2016).

Prior to this work, sociologists interested in racial health disparities have primarily focused upon residential segregation as the driver of disparities (Williams and Collins 2001; Williams and Sternthal 2010). In an obvious example of how status enables resources, residential segregation shapes health by limiting access to quality education, employment opportunities, networks of already employed individuals, quality affordable housing, trusting social networks, safe areas to exercise and play,

and affordable quality food (Massey and Denton 1993; Mullings 2005; Royster 2003; Williams and Sternthal 2010). Access to each of these types of resources is predictive of better health.

At the level of individual bodies, scholars have pointed to the ways in which deleterious stress processes result from prolonged discrimination. Three such processes – John Henryism, the Sojourner Syndrome, and the weathering hypothesis – suggest that coping with everyday discrimination (Feagin 1991) has effects on health ranging from higher infant mortality to increases in hypertension (Geronimus et al. 2006; James et al. 1992; Mullings 2005). One area, however, in which Blacks appear resilient is in mental health. Keyes finds that without discrimination, Blacks would score even higher than they already do, compared to White counterparts (Keyes 2010). Seeman et al. propose that prolonged exposure to stress leads to increases in allostatic load, which in turn has a variety of harmful physiological effects (Seeman et al. 2010).

Another avenue by which racism translates into poor health outcomes is within healthcare settings. Medical mistrust of providers among would-be Black patients was noted in 1899 by Du Bois. Given the history of involuntary experimentation upon Black citizens, such fear is hardly surprising ((Washington 2006)). Within this area of focus falls the patient-provider interaction, in which physicians may allow implicit bias to shape decision-making patterns. Throughout the 1990s, there was greater attention to ethnoracial disparities in diagnosis and treatment (Smedley et al. 2003). Geiger concludes that institutional and provider bias are significant contributors to racial health disparities. It has been suggested that in situations in which there is perceived social distance between patient and provider (as



may often be the case in race-discordant interactions), that each actor is more apt to rely on a priori beliefs about the other and act accordingly (Schnittker 2004).

Finally, as was clearly the case with the lead contamination of the water supply in Flint, Michigan, all of the processes described above create conditions under which racial inequalities lead to greater risk of exposure to environmental toxins (Smedley, Stith, & Nelson, 2002; Williams and Sternthal 2010).

### ***How do positional inequalities shape health?***

Positional inequalities – such as those between a boss and an employee – have implications for autonomy and self-determination (Ridgeway 2011), which may in turn shape health outcomes. Wielding power within the workplace likely means increased flexibility to determine one's schedule. This form of control enables the incorporation of healthy behaviors (e.g., physical activity) and routine medical care without penalty. Within the healthcare setting, doctors and patients are nearly always in an unequal power dynamic, in that the patient may be sick and therefore vulnerable, whereas the provider is a sanctioned professional. Traditionally, physicians have enjoyed high levels of occupational authority, which further advantages them, although patients-as-consumers are purportedly gaining ground (Conrad 2005).

In the past, doctors' position gave them nearly uncontested authority to define the realm of the medical – in other words, what counted as a diagnosable, treatable medical condition. This power allowed some conditions to be excluded from treatment or labeled as suspect, whereas other conditions might be pathologized (Brown 1995). Yet as physician authority has waned over the past few decades (Starr 2008), pharmaceutical companies and managed care have garnered increasing

amounts of power to determine what constitutes a medical condition and which conditions warrant payment by insurance companies (Conrad 2005). As one example of how these processes shape health outcomes, consider direct-to-consumer marketing in the United States, which pharmaceutical companies have utilized to shape consumer attitudes towards previously unmedicalized conditions (e.g., shyness can be described social anxiety disorder) and encourage them to seek help in the form of a pill. Such processes have no doubt resulted in higher rates of diagnosis and treatment of particularly profitable conditions (Conrad 2005).

Finally, at an organizational level, multiple interest groups, including the American Medical Association, have used their access to political decision-makers to advance (or block) specific health policies, as well as sweeping reform (Reid 2010; Starr 2013). In all of these ways, individuals and institutions tap into their relative positions of power to shape health outcomes.

### ***How are resources, prestige, and power intertwined?***

Forms of inequality are generally interdependent; they mutually reinforce one another. Access to resources ensures some amount of status. While one can have status without resources, they are usually a package. The possession of power nearly always requires some form of resources and status. In addition to overlapping forms of inequality *across* Weber's categories, some individuals experience multiple forms of inequality *within* a category (e.g., intersecting status inequalities). As an example of how these forms of inequality combine to shape health outcomes, let us consider racial health disparities among Blacks Americans. Blacks are much less likely to inherit wealth ((Keister and Moller 2000; Oliver and Shapiro 1995), the result of a long history of labor market discrimination (Bonacich 1972; Lieberson 1980),

disenfranchisement (Franklin 2002), limited political power (Lieberson 1980) and enforced residential segregation stemming from discriminatory federal housing policies (Massey and Denton 1993; Oliver 1995; Wilson 1987). Many of these same processes shape access to housing and employment. In addition, deindustrialization and global economic restructuring have resulted in an expansion of “bad jobs” in the service economy, with few benefits such as health insurance (Harrison and Bluestone 1988; Kalleberg 2011; Morris and Western 1999). These processes in turn shape the internal dynamics of neighborhoods, homes, and schools, contexts which continue to lay the track for disease prevention and/or progression. Everyday discrimination increases stress, yet so does a lack of financial resources and a sense of political powerlessness. The quest for labor market domination and resource extraction on the part of colonists over 500 years ago put into play the ideology of racial inequality, which was then embedded in macro-level social structures (Steinberg 2001). The inequalities inspired by an invented status difference put into motion all 3 forms of inequality, the effects are today embodied by Black Americans. This sociological portrayal of racial inequality in the United States shows how diminished resources, status, and power set the stage for health inequity. It is important to understand how social inequalities travel across institutions and throughout the lifecourse. Attending to the family as a unit of analysis will allow me to trace how multiple generations confront and cope with inequalities in various institutional contexts, including schools, housing, employment, and the health system.

### **The Social Determinants of Health**

In 1976, social epidemiologist Michael Marmot began his groundbreaking Whitehall studies that led to the conceptualization of health as falling along the social

gradient (Marmot 2004). Marmot examined the health of civil servants in Britain and found that those with the best health were at the top of the social hierarchy; from there, health outcomes declined in tandem with each gradation of the hierarchy. A few years later, the work of Marmot and another social epidemiologist, Richard Wilkinson, inspired the work of the Research Working Group on Inequalities in Health, entitled “The Black Report” (1992). The Black Report emphasized a comprehensive model of health informed by social conditions, in which health inequalities are the result of social and economic determinants. The Black Report was a transformative document, yet it received little attention outside of public health circles in Britain until years later (Irwin and Scali 2007; Marmot 2004). By the late 1990s, however, Marmot and Wilkinson had undertaken the work of translating the implications of their findings to policymakers, successfully attracting the attention of the World Health Organization (Irwin and Scali 2007). As a result, in 2005, the WHO formed the Committee on the Social Determinants of Health (CSDH) and this paradigm became a central focus of global health efforts. For this reason, I argue that the social determinants of health framework did not explicitly originate within medical sociology, but there was much in it that was a natural complement to work that medical sociologists had been engaged in for decades. At the time of the Black Report and until today, many public health researchers continue to privilege behavioral health models centered on individuals engaged in rational choice decision-making processes (Andersen 1995; Pescosolido 1992). By contrast, the SDOH approach called for a deeper understanding of broad societal processes of inequality and stress (Marmot 2004).

In the realm of stress, the physician Hans Selye had found in the 1930s that rats injected with hormone stressors reacted with what became known as the fight-or-

flight response (Petticrew and Lee 2011). The work of Selye and others was later developed by Leonard Pearlin, who emphasized both the precursors to and effects of continuous chronic stressors on human health and development (Pearlin et al. 1981). This research bolstered claims by SDOH researchers that psychological and physiological mechanisms are key to understanding how social conditions get under the skin (Brunner and Marmot, 2006). Meanwhile, medical sociologists began to pick up the mantle of bringing a sociological lens to the social determinants literature, exploring in-depth how socioeconomic status, race, gender and religion shape health outcomes (Idler 2011; Link and Phelan 1995; Read and Gorman 2010; Williams and Sternthal 2010). In the United States, a rich sociological tradition of race and racism scholarship, dating back to Du Bois, gave rise to a particularly American branch of SDOH research, that of racial health disparities (Braveman 2006). As racial/ethnic health disparities rose to national prominence as an important social issue, government officials under Reagan produced the Secretary's Task Force Report on Black and Minority Health (also known as the Heckler Report; U.S. Department of Health & Human Services, 1985). This report was the first of several over the next three decades on the seemingly intractable gap between Black and White health outcomes on multiple indicators (Smedley et al. 2003).

The social determinants of health approach has been conceptualized in at least two ways, including a materialist perspective and a life-course perspective (Brunner & Marmot, 2006; Blane, 2006). From a materialist perspective, the material conditions of life, from the basic necessities to new clothes or a new car, shape health outcomes. Marmot (2004), however, is careful to distinguish the differences between basic necessities and everyday goods: the absence of the former will have more direct effects on biological measures of health (e.g., vitamin deficiencies), whereas the

absence of the latter may lead to chronic stress and thereby heighten risk for chronic illness. Sociologists have tended to focus more on the material and social conditions in which illness and disease are bred and how these conditions fuel stress processes (Geronimus et al. 2006; Jackson, Knight, and Rafferty 2010; James et al. n.d.; Link and Phelan 1995). For example, Link & Phelan (1995) outline the ways in which socioeconomic status is a fundamental cause of unequal health outcomes, even as the more proximal pathways to illness change. Other scholars examine how everyday stress and discrimination wear the body down (Geronimus et al. 2006) or provoke high-effort active coping that results in higher blood pressure (James 1994). For his part, Marmot has focused much attention on the psychological internalization of perceived status differentials. The social determinants approach has been taken up by sociologists, psychologists, and social epidemiologists alike.

A life-course perspective complements these approaches; it emphasizes how the accumulation of (dis)advantage over the life course is part and parcel of social inequalities shape health (Blane, 2006). To understand how material and social conditions influence our health, we must examine them at each stage of life, from infancy to senescence. Our social environment changes as we age, not only because our access to resources may change, but primarily because we interact with different life spheres and institutions that have implications for health. For example, children and adolescents are strongly shaped by home, neighborhood, and school contexts, whereas adults must often contend with the inequalities present in the workplace. Methodologically, therefore, a comprehensive approach to the social determinants of health must take into account both change over time and how inequalities are linked across institutions.

Despite the widespread utility of the SDOH approach, it does not give sufficient attention to culture or political economy – both of which I intend to address in my dissertation. In Brunner and Marmot’s conceptual model of the social determinants of health (p.9) from Marmot and Wilkinson’s 2006 book by the same name, culture is relegated to a contributing factor to the entire process; as a model construct, it is not contained by a box, nor is it clear *how* it contributes to the model, beyond an arrow pointing from it to the model. The text makes reference to “cultural factors” and “the cultural environment,” but what does this mean? The ways in which social structure, culture and agency interact is at the heart of the sociological tradition; it stands to reason, therefore, that medical sociologists must begin to incorporate understandings of culture. I suspect that the hesitance to explicate culture more thoroughly and integrate it into SDOH accounts is two-fold: the first stems from an understanding of cultural relativism passed on by anthropology. By incorporating an analysis of culture, we run the risk of engaging in the construction of hierarchies of culture – e.g., “this culture is better than the other because it produces greater life expectancy.” The second reason relates closely to the first: in sociology, we have a history of blaming the victim through culture of poverty arguments (Bonilla-Silva and Baiocchi 2001). I am not suggesting we revisit these flawed arguments. Yet attending to the ways in which social structures are inflected by cultural processes is a worthwhile endeavor and one that I have woven through this dissertation. For example, examining racial health disparities in Brazil has at times been fraught because race is conceptualized and symbolized differently in Brazilian culture. Therefore, the processes by which racial ideologies and structures shape health outcomes look different from the United States (Telles 2006). Second, Brunner and Marmot’s model of the SDOH neglects to account for the origins of “material

factors.” Surely an understanding of how unequal conditions came to be and how they are embedded in global political economic systems would be useful – for the sake of knowledge, but also intervention.

### **Racial and Socioeconomic Inequalities in Brazil**

In the context of Bom Retiro, residential segregation can be difficult to untangle. While there are areas of the neighborhood that are more middle class and those that are poorer, all residents nevertheless have access to the health clinic. Furthermore, racial categories are not as discrete in Brazil, at least for the majority of citizens who might broadly be categorized as “Brown.” There are not obvious patterns of racial segregation in housing in Bom Retiro. Rather, residents may experience housing instability for socioeconomic or immigration reasons, that may in turn affect their ability to manage chronic illness or seek healthcare. In summary, U.S. patterns of inequality do not seamlessly map onto Brazil. While many of the social determinants of health may be the same (e.g., racism and poverty), the ways in which they become integrated into the daily lived experience of neighborhood residents can be quite different. In the following pages, I will outline briefly what we know about racial and class-based inequalities in Brazil.

### **The Myth of Racial Democracy**

It is nearly impossible to discuss racial inequalities in Brazil without mentioning Gilberto Freyre and the myth of racial democracy. In 1933, Gilberto Freyre published the first edition of *Casa Grande e Senzala* (English title: “*The Masters and the Slaves*”), launching his career as a Brazilian public intellectual and providing Brazil’s elites with a desperately desired dose of existential Valium. As debates swirled around the Atlantic world promoting and contesting the latest science



on race, Brazilian elites uneasily surveyed their compatriots and found them wanting, in terms of color, class, health, habits, and expressive culture (Stepan 1991).

Widespread “racial mixing” since the earliest encounters of local indigenous peoples, enslaved Africans, and Portuguese colonists meant that this nascent republic stood little chance of measuring up to the genetic purity being touted by Europeans and North Americans. Luckily, Freyre had spun a vivid new historical narrative, which championed Brazil’s racial diversity, and in the process, allowed Brazilian elites to dispense with any thoughts of implementing a program of biological eugenics.

Historian Marshall Eakin describes Freyrean racial democracy as the idea that “all Brazilians, regardless of the color of their skin, carry with them the shadows in their souls, traces of Europe, Africa, and the Americas in their cultural, if not their biological DNA (Eakin 2017). Yet as the state – and scholars in the vein of Freyre -- promoted the image of Brazil as a racial paradise, void of the kinds of racialized strife and violence endemic to the United States, this foreclosed a discursive space in which everyday Brazilians could speak of their experiences of discrimination. While the critique of racial democracy is that it has been used by elites to deny the existence of racism (Guimarães 2012), others argue its endurance as an explanatory model of race relations among the majority of Brazilians demands our attention as scholars (Sansone 2003).

Historian Paulina Alberto (Alberto 2012) has suggested that the notion of racial democracy is fundamentally unstable and has been used as a political and social black box of sorts. While some use it to deny the existence of racism, others – including leaders of Brazil’s Black Movement – have characterized racial democracy as an aspirational stance, invoking it to imagine the ideal Brazilian nation (Bailey 2009; Guimarães 2012).

Beginning in the 1960s, scholars pushed back against the idea of Brazil as a racial democracy. Once again, these Brazilian scholars had primarily been educated in the United States, notably by the Chicago School of race relations. Florestan Fernandes led this charge, emphasizing the prevalence of race prejudice and discrimination in Brazil, and emphasizing the severity of the issue. Carlos Helsenbalg and Nelson do Valle Silva followed up in the 1980s with extensive quantitative evidence of widespread socioeconomic differences by race that could not be reduced to differences in education or income. In other words, these scholars argued that racial disparities could *not* be considered an epiphenomenon of class (Bailey 2009; Telles 2006). These findings were bolstered in recent years by the work of Edward Telles, who also found persistent and widespread racial disparities in health status, education, and income (Telles 2006). Yet in contrast to the United States context, Telles noted the relative absence of racial segregation in housing alongside the common occurrence of interracial marriage. Nevertheless, the myth of racial democracy, both celebrated and repudiated, possesses a certain stickiness. Until today, it is easy to find Brazilians of all colors who proclaim harmonious racial relations as one's of Brazil's national treasures. At the same time, Black and Brown Brazilians have been working for more than a decade to stem the tide of police killings of Afro-Brazilians (Smith 2017). Public proclamations of Black Lives Matter ("Vidas Negras Importam") were also very visible in the streets of São Paulo throughout my fieldwork in 2018-2019.

### **Whitening**

The second pillar of scholarly studies of race in Brazil is that of whitening projects. Early twentieth century politicians developed and implemented programs to encourage European immigration to Brazil with the goal of "whitening," and thereby

elevating, the population. Lesser points out that “Brazilian national identity was often simultaneously rigid, in that whiteness was consistently prized, and flexible, in that the designation of whiteness was malleable” (Lesser 2013). Within this system of logic, European whites reproducing with brown and black Brazilians would result in white children, enhancing the nation’s racial stock in the eyes of Brazilian elites.

Later in the century, doctors and social scientists seized upon Freyre’s notion of racial democracy to construct race as *a way of being* – an attitude in an individual and the culture of a people – as opposed to biological fact. As such, race could be cultivated or weeded out. These elites turned to the arena of education, therefore, to breed Whiteness and suppress Blackness among poor Brazilians of all color (Dávila 2003). Without the devastatingly simple one-drop rule to rely upon, Brazilian racial designations harness an entirely different set of criteria, predicated at least in part on the substance of everyday interactions.

### **Scholarly Debates on Racism in Brazil and the United States**

In 1999 a North American journal published the English translation of a French piece by Pierre Bourdieu and Loïc Wacquant, two well-known French sociologists, in which they lament the export of neoliberal discourses from the United States to the rest of the world. Specifically – yet without regard to the layered historical and political context of Brazil – they call out Michael Hanchard, a well-known North American political scientist and race scholar. Hanchard had written a book a few years earlier exploring the Movimento Unificado Negro (The Unified Black Movement - MUN) in São Paulo and Rio de Janeiro. Bourdieu and Wacquant accused Hanchard of hatching a plan to impose the Black/white dichotomy of race

relations in the U.S. onto Brazil, in an effort to “create” racism where (according to the pair) it otherwise did not exist (Bourdieu and Wacquant 1999).

Hanchard responded, appropriately, to Bourdieu and Wacquant’s strident (and slimly evidenced) critique of his work by pointing out that transnational Black politics are just that – they transcend national boundaries in offering common cause to all people of the African diaspora (Hanchard 2003). He is preceded by historian Mark Alan Healey (Healey 2003), who describes his approach to the Bourdieu/Wacquant essay as “thinking with Bourdieu against Bourdieu,” by using the frame of symbolic domination to critique it. Healey also references much Brazilian scholarship that highlights the very theoretical positions that Bourdieu and Wacquant proclaim as emanating from the U.S.

In a most eloquent response, historian John French mounted a defense of Hanchard grounded in decades of scholarship in Brazil (French 2000). He not only picks apart Bourdieu and Wacquant’s argument piece by piece, quote by quote but offers a panorama view of the politics of race in Brazil in the scholarly context. The scope of his evidence makes plain Bourdieu and Wacquant’s failure to scratch below the very surface of scholarship on race in Brazil, instead taking the myth of racial democracy more or less at face value. As one leg of his defense of Hanchard, French takes the reader on a quick detour in characterizing the scholarship on race by both Brazilian and foreign scholars in the 1980s. At the time, scholars including George Reid Andrews, Carlos Halsenbalg, and Nelson do Valle Silva (mentioned above) began attempting to quantify race in Brazil and use it to demonstrate racial disparities in various social arenas. In attempts to dispense with the Pardo category (the “brown” category on the Brazilian census) and dichotomize Brazilian race categories, they provided compelling statistical evidence for disparities while perhaps reifying stark

categories that do not match Brazilian's experience of race on the ground. In contrast, Hanchard draws race into the interactional domain, painting it as a "discursive phenomenon." French closes his defense by stating that "no Brazilian scholar in recent decades have tried to build a case that Brazil is a society without racism."

One of the more prominent scholarly debates in the sociology of race and ethnicity in the United States in the past two decades has revolved around defining and properly emphasizing the terms "race" and "racism." When Eduardo Bonilla-Silva first published his work on structural racism and the identification of white supremacy as a system of power deserving sustained sociological attention, he was met with rebuke by Mara Loveman, who argued that because no one had successfully developed a theory of race itself, theorizing structural racism was logically inconsistent (Davila 2000). As Winant helpfully points out in a later piece in the aftermath of this debate (Winant 2015), two major sociological camps emerge from this scuffle. The first comprises those who conceptualize racism purely as a boundary-making process – the creation of us vs. them - in which race could be subbed out for any number of identities, including ethnicity or social class. These scholars (see e.g., Wimmer, Brubaker, Loveman) are engaged in what Winant describes as "nomothetic" work, which concerns the study of scientific laws of human social interaction (i.e., the theory of what race *is*). In contrast, Winant's project (along with Bonilla-Silva, Omi, Feagin, and others) is more in the tradition of "idiographic" work, that seeks to understand particular scientific facts or processes, grounded in sociohistorical context.

I position my work moving forward in this latter tradition, in that I am interested in how Brazilian social inequalities represent a historically grounded system of differentially distributed resources that are then ingrained into people's everyday lived experience. Vis-à-vis Brazilian racial categories, sociologists such as

Loveman have sounded the alarm at how particular state projects, such as racial quotas in the Brazilian university system, may have the unintended effect of reifying racial categories (Loveman, Muniz, and Bailey 2012). Yet anthropologist Sean T. Mitchell asks what effects these processes actually have on the day-to-day racial identification of Brazilians. He states: “Transformations in Brazilian racial politics have not *caused* racialization as much as they have opened up the possibilities for kinds of reracialization – or the transformation of the meaning of *already racialized* (and racist) orders.” Mitchell goes on to give the example of an informant who has only recently begun identifying as Black, now that this category has accrued cultural (and perhaps legal) advantages due to newer laws granting land to descendants of enslaved Africans (Mitchell 2017). In another example of “strategic identification,” Goldstein offers a compelling logic as to why many Black and Brown Brazilian women may hold on tightly to the racial hierarchy as it stands. Invoking racism – and identifying as Black rather than *morena* (a term loosely akin to “café au lait” or “light-skinned Black” in the United States) - would mean severing the potential connection to social mobility through *morena*-inflected sexuality. According to Goldstein, the cultural trope of the “sexy Mulata” remains strong in Brazil and expecting impoverished women not to capitalize on it is unrealistic given the widespread income inequality (Goldstein 2013).

### **Racial Health Disparities in Brazil**

Scholars have struggled to conceptualize racial health disparities in Brazil. In large part, this struggle can be attributed to two factors: 1) the public discourse emphasizing racial harmony and 2) the absence of discrete racial categories that map onto everyday discourse and experience, that are simultaneously used in official

government surveys (e.g., the census). While scholars have documented how self-identified Black Brazilians face widespread inequity (Caldwell 2017; Creary 2018), capturing the effects of various forms of racism on the “brown” majority has proven an elusive task. These efforts are complicated by the deep entanglement of race and socioeconomic status, as understood by both scholars and Brazilians alike (Trad, Castellanos, and Guimarães 2012).

As more conclusive research has emerged documenting racial health disparities, researchers and policymakers have begun to call for widespread programming to address these disparities. Pagano provides much solid evidence for racial health disparities in Brazil, where those identifying as Black has the worst health outcomes, whites have the best and Pardos (as identified by the census) are in the middle (Pagano 2014). Yet Pagano demonstrates that what is obvious to researchers and policymakers about racial health disparities can be interpreted in a radically different manner among everyday Brazilians.

While interviewing research participants of all ages being discharged from municipal health posts in São Paulo and São Luis do Maranhão, Pagano found that most people were uncomfortable discussing their racial self-identification. They noted, too, that health care professionals at the health post had also begun asking these questions and many found it distressing. Pagano’s most striking finding, however, was that when asked, 44% of interviewees agreed that racial health disparities are present in Brazil, and of these, 92% were of the opinion that in fact health was *worse* for white Brazilians. Astonished, Pagano followed up and elicited multiple narratives from people of all colors about the Black tolerance for pain and greater strength in the midst of suffering, often attributed to having had enslaved ancestors. Pagano ventures that such views may be explicable by simple *habitus* or to

the fact that realities may look different to people on the ground versus when we examine them at a macro-level, as with population health statistics. The possibility she does not explore is the persistent trope of Black suffering that acts as both a source of Black resilience and a discourse employed by white power structures to inflict violence and sustain harsh labor conditions.

Multiple processes of ethnoracial identification are common to Brazilians. For some ethnoracial group affiliation is deemed clear and salient; for others, claiming a national identity – Brazilian – serves as a proxy for cultural and political beliefs about race and racism. I will explore how each of these unfold, for whom each model resonates, and how individuals may have experienced changes in identification throughout the lifecourse. Regardless of the “strength” of racial group affiliation, a racial hierarchy is invoked and enforced through everyday interactions. As sociologist Elizabeth Hordge-Freeman highlights in her account of racial socialization in Afro-Brazilian families: “even in the absence of a physical colonizer, social relations are structured by a dominant ideology that often reproduces white supremacy” (Hordge-Freeman 2015).

Census data released by the Instituto Brasileiro de Geografia e Estatística (IBGE) indicate that for the first time since census-taking began, a majority of Brazilians self-identify as Black (Negro/Preto) or Brown (Pardo) (Phillips 2011). While it has intrigued scholars of race and ethnicity, little formal research has been undertaken to explore how, if at all, this shift mirrors changing trends in perceptions of racial categories and self-identification in everyday life, and in turn, how these changes may shape health outcomes.



Anthropologist James Holston has characterized Brazilian social inequalities as marked by “differentiated citizenship,” in which some classes of citizens have access to rights and recourse to the law, while others do not (Holston 2008). Housing instability, in which individuals live in fear of eviction and the state favors inequitable housing policies, is rife in Brazil’s urban metropolises (Perry 2013), yet little research has examined how these kinds of inequalities may be tied to poor health.

Sociologists have recently begun to explore how micro-level processes, particularly patient-provider interactions, may have a hand in reproducing health inequalities. Specifically, Janet Shim (2010) has theorized “how broad social inequalities operate in patient-provider interactions and shape the content and tone of health care encounters,” thereby reinforcing health inequities. Patients with greater cultural health capital achieve better clinical outcomes. Adapting the ideas of Pierre Bourdieu, Shim describes cultural health capital as a patient’s “repertoire” of cultural skills, attitudes, behaviors, and interactional styles that allow for easy communication with clinicians. Yet scholars have not widely applied this theoretical approach to empirical studies outside of the United States.

## Chapter 2: Immigrants, Migrants, and Paulistanos: Racialized Geographies of Labor and Health in São Paulo, Brazil

### Introduction

Imagine you find yourself, as I did one fall evening in 2019, strolling through a city square. Beneath the leafy canopy of the tall trees, a dozen young people are practicing traditional Bolivian folklore dancing. A man stands off to the side, calling out moves in Spanish while music plays from a portable speaker. Elderly Korean men and women occasionally stop to watch the spectacle, while others walk the edge of the square speaking to one another in low tones with hands clasped behind their backs. Taking in this scene, you might be surprised to learn that you are in Brazil, rather than the Andes or East Asia. The neighborhood of Bom Retiro, in central São Paulo, has been a destination for multiple waves of immigrants since the mid-19<sup>th</sup> century. Initially, many came as part of São Paulo's explosion as an industrial hub. Over time, however, the neighborhood became associated more specifically with the textile industry. Many of the first wave of immigrants arrived to seek work in this industry or to join family members already established in the neighborhood (Lesser 1999). Today, Bolivians, Paraguayans, Koreans, and Chinese are the largest immigrant populations in the neighborhood.

Healthcare providers and community health workers (CHWs) at the Bom Retiro Public Health Clinic (BRPHC) serve this diverse population. Clinic staff invoke racialized geographies, a term I use to refer to the ways that individuals organize the neighborhood around them in ethnoracial terms. Such geographies meld the symbolic (the meanings that providers attach to *who* lives and works in certain kinds of places) and the material (the built environment and the physical conditions of spaces that different patients occupy). The complex histories of race and immigration in Brazil, and more specifically in São Paulo, inform these internalized cognitive maps, which are then refined through everyday interaction

with local residents. I use the term racialized geographies for two reasons: 1) while they are certainly inflected by additional status hierarchies (e.g., class, gender, age, and occupation), ethnoracial categorization remains at the forefront; and 2) providers employ these schemas to make spatial sense of the neighborhood.

In the pages that follow, I show how histories of race and immigration in Brazil shape these racialized geographies, as well as how labor and housing conditions situate ethnoracial groups in relation to one another in the neighborhood. The racialized geographies that I detail below are relational in nature; categories are co-constructed in reference to one another (Molina 2014). As one example, part of being “Bolivian” in Bom Retiro means living and working in places where Brazilians and Koreans typically do not. After portraying the contours of these geographies, I turn to asking how racialized geographies of labor shape the provision of primary care in Bom Retiro. To answer this question, I conducted 15 months of ethnographic fieldwork, including over 450 hours of participant observation and 58 in-depth interviews with patients and providers.

I demonstrate how providers and CHWs use these racialized geographies as a lens through which to observe and interpret utilization of services at the BRPHC. My findings answer a call to bring back analyses and race and ethnicity into the sociology of immigration (Jung 2015) and aim to add to this literature’s sparse accounts of South-South migration (Silveira et al. 2016). I demonstrate how local economies and spatial configurations of labor are crucial to understanding Brazilian racial dynamics, as I explore how healthcare providers and CHWs position immigrants, migrants, and those from São Paulo within Brazil’s racialized social system (Bonilla-Silva 1997). I conclude by discussing how these geographies shape prevention and treatment efforts towards particular groups and the implications for health equity.

### ***Race, (Im)migration and Housing in São Paulo***

Space has long constituted a great paradox in Brazil, as the State has struggled with how to manage and make legible such a vast territory (Hecht 2013; Scott 1998). At the same time, densely populated urban metropolises house the majority of Brazilian citizens. Enslavement, forced relocation, internal migration and immigration from abroad have all shaped the urbanization and development of São Paulo (Andrews 1991; Britt 2018; Fontes 2016; Lesser 1999). Stratified economic and political agendas compete until the present day to determine belonging, ownership and use of the urban landscape (Cohen 2016).

Despite the abolition of slavery in 1888, the newly founded republic left Afro-Brazilians bereft of land and livelihood (Butler 1998). Many formerly enslaved people departed from the coffee plantations in São Paulo's interior to seek work in the city. Soon after, powerful elites instituted whitening policies, in which millions of Europeans were incentivized to emigrate to Brazil (Lesser 1999). This dual influx of people, alongside São Paulo's industrial growth, created intense demand for housing. Neighborhoods in central São Paulo, including Liberdade, Bexiga, Barra Funda, and Bom Retiro, housed many of the city's Black residents at the turn of the twentieth century (Britt 2018). Yet as European immigrants (e.g., Italians, Poles) flocked to the city, soon followed by Middle Eastern and then Japanese arrivals, Black Brazilians were forcibly relocated to outlying neighborhoods or to the windowless basement spaces (*porões*) below central tenements (Butler 1998).

Between the 1920s and 1960s, efforts were underway to clear out and demolish these tenements (known as *cortiços*) in the central region of the city (Britt 2018). Cortiços are “a type of tenement occupied by workers who cannot afford to own a home” (Caldeira 2000). They typically appear like a single-family or multiple-story home on the outside, while beyond the entry door lies hallways that give way to small rooms that may be occupied by an entire family. Bathrooms and kitchen areas are usually communal. While some were destroyed in the mid-twentieth century, *cortiços* persist in central São Paulo until today, including in Bom Retiro.

Seventeenth century European enslavers shipped many of the first enslaved Africans to labor on the sugar plantations in Brazil's Northeast region. Once coffee replaced sugar as Brazil's most desirable export in the 19<sup>th</sup> century, the remaining inhabitants of the Northeast region experienced widespread poverty and drought. As the center of power shifted to the Brazil's Southeast region, dominated by São Paulo and Rio de Janeiro, Northeasterners (*Nordestinos* in Portuguese) began a massive internal migration to the Southeast (Schwarz and Starling 2018). Millions of *Nordestinos* sought economic opportunity in São Paulo (Fontes 2016; Melo and Fusco 2019). While many did find work, they also found the city ill-equipped to house all of the new arrivals, further exacerbating São Paulo's housing shortage and the expansion of the periphery, a crisis that persists to the present day (Rolnik 2019).

Known as one of the garment districts of São Paulo, Bom Retiro residents included individuals from each of these groups (Afro-Brazilians, Jewish and Catholic European immigrants, and *Nordestinos*) over time. Indeed, despite their varying historical trajectories, descendants of all of these groups remain present in the neighborhood until today. Over the decades of the twentieth century, some of these immigrants (e.g., Jewish Europeans, Italians) gained socioeconomic power, and thus social mobility, eventually moving to newly developed upper and upper-middle class enclaves across the city. Bom Retiro nevertheless retains a small number of older adult Western and Eastern European immigrants (both Christian and Jewish) who by now have lived in Brazil for most of their lives. In the 1970s, Koreans fleeing civil strife arrived in São Paulo (Yoon 2015). By the 1970s, many had moved to Bom Retiro to live adjacent to the textile shops and retail stores where they were already working. In the ensuing decades, the ownership of the textile industry changed hands in significant numbers from Jewish Europeans to Koreans (Chi 2016).

Three-story buildings line the main commercial street of Bom Retiro. The first floor is often a retail space, showcasing clothing or wholesale fabric. Bargain hunters from São Paulo and elsewhere in Brazil travel to Bom Retiro to look for deals and buy wholesale. The second floor of the tenement is often an *oficina*, which is Portuguese for “workshop”, but is often translated as “sweatshop” (Buechler 2004). The *oficinas* are replete with sewing machines for making the clothes on sale downstairs or across the city. In some cases, the employees who sew in these shops live either on the third floor of the tenement or behind the workshop floor. The majority of these sweatshop employees are South American immigrants, among them Bolivians, Paraguayans, and Peruvians, who have come to São Paulo seeking economic opportunity. Bolivians are by far the largest group; they began emigrating to Bom Retiro in the 1990s to work in the textile industry (Aguiar and Mota 2014). As of 2019, Bolivians were São Paulo’s largest immigrant group (Bernardo, 2019). While most South American immigrants are employees of the *oficinas*, they are increasingly opening and managing their own shops.

### ***Space, Place, and Racialization***

Ethnoracial categories are not merely constructed through discursive practice, but also through the spaces in which people live and work, past and present (Lipsitz 2011; Soja 1996). Like many cities in Brazil and elsewhere (Hunter and Robinson 2018; Perry 2013; Teelucksingh 2006) São Paulo is marked by racialized spaces. Residential segregation in the city dictates that while a certain proportion of whites live in the periphery, very few Black people own apartments in the wealthy city center and the posh neighborhoods east and south of it. Furthermore, particular urban spaces by name alone are associated with poverty and Blackness in the public imagination

and in news media (e.g., *favelas*). Vargas (2006) argues that the specter of the *favela*, or urban slum, merges racial and spatial schemas quite seamlessly. I contend that *oficinas* in Bom Retiro do some of the same symbolic work, albeit on a smaller scale, as the *favela* in Rio de Janeiro. Racial and spatial schemas merge, as phenotypically Andean indigeneity frequently maps on to bleak living and working conditions of the *oficinas*. Meanwhile, many Korean and Korean Brazilians occupy upscale apartment buildings, restaurants, and retail shops. As I argue in the results section, who lives where and in what kinds of conditions entwines with long-extant Brazilian racial scripts (Molina 2014).

Sociologist Moon-Kie Jung (2015) asserts that racism operates through both cultural schemas and allocation of material resources, hence making use of both structure and culture as race is manipulated and reproduced by individuals. Notions of space (materially constructed) and place (socially constructed) mirror this duality of structure (Lefebvre 1991; Sewell 2005) By focusing on the entry of immigrants into an already established ethnoracial order, Jung (2015) emphasizes a politics of belonging as central to (im)migration dynamics.

Omi and Winant (2015) define racialization as “the extension of racial meanings to a previously unclassified relationship, social practice or group.” A racialization framework can be used to understand macro-level structural inequalities as well as everyday experiences of discrimination based on one’s perceived ethnoracial category (Gonzalez-Sobrinio and Goss 2019). In this paper, I focus on these everyday experiences, exploring how the process of racialization unfolds via spatialized healthcare interactions between providers, CHWs, and patients.

Racialization occurs when a member of the dominant group interprets the behavior of an individual as indicative of all people from that group. Members of the dominant group may test their interpretation among like others, seeking feedback or confirmation; these others may contest what is being said (and offer contrary evidence) or agree (and offer concurring evidence). The listener may have had few interactions with the group under scrutiny or have had little exposure to cultural messages about the group. Nevertheless, growing up in a racialized social system such as Brazil or the United States, means knowing, even if only implicitly, that ethnoracial groups are categorized and ordered in a hierarchy (Golash-Boza and Bonilla-Silva 2013). As individuals further articulate, contest, refine, and reiterate racialized beliefs, such beliefs sediment into a more or less coherent ideology. Social structures absorb and rechannel racial ideologies through institutions and organizations (Bonilla-Silva 1997; Ray 2019), in this case the primary care clinic.

### ***The Bom Retiro Public Health Clinic***

Under Brazilian law, anyone on Brazilian soil, regardless of citizenship status, may receive care through SUS (the *Sistema Único de Saúde* or Unified Health System), Brazil's public healthcare system. From its inception in 1988, the founders of SUS, aligned with the Primary Health Care movement symbolized by the 1978 Alma Ata conference, declared health as a human right (Jurberg 2008). Thus, the BRPHC aims to reach neighborhood residents of all origins. Furthermore, SUS delivers all services free of charge; patients do not need any form of insurance to receive care at the BRPHC, though they must offer proof of neighborhood residence.

Of the neighborhood's nearly 40,000 residents, 70% seek primary care at the Bom Retiro Public Health Clinic (BRPHC; UBS Bom Retiro, 2019). In 2019, the



BRPHC registered 2,576 new patients from Spanish-speaking South American countries, namely Bolivia, Paraguay, and Peru. Korean and Chinese immigrants constituted 591 and 58 newly registered patients, respectively. Of the 16,173 newly registered patients in 2019, according to the BRPHC's internal recordkeeping, 10,087 of them (or roughly two-thirds) recorded Brazil as their country of origin. Of these more than ten thousand Brazilians, CHWs marked their racial categories as follows: white = 4,737; Brown = 3,340; Black = 416; Yellow = 148; Indigenous = 9. Nine-hundred and forty-one entries were left blank; 491 entries were recorded as "no information" for the race/color question.

Despite Bom Retiro's reputation as a neighborhood of immigrants, a slight majority of residents are in fact Brazilian. When a community health worker (CHW) from the BRPHC ventures out into the neighborhood to register a new patient or family, one item on the registration document asks each person's "race or color" (*raça ou cor*). SUS provides five race/color categories; only one can be marked. The five categories (translated literally) are Black, Brown, Yellow, White, and Indigenous. CHWs sometimes ask the patient with which category they identify; other times they fill in the information without asking or leave it blank.

The ethnoracial and linguistic composition of Bom Retiro is indeed diverse, much like Brazil itself. Community health centers commonly use ethnoracial data such as these, linked to health outcomes, to design and tailor programs and interventions for their patient population. At the BRPHC, however, staff must respond to city, state, federal, and even global initiatives aimed at particular health behaviors or population groups. When opportunities do arise for locally informed primary care responses, BRPHC staff rely not on data such as those I present above. Rather, they

employ their own everyday understandings, rooted in racialized geographies, of the needs of various patient groups.

Unlike primary care in the U.S., where patients at a given clinic may live great distances apart, the BRPHC serves residents who reside in what is called the “coverage area.” The coverage areas are determined at the municipal level, through a process known as territorialization (Andrade et al. 2018). Given this structure, health professionals at the clinic are disposed to conceptualize their work spatially, and they use street names and building descriptions often when communicating to one another about patients. The coverage area is divided into five subsections, each of which serves approximately 4,000 patients and is denominated by a color (e.g., the green area). Each subsection is managed by a strategy team (named such because they exist in accordance with the Family Health Strategy), consisting of a physician, a nurse, two nurse techs, and six community health workers; the team is subsequently referred to by the same color name as their subsection (e.g., the red strategy team serves the red area).

Each CHW is responsible for a micro-area: a subsection of his or her team’s larger area. They must visit each registered household residing in their micro-area on a monthly basis. Given their presence outside of the clinic, and the fact they outnumber physicians and nurses, CHWs are the forefront of SUS’s public interface. Coincident with the emphasis on their role as community liaisons (Georges 2018), CHWs must reside in the neighborhood in which they are contracted to work. Beyond this requirement and a high school diploma, CHWs have little training prior to interacting with patients. As they go about their daily routines, CHWs and providers observe and interact with patients of diverse backgrounds, both inside the clinic and within patients’ homes.

These interactions become the context in which racialized geographies emerge as salient, as BRPHC staff reach into the past for racial scripts that can be applied to present-day structures. As I further detail below, CHWs and providers use these racialized geographies as a basis for primary care treatment and public health programming. We can imagine, however, that racialized geographies factor into a variety of neighborhood, city, and even federal decision-making and policies. The historical patterns of racialized residential and occupational conditions, both material and symbolic, shape everyday interactions within those spaces.

## **Methods**

I began this community-based ethnography at the Bom Retiro Public Health Clinic (BRPHC) in August 2018. I entered the field with an interest in understanding how Brazilian CHWs navigated relationships with immigrant patients, given that much of the public health literature assumes a sociocultural “match” between CHWs and those they serve (Katigbak et al. 2015), a topic I explore elsewhere in my work (*see Pingel, Dissertation Paper #2*). I gained access to the clinic through professional connections to the director and a physician. I visited Bom Retiro for several weeks in the summer of 2017, met with the director, and spent time following the physicians and CHWs in their daily routine. I returned in 2018 to conduct 15 months of ethnographic fieldwork, including participant observation and in-depth interviews, both semi-structured and unstructured, with health professionals and patients.

During the period of data collection in São Paulo, I spent over 400 hours engaged in participant observation, primarily in Bom Retiro, but also at community health events in different parts of the city. A typical day of participant observation included sitting in with a physician while she saw patients for appointments,

following CHWs on home visits, or joining a team meeting in the clinic's tiny conference room. CHWs must complete 210 home visits per month, as dictated by their contract with the private Health Organization that the municipal government has contracted to administer the public health system. I walked with CHWs to their micro-areas and visited with single patients or entire families, while CHWs would do tasks such as registering new patients, passing along information about upcoming appointments, and checking vaccine records. CHWs do not provide any medical care to patients; rather, they are strictly liaisons between the patient and medical providers.

Each color team spends one afternoon a week meeting together to discuss priority cases and to trade information on the status of particular patients and families. Team meetings were a particularly rich source of ethnographic observation. Health professionals used team meetings to discuss patient behavior, reflect on their experiences while on home visits, and build solidarity with one another through shared jokes and rituals.

In addition to participant observation, I conducted 58 in-depth, semi-structured interviews with healthcare providers (N=12), CHWs (N=22) and patients (24 interviews, 29 participants). Five patient interviews were with two participants simultaneously -- three sibling pairs, a stepmother and daughter, and one couple. With providers and CHWs, the interview guide covered topics including work history, initial training and orientation, interactions with patients, experiences with other professionals at the clinic, and description of CHWs' micro-area. Patient interview topics included one's history with the neighborhood, health history, and interactions with the clinic. In-depth interviews lasted between one and two hours and were audio recorded and transcribed. I conducted nearly all of these interviews in Brazilian Portuguese at several locations in the neighborhood outside of the clinic. Three

patient interviews were conducted in Spanish, per participant preference. For participants characteristics, such as race and gender, please see Appendix One. Prior to the interview, I asked each participant to choose a pseudonym that would be used when study results were presented. All research procedures pertaining to this study were approved by Emory University's Institutional Review Board.

I approach the topic of racialization in São Paulo as a middle-class cisgender woman from the United States. Being white in both Brazil and the United States means that I do not have a personal history of experiencing racialization as a person of color. The contexts in which I *have* been racialized – times when my whiteness was made visible or remarked upon – never constituted a systemic loss of power. In other words, I have always resided in societies rooted in white supremacy. Becoming sensitized to processes of racialization was thus voluntary, accomplished through academic study and listening to and engaging with the experiences of people of color over many years. Especially in the first few months of my fieldwork, my whiteness was a focus of daily conversation. The CHWs routinely commented on my hair, my facial features and my body shape – linking their approval explicitly to the aesthetics of whiteness.

These discussions, however, opened an early window onto how everyday talk is laden with racialized ideas about bodies and the people who inhabit them. As a white foreigner, I was granted some leeway into asking frank questions about immigrant groups in the neighborhood, whereas I found my participants much less apt to comment explicitly on the extant racial order *in* Brazil. My interviews with CHWs and providers did not begin until after I had completed five months of participant observation. In this time, clinic staff became accustomed to my presence (and my strange questions) and were able to determine for themselves that the objective of my

work was neither to disrupt their daily routine nor to keep tabs of them on behalf of the clinic's administrators.

I analyzed these data using an abductive approach (Tavory and Timmermans 2014). Abductive analysis requires the researcher to tack back and forth between systematic empirical observation and an evolving theoretical framework, thereby developing generalized inferences about the social world being studied. By comparing observed realities to multiple established theories of social action -- in this case how racialization processes unfold given the specific historical conditions and social positions of CHWs in São Paulo vis-à-vis immigrants, migrants and Paulistanos -- I was able to see new avenues for understanding the processes I observed and about which CHWs providers offered their own insight. Through iterative research design involving immersion in the field site, recording and analysis of field notes, and conducting interviews and rereading transcripts, I began to draw conclusions in response to my research question. Beyond my own empirical observations, however, my account draws on theories of space and racialization, histories of race and racism in Brazil, and practices of community-based public health.

## **Results**

### ***Racialized Geographies in Bom Retiro***

BRPHC staff constructed racialized geographies of patients along intersecting axes of ethnoracial categories, occupation, and living space. As we shall see below, these geographies rely on both perceptions and material facts, infused with racial scripts that originated in local and national histories. Providers and CHWs *theorize* how the neighborhood fits together: they iteratively observe the neighborhood around them, communicate with others about it, and bring forth (consciously and

unconsciously) longstanding ideologies to make sense of their findings. I demonstrate how the racialized geographies constructed by CHWs and providers must be analyzed within histories of immigration and racialized identities in Brazil. Furthermore, I highlight how the presence of multiple racialized groups in Bom Retiro facilitates a relational understanding of racial categories.

Bom Retiro has been home to immigrants, as well as Black, Brown, and white Brazilians, for over a century. Opportunities within the textile industry, and the micro-economies that sprout up around it, has drawn these varied groups to the neighborhood. In this environment, racialization unfolds relationally as the characterization of one group is often made in reference to another (Molina 2014; Molina, HoSang, and Gutiérrez 2019). While inherently unstable and always subject to negotiation, I present below the basic contours of the racial geographies circulating among clinic providers and CHWs. I also heard many of these assertions echoed by neighborhood residents in their portraits of Bom Retiro.

In contrast to physicians and nurses, who commonly hail from the middle and upper-middle class and are of primarily European descent, CHWs are more likely to descend from earlier Northeastern migrants or long-term Afro-Brazilian residents of São Paulo. Northeastern migrants and their descendants comprise the working and lower middle class – staffing the retail shops, for example, and living in smaller apartments. CHWs and providers view Koreans as more affluent, often owners of the *oficinas*. Koreans live in a particular section of the neighborhood, along with older European immigrants (long-time residents), in spacious, sometimes modernized, apartments. The local racial hierarchy relegates to the bottom rung Bolivians living and working in the *oficinas* along with impoverished Black and Brown Brazilians living in occupied buildings (akin to a squatter settlement) or pensions (one room per

family and shared bathrooms). Less remarked upon, yet nevertheless present in numbers, are *Paulistanos* (meaning, to be from the city of São Paulo), both Black and white.

In the paragraphs that follow, I offer details that inform these racialized geographies, centered around local housing and labor conditions. CHWs, many of whom have lived in Bom Retiro for decades if not their entire lives, bring their prejudice to bear in pronouncing which ethnoracial groups “belong” and which do not. Maria, a self-identified Afro-Brazilian woman who has lived in Bom Retiro since early childhood, described her conception of the neighborhood:

Today you have an immense quantity of Koreans. So you have the Koreans, the Jews, who are traditional, the Bolivians. Today you have Paraguayans arriving, Angolans. So, it’s a very mixed neighborhood. But – those who are *truly* from the neighborhood know each other...so you can go to the corner fruit stand and the owner knows you’ll pay at the end of the month. But when a new foreigner arrives, we all know, look, this foreigner is new. And that has happened really quickly...and since it is a commercial neighborhood, people come in to work. They come to work and then they leave, but we stay. So, we know who is actually *from* the neighborhood.

In Maria’s racialized geography, newer arrivals (e.g., South American immigrants) are not quite part of the neighborhood, rather they are passing through. Later in the interview, she is careful to explain how the city used tactics such as demolition and the building of roadways to disrupt and displace Afro-Brazilian communities from the central neighborhoods of São Paulo, consistent with Britt’s work (2018). Maria described how Black and Brown Brazilians from the Northeast region of Brazil (known as *Nordestinos*) were present in Bom Retiro insomuch as they comprise the majority of doormen, building supers, and domestic workers. For Maria, these migrants and their descendants were rooted in the neighborhood in a way that



transient South American immigrants laboring in the *oficinas* were not. Living space and occupation were thus intimately entwined with ethnoracial categories.

If you were to stroll the main commercial streets of Bom Retiro hunting for sales in the retail clothing stores, as hundreds of people from around Brazil do each day, the *oficinas* towering above would likely remain invisible to you. Behind unadorned walls smattered with grimy, barred windows, South American immigrants toil at the sewing machines and ironing boards. Hints of this industry litter the streets in the form of trash bags, splitting at the seams with fabric swatches. Bom Retiro is neither a wealthy enclave, despite its central location, nor populated by an amalgam of informal housing units, as in much of the periphery. Its housing stock varies widely, from dark and dilapidated improvisational shelters to spacious sun-filled apartments. Residents of the *oficinas*, however, are overwhelmingly South American immigrants. Therefore, as CHWs make visits to the *oficinas* and apartments, their gaze is inflected by such racialized conceptions of space.

Bolivians, Paraguayans, and Peruvians frequently reside within the *oficinas*, in rooms or makeshift sleeping quarters adjacent to the sewing areas. They work long hours for very little pay, in buildings with poor ventilation and little light. Not surprisingly, the neighborhood tuberculosis incidence remains among the highest rates in the city (Pinto et al. 2017). From CHWs and providers' perspective, Paraguayans are a small step up from Bolivians. Brazilians describe them as more apt to speak Portuguese, having lived in border regions in Paraguay. Phenotypically, they are also more likely to read as "white," against Bolivians' "indigenous" features. Nevertheless, CHWs and providers portrayed Bolivians and Paraguayans, along with smaller numbers of Peruvians, as impoverished compared to Korean and European immigrants.

In the following passage, CHW Esther, who has spent her entire life in Bom Retiro, relates how the trajectories of various ethnoracial groups are bound up with the textile industry.

**Esther:** The majority of people were Jews, back in the day. So they lived here and they had their churches [sic], their bakeries, their schools. I don't why, but they began leaving the neighborhood. The main commercial street, the majority of the stores were theirs, you know, Jewish merchants. And then, with time, they began leaving, and going to Higienópolis [another central neighborhood]...and other immigrants arrived. So that was a really big change that we noticed. Many immigrants came to live, to work here in the neighborhood. And automatically, a lot of filth...in the streets, that wasn't there back in the day, when the Jews were here...the streets are really dirty. A lot of immigrants. So...I don't know if it has to do with them [the immigrants], but that's how it is. Koreans, Bolivians, Paraguayans....What really attracts them is the trade [the textile industry]. The stores, the majority of the merchants are Korean. The sewing, that's the Bolivians and the Paraguayans who do that part, mostly for the Koreans....and earning very little. Because they pay very little to them. Working hours and hours....

**Emily:** Would you say that these groups, for example Bolivians and Koreans, occupy the same space in the neighborhood? Do they do work on the same thing?

**Esther:** No. Because the Koreans, they have greater purchasing power, right? They have the stores, they buy the stores. There are lots of cafés that belong to them, you know? They arrive here in Brazil and their money goes a long way here I think, I don't know. So they open things. And then they put foreigners to work for them.

There are two notable references in this passage. Esther (who self-identified racially as Brazilian) mentioned that many Jewish families (who were never, in fact, a majority in Bom Retiro; (Truzzi 2001) moved to Higienópolis (*Hygiene City*), a neighborhood whose name was designed to evoke a healthy populace. Esther then follows up with mention of the “filth” of Bom Retiro, questioning whether the new

immigrants are responsible for it. Such dirtiness, which supposedly tarnishes the city streets, fuels an imaginary linking immigrants and the poor to unsanitary living conditions and disease. Public discourse of this kind dates back over a century in São Paulo (Caldeira 2000; Chalhoub 1996). The Sanitary Reform movement of the early 20<sup>th</sup> century, coupled with elite eugenics projects around race and nationalism, sought to civilize the poor through cleanliness and whitening (Lima & Hochman, 1996; Stepan 1991). In some cases, sanitary agents conducted home visits to literally disinfect residents (Sobrinho 2013).

Esther's second reference of import is the insinuation that Koreans' capital, and thus entrepreneurial dominance, springs from questionable business practices. This characterization emerged in multiple narratives, hinting at resentment towards Korean wealth and success. Liz (self-identification: white), a CHW who grew up in Bom Retiro and whose parents owned a clothing store when she was child declared that when the Koreans moved in to Bom Retiro, they arrived with connections and capital that allowed them to undercut the prices of then-owners (white Brazilians, Jewish and Christian European immigrants) and employ cheap Bolivian labor. On a home visit with Dona Amélia, a white Brazilian woman in her sixties, she exclaimed to her CHW and me that "You shouldn't speak ill of anyone, but the Koreans are terrible." She offered her account of how Koreans came to dominate the textile market in Bom Retiro, forcing established businesses to close. She maintained that some Korean owners would close up shop overnight, with debts unpaid, and flee the country. These experiences led her to say that Koreans "aren't good to work with because you can't work with someone that you can't trust," adding, "and the Bolivians are the same way." Dona Amélia's comment is an example of what historian Natalia Molina (2014, pg.6) terms "racial scripts": "Once attitudes,

practices, customs, policies, and laws are directed at one group, they are more readily available and hence easily applied to other groups.” Racial scripts engender the meanings that one group attaches to others, the scaffolding on the spatial structures beneath. Indeed, we find evidence that a century ago, Brazilians expressed similar disgust and fears about the presence of Jews in Bom Retiro (Lesser 1995).

Whereas the ownership, management and labor of the *oficinas* binds together Korean and South American immigrants, Brazilians frequently worked in the retail clothing shops, as professionals (e.g., dentists), or in the service sector, as caregivers, domestic workers, or doormen. Some of these Brazilians also lived in the neighborhood, such as doormen, among whom it is common to reside in the building where one works. I accompanied CHWs on visits to *ocupações* (“occupations”). The Centro region of São Paulo passed through a period of extensive decline in the 1960s, as economic capital moved to new locations and many houses and apartment buildings fell into disrepair. Residents scrambling for adequate shelter often occupied buildings and homes, sometimes managing to eventually obtain collective ownerships rights. Pensions are another common form of urban dwelling in central São Paulo in which rooms are rented to individuals or entire families and all of the tenants share a bathroom. CHWs pointed out to me that the *ocupações* and pensions were more often home to Northern and Northeastern Brazilians. I noted, in turn, what was not articulated, namely that many of the large single-family apartments belong to Brazilians of Southeast or Southern origin – the two most affluent and “white” regions of the country.

The intersecting ethnoracial, class and regional axes that shape status hierarchies among Brazilians in Bom Retiro reflect those of Brazil more broadly. Nordestinos have faced much discrimination over the past century, being identified by

Paulistano elites as the impoverished masses of the city, racialized as Black and Brown partly as a function of class and regional origin Guimarães, 2000; Weinstein, 2015). CHW Júlia (self-identification: white) reflected on how labor patterns inform this regional bifurcation in the city.

I think that Nordestinos, they're not ashamed to leave the Northeast in order to come here and wash bathrooms. And a...a Paulistano, he's not going to study, to finish high school, and then say that he has become a doorman. As if it was something bad. It's not bad. But it's like this: I think that for them [the Paulistanos], it's a *profissãozinha* [a job, rather than a career], so they, people from here, people from São Paulo, they're very proud, I think. And Nordestinos, you don't see that with them. They leave there [the Northeast], come here to work. With them [the Paulistanos], that doesn't exist. It would be really hard to find a bricklayer from São Paulo. People say about the city of São Paulo, "Ah, São Paulo has so many hard workers!" Sure. But there are lot of lazy people too. I think that people who come from elsewhere, from the Northeast, I think [that is] what helps São Paulo have this, this...perception of itself as hardworking....

While Júlia is from São Paulo, many of the CHWs are themselves Nordestinos or the children of Nordestinos. They identified with the struggle to carve out dignified labor and living conditions in the metropolis. Middle and upper-middle class white Paulistanos, on the other hand, were very nearly an unmarked category among healthcare providers, known but not explicitly discussed. In part, this present absence may be explained by the fact that few in this group seek services through SUS, opting instead for private medical care.

The racialized geography of Bom Retiro was evident one afternoon as I arrived with several CHWs at a luxurious apartment building with a brightly lit white marble entryway. This section of Bom Retiro - also home to some elderly Jewish and Catholic European immigrants, often long-time residents – is visibly more affluent. The building facades are in less need of repair and the local shops cater to a middle-

class clientele. We were there to administer the measles vaccine, amidst outbreaks throughout the city and several cases in the neighborhood. As the residents lined up, I copied their name and date of birth from their government-issued ID to a vaccine card that they would receive after the shot. Looking around, I noted that the building's inhabitants, whose information I collected as part of the clinic's vaccination records, were either Jewish Brazilians of European descent, Catholic European immigrants, or Koreans. Nearly all of the residents were over fifty and displayed the trappings of their class (neatly coiffed hair, clothing and jewelry that appeared expensive). Meanwhile, those in the building for work - the CHWs, along with the doorman and the woman hired to clean the hallways of the building - were Black and Brown Brazilians. South American immigrants were absent from this scene and indeed would have appeared out of place – they neither live nor work in this kind of space.

### ***Racialized Geographies and the Utilization of Primary Care Services***

Racialized geographies, in which class, labor, and living space are mapped onto racial categories, shape utilization of primary care services at the BRPHC as well as providers' perceptions of patients' needs. For many South American immigrants, the clinic is their only link to biomedicine. Access to healthcare in their countries of origin is heavily dependent upon class and proximity to urban centers. Bolivians that I spoke with typically expressed gratitude for the existence of the public health system, explaining that such services were not available to them back home. Furthermore, South American immigrants sometimes travelled to Brazil to obtain services. Others stayed in São Paulo for a longer period than first anticipated when confronted with a medical issue so that they might access what they perceived as superior (and free) care through SUS. Given Paraguay and Bolivia's relative proximity to Brazil,

immigrants commonly made the trip home once or twice a year. In the case of one Bolivian family that I interviewed, an adult brother and sister related how they had returned to Bolivia, and then brought back two ailing siblings to São Paulo with them for treatment.

By contrast, Koreans were more apt to mention seeking medical care while home in South Korea, asserting their belief in the superior quality of the healthcare system there. I observed a consultation one afternoon between Dr. Caetano (self-identification: white), a physician at the BRPHC, and a Korean couple in their early sixties. The woman did most of the talking in heavily accented Portuguese. She had lived in Brazil since the age of 2; her husband emigrated to São Paulo at the age of 37. He had been diagnosed with emphysema and had travelled to South Korea to receive treatment. Now that they had returned to Brazil, he needed the medicine he had been prescribed while in South Korea. His regular physician in Bom Retiro, a fellow Korean whom he saw through privatized health coverage, suggested that he look into getting the medicine through SUS, as it would be free. Dr. Caetano was eager to help; his Korean patients often came to him for free services and medication on the recommendation of their primary Korean physicians. I noted that this woman complimented Dr. Caetano three times throughout the visit, congratulating him on being “very handsome and an excellent doctor.” Cases such as these, along with cash gifts given by Korean patients, cemented provider perceptions of Koreans’ relative wealth, healthcare access, and cultural health capital (Shim, 2010), which stood in sharp relief against Bolivians’ limited options and low levels of education.

Although SUS is present throughout Brazil’s territory, regional differences exist in the quality of care (Anjos & Boing, 2016; Guimarães et al., 2015; Ribeiro et al., 2017). Brazilians from various regions acknowledged to me that São Paulo’s

public hospitals and clinics, while imperfect, are superior to much of the rest of the country, given the city and state's comparative wealth. São Paulo drew Northeastern migrants seeking better medical care, including within Bom Retiro. I heard stories and encountered multiple Nordestino families who spoke of family members who had travelled to São Paul to receive care for more complicated medical conditions. In one case, I accompanied a CHW to register a new patient who had recently moved from the Northeastern state of Alagoas so that he could get on the waiting list in São Paulo for a complex surgery.

Long- and short-term Nordestino migrants residing in Bom Retiro portrayed São Paulo as a stressful place ripe with economic opportunity. The Northeast, by contrast, represented a friendlier, slower pace of life, but with fewer jobs, making it harder to support a family. I observed multiple Nordestino patients presenting in medical consultations with conditions often linked to stress and anxiety, such as gastritis and ulcers. They attributed these issues to their arrival in the city and the stressful nature of life there. Meanwhile, they imagined the Northeast, with its pastoral landscapes and sun-soaked beaches as “a place to rest.” Indeed, Nordestinos with the means returned home periodically as a treatment of sorts. Discussing the case of a 40-year-old doorman while in a team meeting one afternoon, the physicians and CHWs praised his decision to go home to the Northeast “to get some relaxation” in the face of his depression.

Average age differences between South American immigrants (more likely to be of childbearing age) and Korean and European immigrants (typically past childbearing age) was another factor determining which kinds of services each group sought at the clinic. From a lifecourse perspective, one would expect that South American immigrant women in Bom Retiro would require maternal and child health



services. Although Brazilian women also regularly visited the clinic with their children to obtain prenatal, reproductive and pediatric care, providers and other patients often commented on the large number of babies Bolivian women seemed to have. This imaginary, which sews together stereotypes of hypersexuality, high fertility, and large impoverished families sapping governmental resources, has been applied by the dominant caste to various groups across time and space (Collins, 2002; Lesser, 1999; Lopes & Silva, 2019).

One morning as we were finishing up a visit with a pregnant Bolivian woman, an older white Brazilian woman approached me and a CHW named Susan (self identification: Brown/white) in the hallway of the building. She looked accusingly at Susan. “You never come see me anymore! Apparently, you have to be Bolivian to get a visit.” Susan protested this assertion. The Brazilian patient continued, “Every time I come to the clinic, that’s all I see, Bolivian women with big bellies, one after another. She then turned to her Bolivian neighbor for confirmation, asking “Isn’t it true?” Both overt and subtly racist remarks are common in everyday conversation in Brazil, as societal taboos on expressing racist beliefs and attitudes are less widespread than in the United States.

South American immigrants working in the *oficinas* occasionally denied entry to CHWs who had arrived to see patients there. Such refusal of entry could be a directive from management, so as not to disrupt production, or it could be a personal choice (for a multitude of reasons) on the part of workers. By drawing a physical boundary between themselves and agents of the State, South American immigrants may have been protecting themselves from a risky intrusion in an uncertain environment. Yet for the CHWs, such an act was an affront, as it stymied not only healthcare delivery, but also the expectation of *convivência*, a Portuguese word for

“living together” that underscores the importance of social relationships with one’s friends and neighbors. Furthermore, CHWs could not simply ignore a closed door; their duties require them to check for updated vaccines and cases of tuberculosis, among other public health surveillance activities. CHWs maintained that denial of entry was especially common among Bolivians, whom they characterized as “closed” (*fechado*) and “cold” (*frio*). CHWs thus developed theories about the behavior of Bolivian immigrants, testing these theories among each other and with Brazilian neighborhood residents. Refusal of entry marked Bolivians in the eyes of CHWs as distinct from all other patients in the neighborhood, as did their mixing of living and working spaces (i.e., the *oficinas*).

Although Paraguayans also commonly lived in the *oficinas*, Bolivians received the brunt of complaint. An exception to this was CHW Liz (self-identification: white), who early in her interview described how a fellow CHW, who was from Bolivia, helped her gain access to Bolivian families in her micro-area by accompanying her on home visits and introducing her to the families. Later in the interview, she asserted that the Paraguayans gave her trouble by keeping her on their doorstep, adding that “Bolivians aren’t really like that.” Interestingly, CHWs also mentioned being refused entry by Korean patients, yet seemed much less affronted by it. Koreans usually communicated their desire to be left alone through the building’s doorman, who relayed it to CHWs waiting in the lobby. I place these differing reactions in the context of class, in which middle and upper-class immigrants enjoy the latitude to decline a visit without great social penalty, whereas lower-class immigrants ought not to refuse free services from the State.

Rather than accounting for the structural barriers to optimal utilization of services (e.g., 18-hour work days), BRPHC providers and CHWs were more apt to

attribute Bolivian health behaviors to their “culture.” As CHW Maria (self-identification: Black) stated, “As a counterpart [to Brazilians], we have the Bolivian community who have another culture. In their country, vaccination programs don’t exist, and services have to be paid for. So we always have to question them.” In fact, Bolivia’s vaccination rates have greatly increased since President Evo Morales began the implementation of a nationwide healthcare system built with democratic participation (Bernstein, 2017). Later in the interview, I asked Maria if she had ever been mistreated by a patient. She responded, “Bolivians. Bolivians. When you go to talk to them about vaccines. Because in their culture, there isn’t this idea of vaccines. They don’t like to let you into the home, they make you wait outside, so it’s that whole thing.” In another interview, the CHW Débora (self-identification: white) explained to me that Bolivians do not have a culture of health. “They don’t care about health. It is simply not important to them.” While on our way to a home visit one morning with several medical students, the family’s CHW assured us that we would be allowed in because unlike most Bolivians, this Bolivian family was already “very Brazilianized” (*bem brasileira*). Bolivians that I interviewed, both patients and providers, punctuated their overall positive remarks about Brazil’s healthcare system with specific criticism of the prejudice of some Brazilian providers. Several also proudly explained to me that Bolivia was in the process of implementing a healthcare system similar to SUS.

Providers suggested that Koreans were especially eager to get vaccines. One reason for this may have been that for many Korean patients, vaccination was the only service that they utilized at the clinic, obtaining all other medical care through the private system. Many vaccinations in Brazil are only (or most easily) available through SUS, meaning that patients who do not otherwise seek care at the clinic show

up during vaccination campaigns. About three months into my fieldwork, a new doctor was contracted at the clinic. In the course of Dr. Antonio's first day, the members of the Blue team briefed him on what to expect from the patient population. The nurse, Vitória (self-identification: white) asked him if he spoke Spanish. When he shook his head no, she said:

Yeah, because many of our patients are immigrants, mainly Bolivians and Koreans. What is it now, 40%? And the Koreans adore getting vaccines, so if you're not careful, they'll get the vaccine more than once...And no one speaks Korean – and Blue has a lot of Koreans, so it's better if there's someone there with the patient [i.e., a family member to translate].

The nurse elaborated by discussing how Bom Retiro has a whole spectrum of people, from those in a very vulnerable situation to those with plenty. “And you have that kind of poverty, that isn't just financial, it's cultural. That's ignorance.” These racialization processes – whose interactional dynamics will describe in the following section – are engendered in a kind of “common sense” (Geertz, 1975) about the neighborhood displayed by the nurse quoted above.

Koreans also had a reputation among providers for giving gifts and money as a symbol of gratitude for good care. I accompanied Dr. Caetano and the CHW Maria Eduarda (self-identification: Brown/white) on a home visit one morning to an elderly Korean couple, living in a spacious, finely decorated apartment. I later interviewed the husband, Daniel (self-identification: Korean), and learned that while they had lived elsewhere in Brazil for decades, his adult children encouraged his wife and him to move to Bom Retiro much later, so that they could be in community with other Koreans. On the day of the home visit with Dr. Caetano and Maria Eduarda, Daniel did all of the talking, as his wife spoke little Portuguese. After nearly an hour, we

made to take our leave. Daniel rose from the couch and handed Dr. Caetano an envelope. Once on the street, we discovered that the envelope contained \$300 Reais, money enough to get food catered for the ten-person team meeting three weeks in a row.

Providers and CHWs always expressed admiration and appreciation for gifts like these, making starker the differences between patients who could and could not offer them. CHWs' and providers' descriptions of neighborhood ethnoracial groups was often more pointed in the case of those perceived to be lower class or lower in the racial hierarchy (e.g., Bolivians). In addition, CHWs asserted that some groups were in greater need of being held to account for their health behaviors and life choices. Individuals might reserve judgment or be more forgiving of perceived "cultural differences" when the immigrant in question held higher social status.

### ***Racialization through the Lens of Class and Gender***

One afternoon, during a discussion by a team nurse about new openings in the schedule for patient pap smears, Maria Eduarda (Brown/white) blurted out that she had heard that Bolivians who come in for pap smears smell bad, that specifically their vaginas have a terrible smell. A fellow CHW immediately denied any truth in this, arguing that it "completely depends on the individual." The nurse also quickly responded, saying, "No, no, people are all different." This moment, however, laid bare the process by which racialization occurs, as beliefs about and experiences with a non-dominant group are mapped onto the body. It also underscores how racialization is not only projected onto another group, but also emerges from self-judgements about one's own position within social hierarchies. In the following section, I explore how

CHWs racialization of immigrant bodies can be understood through the notion of gendered preoccupations.

CHWs' everyday talk about Bolivian immigrants revealed their own moral judgments and class anxieties as Brazilian women, rather than any essential truth about their patients. Of 30 CHWs at the BRPHC, 27 identify as women. Most of them employ working class strategies to get by and provide for their families, including working informally on the side, living with multiple generations of family to pool income, and trading tips about ways to cut the costs of daily living. Their salaries are slightly higher than minimum wage while still significantly less than the average wage (Take Profit, 2020) and yet many profess feeling lucky to have employment in Brazil's sluggish economy. CHWs' class status, as much as their own racial identity, informed their views on the desirable traits of femininity.

As I spent more time in conversation with the CHWs, the outline of what it meant to be a good woman became more evident to me. At a basic level, based on CHWs prescriptions and judgments, a good woman was both a loving mother and not openly promiscuous. Beauty, and its trappings (e.g., nice clothes, maintenance of one's beauty regime) was certainly desirable in women, and commented upon at length, yet was also understood to be unattainable without money. Just as my participants imposed these standards on each other, so did they impose them on patients, both Brazilian and otherwise. Not surprisingly then, their commentaries on Bolivian patients were most often directed at women, and were fundamentally a way of policing gender.

Beyond the example above of one CHW suspecting that Bolivian women's bodies smell differently, CHWs occasionally chatted about "how Bolivians look."

Multiple people at the clinic described knowing that a patient was Bolivian by their indigenous appearance, in which they included their brown skin, straight black hair, tendency to be shorter and stouter, and their indigenous facial features. Another marker that Brazilians pointed out to me was Bolivians' poor dental health – many had rotting teeth. At times this poor dental health was attributed to the poor living conditions in Bolivia, but at other times, it was again relegated to the realm of Bolivians not having “a culture of health.” On several occasions, Bolivian women's bodies became the object of scrutiny in conversation. In a team meeting one day, CHW Júlia (white) explained that she simply did not find Bolivian women beautiful. To bolster her argument, she mentioned two co-workers on another team, both of whom were Bolivian women. According to Júlia, everyone could agree that the first woman was categorically ugly, whereas the second woman was thought by some to be beautiful, yet she was not by Júlia's standards. Others mumbled their own opinions, agreeing and dissenting. Neither of the two Bolivian women were present, but another team member at the meeting had a Bolivian girlfriend. Júlia was careful to reassure him that his girlfriend was the exception to her rule.

Occasionally, providers and CHWs discussed a case in which a Bolivian patient was being treated for drug addiction. Everyone assured me of the rarity of addiction among Bolivians, giving their “closed” and quiet nature. In another example how racial categories are relationally intertwined, Bolivians were often portrayed as virtuous in terms of sex and drugs, especially as compared to Paraguayans. Multiple CHWs noted in their interviews that they had felt in danger when alone in the presence of Paraguayan men. As CHW Odete (Brown/white) recounted:

There are places where I will not go unless I am accompanied by someone else. I go into the *ocupação* alone, but there are houses that, with men, I do

not go into alone. Paraguayans, for example. Paraguayans are people who...I don't know how to say this...they don't show what they really want...I went to visit a family of Paraguayans and I did not feel comfortable, you know? So I didn't go in. The moment he opened the door, the way the man looked at me and all, I did not go in...the way he looked at me, it's how men look at women. Understand? So that scares me.

Another woman emphasized how when she was first hired, fellow CHWs warned her of the danger of entering a residence if only Paraguayan men were present. CHWs also maintained that Paraguayans were more likely than other immigrants to have sexually transmitted infections. CHW Maria Eduarda (Brown/white) explained how Paraguayans frequently changed sexual partners. "You go on visits, and they have a new partner and you think, "but wasn't that your friend's husband?" There are a lot of them that live on my street." By comparison, when a new case of HIV was diagnosed in a Bolivian patient, people expressed surprise and the staff psychologist commented that "Bolivians don't usually have those kinds of problems." These conversations provide evidence of the relational nature of racialization. In other words, Bolivians are not only being characterized as a group unto themselves, or one that is different from Brazilians; rather, they are understood in relation to other immigrant groups as well.

While acknowledging the ways in which Brazilian CHWs racialized their Bolivian patients, I want to emphasize their occasional expressions of empathy. Multiple health issues are present among Bolivian residents in Bom Retiro, including tuberculosis and chronic pain due to the repetitive movements involved in sewing full time. Yet CHWs most often spoke about frequent intimate partner violence against Bolivian women, and their relative lack of reproductive choices in a male-dominated



culture. When CHW Odete (Brown/white) spoke about Bolivians generally, she noted that she got her information from one of the Bolivian CHWs.

She said that the men don't let women converse. There are places where you go and you speak to the woman and she doesn't respond. It's the man who responds. You are speaking to her but it's him who responds, she just nods. It's their culture. She said it's changed a lot, but it still continues. The women are submissive, they're afraid of the men, they get hit. There are a lot of cases of violence, with the Bolivians, you know?

Bolivian men were known to be much less likely to seek care at the clinic. "The women come in because of their children," one CHW explained to me. Brazilian women empathized with Bolivian women when they could see themselves reflected in patients' predicaments. As they recounted in their own interviews, many CHWs themselves had experienced intimate partner violence and the struggle of caring for multiple children with little emotional or financial support from male partners.

Júlia, who earlier had declared the lack of Bolivian women that she found beautiful, took me along on a home visit one morning to register a Bolivian woman as a new patient. We stopped at the gate and rang the bell. A man standing in front of the convenience store next door asked us who we were looking for and we told him the name. "That's my apartment. I'll call there for you, because the intercom buzzer doesn't work." He dialed on his phone and then assured us that his wife was coming down. The gate to the open-air corridor was locked with a padlock and chains, which the woman unlocked once she had descended. Júlia asked her, "And your husband, doesn't he want to get registered too?" She laughed softly and shook her head. Júlia rolled her eyes. "Men never want to, do they?" The woman shook her head again. Júlia asked the woman if she had any children. She paused for a few seconds, staring at the ground, then mumbled, "I had a baby, but he died." Seven years ago, she gave

birth at a nearby hospital. The baby was born perfectly healthy, but died eleven hours later, having “*engouliu a sujeira*”, or “swallowed the dirtiness.” We three mothers all stood in silence for a few moments, absorbing this weight. On our walk back to the clinic, Júlia told me in her stern and direct way that “there’s a lot of prejudice against the Bolivians, Paraguayans and Peruvians at the hospitals. And imagine seven years ago, it would have been even worse.” She had given birth at the very same hospital as the patient. As she recounted to me her own traumatic birth story, she noted that she heard the nurses on the other side of the curtain screaming at a Bolivian woman in labor, “Push!!! You’ve already had five kids, you can do better than that!” Júlia lamented her own poor treatment by the hospital staff and shakes her head: “this was *me*, with my health worker ID, and I was still treated that way. So imagine her, that Bolivian woman.”

## **Conclusions**

I conclude by emphasizing that racialized geographies are borne of the currents of global capitalism, fueling demand for the kind of cheap labor that has long sustained Bom Retiro’s textile industry. Brazil’s racial hierarchy, bolstered by its structures, institutions, and cultural ideologies, shapes the everyday stereotypes that are then layered upon occupational and residential configurations. The racialized geographies present in Bom Retiro are unstable and thus subject to change, consistent with Omi and Winant’s racial formation theory (1986), yet they also make use of recycled racial scripts. (Molina, 2014). As such, we find the same stereotypes and fears (e.g., equating immigrants with poor hygiene) applied to different immigrant groups a century apart. We might thus interpret racialization as a means of shifting blame for institutional failures from society to individuals.

Beyond the immediate repercussions for patient care that I describe above, immigrants likely experience greater stress in an environment in which they are daily subject to racialization by the majority group (e.g., Brazilians). Researchers in the United States have established how such daily racialized stress affects long-term health outcomes (Geronimus, Hicken, Keene, and Bound, 2006). The results of this study encourage us as scholars and public health practitioners to rethink how we provide care across difference. At one level, healthcare systems can be strengthened by cultural humility training of professionals and the hiring of more professionals that do “match” the population (e.g., Bolivian, Paraguayan, or Korean CHWs). Yet ultimately, we must continue working towards dismantling structural inequalities. While seemingly in line with efforts to make medicine more holistic, some have argued that the use of CHWs to gain access to particular populations is a form of neoliberal governance in which the emotional labor of poor women is commodified and the private space of the home is made legible to the State (Georges, 2018, georges and santos, 2014. After all, what does it mean that CHWs in São Paulo are urged by the State to enter and observe the homes of the poor, while elites are rarely subject to such scrutiny?

Finally, my findings raise important questions about public health decision-making in community settings. While possessing its own biases, local epidemiological and community-based data has the potential to dispel some of the everyday stereotypes encountered in Bom Retiro. Currently, the design of the clinic’s everyday activities is in response to data that do not capture the needs of this particular neighborhood. Those whom public health experts typically turn to for local knowledge – community providers and public health practitioners – do not always adequately represent the surrounding population. At the root of this issue is not

difference, but entrenched racism, wrapped up with national identity. Much like the United States, Brazil's most pressing social problems, structural and everyday racism among them, will not be solved without a historical reckoning.

## **Chapter 3: Seeing Inside: How Stigma and Recognition Shape Community Health Worker Home Visits in São Paulo, Brazil**

### **Introduction**

*I met the community health worker Maria outside of the Tiradentes metro station, on the edge of the neighborhood of Bom Retiro in central São Paulo. She was hurrying to catch up with me, having been detained at the clinic by an impromptu meeting with the head nurse. Once Maria arrived, we crossed the boulevard, veered off on a side street and entered the warren of one- and two-story residences that comprised this part of the neighborhood. These quiet, narrow streets constituted Maria's micro-area, a geographically defined space determined by São Paulo's municipal health secretariat, each with approximately 500 registered patients. That day, we would visit more than a dozen homes, checking in on patients and following up about referrals.*

The Bom Retiro Public Health Clinic (BRPHC), where I spent fifteen months conducting ethnographic fieldwork in 2018-2019, assigns each community health worker (CHW) to a micro-area. The Family Health Strategy (FHS), an initiative implemented within Brazil's public healthcare system (known as SUS) in 1994, requires CHWs to visit each registered address in their micro-area a minimum of once a month. The BRPHC employs 30 CHWs to attend to patients residing in the area that pertains to the clinic. Individuals must only register at the clinic if they wish to receive care through SUS. Those who access the private system (for which they may have insurance or pay out-of-pocket) do not receive visits from CHWs.

Since at least the 1978 Alma Ata Declaration, public health scholars from around the world have affirmed the fundamental role of primary care in global health efforts, including CHWs in the workforce (Lawn et al. 2008). Home visits are central to the everyday work routine of CHWs in São Paulo as they respond to the health and well-being of neighborhood residents. Yet CHWs receive no orientation and little training prior to conducting home visits. Rather, they are hired based on their residence in the neighborhood and a determination of their suitability for the job based on a psychodynamic test, in which they are asked how they might respond to a variety of scenarios.

Clinic administrators assign new CHWs to a micro-area and arrange for a fellow CHW to accompany them on home visits for several days, to answer any questions and give guidance. After approximately a week, new CHWs conduct home visits on their own. The assumption underlying the CHWs' position is that life experiences and familiarity with the neighborhood comprise all the knowledge needed to do the job. It also reflects a gendered division of labor, in that working class women's "expertise" is their social connections to others, for which they are paid little.

CHWs comprise an important part of the global healthcare workforce, yet their roles, responsibilities, compensation, and level of professionalization vary widely by country (Kane et al. 2016). In São Paulo, CHWs became widespread in the early 2000s as Brazil's government invested more in the Family Health Strategy (Andrade et al. 2018). Despite working for the public healthcare system, CHWs are not public employees. Rather, HMO-style organizations contract them to serve in their neighborhood, meaning that pay and responsibilities may not be consistent from one primary clinic to the next. A union for CHWs exists both for the São Paulo

metropolitan region, as well as at the state level, yet I never heard mention of it from any of the CHWs in Bom Retiro.

Wearing blue vests so that they are recognizable as they traverse the neighborhood, CHWs learn to handle paperwork and other technical aspects of the job as they go. When I began fieldwork in August 2018, the clinic had just begun rolling out the use of tablets to collect patient information. Few of the CHWs trusted the tablets, however; for the duration of my time there, most continued to rely primarily on paper forms for keeping patient records. Each CHW belongs to a team, comprised of a nurse, a physician, two nurse techs, and five other CHWs. Besides their weekly team meetings, CHWs spend much of an average day visiting patients in their homes. Using the lens of home visits, I investigate how CHWs navigate interactions with patients, particularly those who do not share their ethnoracial or class status.

### ***Home Visits in Bom Retiro***

*Arriving on the threshold for a home visit, CHWs rang the bell, clapped, or yelled the patient's name while standing beneath a window. "Hey! Dona Antonia! It's Maria from the health post!" (The prefix "Dona" is a form of polite address akin to "Mrs." that is typically applied to middle-aged or older women). Homes in Maria's section of the neighborhood are nestled right up against the sidewalk - concrete meeting concrete in perpendicular fashion. The house may contain a single dwelling or two, painted and tiled. Alternatively, one might see an open-air corridor with multiple rooms separated by crumbling bricks, doorframes and windows wearing billowing bedsheets. Until one crosses the threshold of the pastel painted façade, the internal structure remains a mystery.*

*On my outing with Maria (an Afro-Brazilian woman who grew up in the neighborhood), our first stop brought us to a thick iron gate. Beyond it, a brown-skinned Bolivian woman named Ana approached. She appeared to be in her early twenties, and had shiny, straight black hair. She opened the gate and led us up to a room on the second floor. Inside, there were three sewing stations. Swatches of fabric littered the floor. A man and woman, also Bolivian and in their twenties, were each seated at a sewing station. “You disappeared,” Ana teased Maria in Portuguese. “Well, I can only visit once a month, or the boss will have my head.” Maria smiled and rolled her eyes. Ana’s role as the sole Portuguese speaker in the household meant that she was responsible for translating and responding to Maria’s questions. As we chatted, the man and the woman continued sewing. Maria then asked the seated woman – Larissa – how her pregnancy was going, and I followed up, congratulating her and asking how many weeks had passed. She giggled and turned to Ana, who then said to us, “she doesn’t understand.” Ana and Larissa continued to converse in Spanish, and then Larissa indicated in Portugol (a mix of Spanish and Portuguese) that she was unsure when the baby would be born. “Maybe in three months.” Maria then turned to the man and asked if he was registered as a patient at the post. “For what?” he responded, staring straight ahead at the sewing machine. “At the health clinic,” Maria tried to clarify. “I don’t have a health plan,” he responded through Ana. Larissa and Ana both began talking at him, assuring him that services at the post were free and that it was located in the neighborhood. He smiled: “No, I’m good for now.”*

Past health science research, including in medical sociology, has devoted much space to patient-physician interactions (Heritage and Maynard 2006). Patients, however, engage with other healthcare providers and professionals in addition to



physicians, from clinic receptionists to nurse practitioners. Given these realities, conceptualization of the medical encounter must include interactions such as that of the home visit between patient and CHW. The home visit is the obvious “community” parallel to the clinical encounter in the consultation room.

While in the United States we might envision home visits as akin to the house calls once made by doctors (Kao et al. 2009), in Brazil home visits originated with nurses. In the early 20<sup>th</sup> century, Brazilian physicians were most often men from elite families; they viewed home visits as unscientific and below their social position (Santos and Kirschbaum 2008). Anthropologist Roberto Da Matta famously proposed that Brazilian society can be understood as firmly divided between the domains of the house and the street (Matta 1997). Traditionally, the home was conceived of as the private, feminine domain, where family takes precedence; the street was the public domain of men and their institutions: governmental, religious, and commercial. Given this framework, it is hardly surprising that male physicians considered home visits the province of their female colleagues. Until today, care work in São Paulo, of the kind that CHWs perform within the public health system, remains overwhelmingly the task of underpaid women (Araujo Guimarães and Hirata 2021; Georges and Santos 2014).

### ***Recognition and Stigmatization***

*As we approached a second home, I heard someone release the bolt on a window shutter. A woman peeked her head out; she was 42 years old, white-skinned with long, wavy brown hair. She recognized Maria and pointed to the iron gate. Backing away from the window, she reappeared two seconds later at the entrance and unlocked the rectangular gate lock. A toddler guided a scooter down the corridor. The home was a single room, about 10 by 10 feet. A double bed hunched up in the*

corner hosted a 7-year-old boy, splayed out and watching a flat screen TV mounted on the wall above him. Chewing on a piece of bread, he turned around to stare at us. In the opposite corner of the room was stationed a sink, a tiny stove, and a table.

Maria asked the woman, Nelina, if her nausea had abated. "Girl, the things women go through for this," Nelina responded, motioning to her slightly round belly. In a month, she planned to return to Pernambuco, a state in the Northeast of Brazil. There, her mother could look after the two boys, as well as the new baby. "If it doesn't work out, we'll come back to São Paulo." She sighed, then added, "I'm hoping to have a cesarean because I want to have the operation already. I'm forty-two after all. I'm done." "The operation" is a tubal ligation, which Nelina wished to have done within minutes of her delivery. In Brazil, tubal ligation cannot be performed legally until at least 42 days after delivery, except in cases deemed high-risk (Berquó and Cavenaghi 2003). Nevertheless, both doctors and patients told me that the procedure was still regularly performed soon after birth if the mother requested it, and in some cases, even when she did not. Maria expressed her excitement for Nelina's pregnancy and wishes that all would go smoothly with the travel and birth.

Lamont, Beljean, and Clair (2014) contend that social scientists have neglected the role of cultural processes in the production of inequalities. They identify multiple cultural processes, including recognition and stigmatization, with demonstrable effects on societal inequalities (Lamont, Beljean, and Clair 2014). In this paper, I focus on recognition and stigma as cultural processes guiding CHWs interactions with patients. Recognition underscores how CHWs acknowledge and affirm patients' dignity. In *recognizing* the patient - and by implication his or her medical complaints - as having worth and credibility, the CHW extends an

institutional embrace that allows for better health outcomes. Some patients, however, incur stigmatization from CHWs on the basis of assumed or known social identities (e.g., being gay) or health statuses (e.g., being HIV-positive). Braveman (2006) has defined health equity as working towards the elimination of health disparities, which in turn describes social conditions (e.g., racism, poverty) that systematically advantage the health outcomes of groups with greater wealth, power, or prestige. Whereas recognition bolsters equitable health outcomes, stigmatization disadvantages marginalized patients erodes the quality of care (Aggleton, Parker, and Maluwa n.d.; Link and Phelan 2006).

### ***Cultural Schemas of “the Other”***

*Nelina’s next-door neighborhood Bete was waiting behind her gate as we left. “My granddaughter has something,” she declared to us. Bete had brown skin and wavy black hair pulled back into a tight ponytail. She looked to me to be about forty-five years old. She opened the gate for us then turned and retreated back into the house. I started to follow her, but Maria touched my arm and warned me, “She usually doesn’t like anyone to come in.” Bete reappeared, however, and motioned for us to enter. Maria raised her eyebrows in surprise. Inside, two little girls sat on the wood floor playing with a white kitten. The younger girl, about two, whined and extended her arms to be picked up. “I think she has a fever,” Bete remarked to Maria. The little girl had red blotches covering her forehead. “I don’t usually do this, but I’ll make an appointment for you,” Maria said, planning to do so when she returned to the clinic. The BRPHC requires patients to make appointments in person at the clinic, allegedly in order to encourage patients to be engaged in their own care. In practice,*

*this meant that patients who lived further away might forego routine care. CHWs sometimes made exceptions for patients, usually as a favor to them.*

Looking around, I noticed fabric piles stacked against living room walls, indicating that Bete used her home as an *oficina*, a space in which to sew wholesale textiles. This *oficina* was the only one that I encountered during fieldwork that was operated by a Brazilian resident. Bom Retiro has been central to São Paulo's textile production for well over a century, yet until today, most *oficinas* are owned and staffed by immigrants. For this reason, CHWs frequently interacted with immigrants representing a multitude of countries and languages. Today, the predominant immigrant groups in Bom Retiro are South American immigrants (the majority from Bolivia, but also Peru, Paraguay, and Ecuador) and Korean immigrants. The histories of immigration and local textile manufacturing inflects each of these groups with class status as well.

Koreans mostly began arriving in the 1970s, staffing *oficinas* owned by both Catholic and Jewish European immigrants. These latter immigrants emigrated to Brazil mostly prior to World War II. As they gained socioeconomic stability and enjoyed global economic shifts of the 1990s, they increasingly bought up the *oficinas* (Chi 2016), later employing South American immigrants to sew. Having access to more capital, Koreans also tend to live in the more spacious, updated apartments of Bom Retiro, frequenting the many Korean grocery stores, churches, and restaurants dotting the east end of the neighborhood. Whereas many Korean residents spoke limited Portuguese, the clinic staff perceived them as affluent, a bit aloof, and less in need of specialized attention, given their access to private medical services. The idea of hiring a Korean-speaking CHW never arose in my presence.

Bolivians and other South American immigrants began laboring in the *oficinas* as early as the 1990s. While more often encountering Bolivian patients who had emigrated Brazil within the last few months or years, I did visit *oficinas* owned by Bolivian families for more than a decade. Bom Retiro's ongoing influx of South Americans, many of whom originate from conditions of poverty in their home countries, creates a need for specialized services catering to this population. Furthermore, the housing conditions into which many South Americans arrive are abysmal, comprised as they are of cramped, poorly ventilated quarters adjacent to sewing rooms for working long hours.

Home visits provide CHWs with a window onto the conditions of both Koreans and other South Americans, as well as the middle-class and poor Brazilians that reside in Bom Retiro. Living spaces are rife with class markers, from size to decoration (or lack thereof). Furthermore, residents of São Paulo, bolstered by state-sponsored messages about the importance of hygiene, have a long history of citing unsanitary housing conditions as evidence of the disease-ridden nature of the immigrant. Historian André Mota evokes this history through the public speeches and newspaper editorials of government officials of a century ago. Their urgent pleas to clean up the living conditions of immigrants in the city are simultaneously laced with disgust (Mota 2020). Furthermore, as I demonstrate below, their descriptions echo the very same language used by CHWs to describe the *oficinas*. In the early 20<sup>th</sup> century in São Paulo, neighborhoods including Bom Retiro suffered from a lack of affordable housing (Ball 2020). Government officials used "hygiene" as a motivating force to push undesirables, such as immigrants and Afro-Brazilians, to the city's periphery, although many individuals from these groups also remained. These histories, and the powerful cultural imaginary linking immigrants and disease, reverberate until today.

In my interviews with CHWs from the BRPHC, the majority of them described their relationships with older adult patients in glowing terms. Typically, these “favorite” patients truly benefitted from the frequent social connection that CHWs were able to provide during home visits. The “most difficult” cases, on the other hand, were often those patients whose needs they could likely never meet – those working 18-hour days in the *oficinas* or those in precarious living conditions. CHWs articulated a feeling of helplessness with such cases, which sometimes spilled over into resentment. In everyday talk with fellow health professionals, CHWs might blame patients for their own health issues, while at other times invoking social explanations, such as poverty. In the analysis that follows, I explore how home visits provide the scene for these judgments. What purpose do home visits serve and how do they contribute to and detract from efforts to achieve health equity?

## **Methods**

The analysis presented below forms part of a larger ethnographic fieldwork project I conducted in the Bom Retiro neighborhood of central São Paulo from August 2018 to November 2019. Through this work, I investigated how inequalities are reproduced in the midst of efforts to achieve health equity. In this particular analysis, I ask how home visits shape the provision of primary care to neighborhood residents, given that such visits are central to CHWs daily routine. To answer this question, I analyzed over 500 hours of participant observation, including more than 100 home visits. In addition, I interviewed 34 healthcare providers and clinic staff, including 22 CHWs, from the BRPHC.

### ***Participant Observation***

In early fieldwork, home visits constituted an ideal opportunity to spend one-on-one time with the CHWs, to meet a variety of patients, and to familiarize myself with the neighborhood. Accompanying CHWs on home visits typically meant that we would leave the clinic together and walk across the neighborhood to the CHWs micro-area, where (s)he would visit patients. CHWs planned some of these visits in advance, based on follow-ups that physicians had requested, or CHWs own schedule to meet their monthly quota of one visit per family. On any given day, each CHW had the autonomy to organize their visits however they saw fit. Other visits were impromptu. Often, CHWs encountered patients on the street while walking around their micro-area; they would then follow the patient into their home to talk further as needed.

I encountered difficulties when I attempted to establish appointments in advance (e.g., via WhatsApp) to accompany a particular CHW. Their schedules were subject to last-minute changes that made this approach unreliable. I quickly learned that the best way to tag along on home visits was to arrive at the clinic between 8 and 9am and sit out front. All CHWs had to clock in at either 8 or 9am, and unless they had another obligation (e.g., a vaccination campaign), they would emerge from the clinic after some coffee and chit-chat with co-workers. As they walked out of the clinic in their distinctive blue vests, I jumped up and simply asked if I might join them on their rounds. This strategy also allowed me to vary with whom and where I went in the neighborhood, which was important for establishing rapport with members of all five Family Health teams. Some CHWs erroneously thought that I only worked with the Orange Team, as the Orange Team's physician was one of my key informants in the field and primary point of entrée to the clinic. In the first few months, I therefore intentionally sought out CHWs from other teams in addition to the Orange Team.

If it were my first outing with a particular CHW, I would use our walk to ask them about their background and to tell them about my project, thus contextualizing my presence at the clinic. On subsequent outings, I followed up about specific patients we had visited together in the past, and sought answers to the myriad of questions I had about their daily routines and the organization of the clinic. CHWs frequently offered a bit of the medical and personal history of the patients we intended to see.

Once on the threshold of a patient's residence, I introduced myself and briefly explained my project. I then asked for verbal consent to remain present during the visit. Patients' reactions to my presence ranged from complete indifference to a barrage of questions. In the latter case, I engaged patients while also trying to brief, such that I would not overly intrude upon CHWs' time and space. In later months, I began visiting patients on my own to conduct informal visits as well as semi-structured interviews. While CHWs spoke with patients, I often jotted down notes, which I then converted into formalized fieldnotes at the end of each day (Emerson, Fretz, and Shaw 2011). These notes focused on the interaction between the CHW and household members, alongside observations of the home environment.

### ***In-Depth Interviews***

After several months of observing home visits, I used my fieldnotes and memos to develop an in-depth, semi-structured interview guide for CHWs. Any CHW working at the BRPHC was eligible to participate. As I was present at the clinic daily, I was able to talk with CHWs about my plans to conduct interviews and answer any questions about participation beforehand. When a CHW expressed interest, we agreed



on a date and time. For CHWs convenience, the interview sites were within walking distance of the clinic.

I conducted interviews in two designated locations in the area: the Oswald de Andrade Cultural Center and the São Paulo Museum of Energy. The Oswald de Andrade Cultural Center is located in an historic building in Bom Retiro that once housed the University of São Paulo's School of Medicine. It offers open spaces for community use, that while less than perfect because of background noise, proved to be the preferred location for interviews with CHWs, given its proximity to the clinic. I am indebted to the staff at the Museum of Energy, who very kindly allowed me to use their private rooms to conduct interviews. Quiet, closed-door space for free, public use is not easily found in São Paulo, in contrast to widespread access to public libraries and other free community spaces in major U.S. cities.

CHWs typically chose to meet me during working hours; their supervisors were aware and approved of their participation. At the same time, I reassured CHWs prior to the interview that our conversation would remain confidential, and would not be shared with anyone at the clinic or in the neighborhood. Two interviewees mentioned that when I first arrived, they believed that I might be working for the clinic director, but that my long-term presence (without any corresponding changes to their work) dispelled this idea.

Interviews lasted for 1-3 hours; I conducted all interviews in Brazilian Portuguese. Each interview was audio-recorded and then uploaded to Emory University's firewalled server. I obtained written consent prior to beginning the discussion. In-depth interview topics included how CHWs had come to work at the BRPHC, what they identified as the primary health issues in the neighborhood and

why, how they defined their professional role as a CHW, descriptions of their micro-areas and patients, what they enjoyed about their work, and what they would improve about the clinic if given the option. The interviews also proved a particularly useful space for me to dig deeper into questions stemming from my field observations. When I witnessed behaviors and interactions that piqued my ethnographic curiosity, or which I did not know how to interpret, I sought clarification and reflection from CHWs, enriching the data through the iterative cycle (Hennink 2020).

At the beginning of each interview, I asked participants a series of close-ended questions (length of time at the clinic, age, race/color, gender) and asked them to choose a pseudonym. Twenty-two CHWs (out of 30) participated in the interview process. All but 3 identified as women. Four participants identified as Black, five as Brown (*Pardo/a*), six as white, two as indigenous, one as Amarela (“yellow,” the Brazilian racial category typically chosen by those who identify as being of Asian descent), and one as “Brazilian.” Three participants stated that they were uncertain about which racial category they identified as, explaining that how they labelled themselves and how others labelled them did not always match<sup>1</sup>.

### ***Data Analysis***

Given recent debates in sociology on the utility of different ethnographic tools (Jerolmack and Khan 2014; Rinaldo and Guhin 2019), I found that examination of an interactive event such as the home visit benefitted from both observation and the solicitation of views made possible by in-depth interviews. For this analysis, I triangulated multiple sources of data focusing on home visits (fieldnotes, memos, and

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<sup>1</sup> For recent scholarship on Brazilian racialization, see (Da Costa 2016; Loveman, Muniz, and Bailey 2012; Mitchell 2017; Paschel 2016).

interview transcripts). Examining different sources of data against one another (what people *do* compared to what people *say*) allowed me to note the discrepancies that point to pieces of the structures and cultures undergirding and infusing human interaction (Becker 1998). I noted early on that some patients seemed to truly enjoy their visits with CHWs, whereas others were much more reserved. CHWs, in turn, spoke in contrasting ways about different kinds of patients. This observation formed the seed for this analysis. Consistent with abductive analysis (Tavory and Timmermans 2014), I continually held my findings up to the theoretical frameworks gained in my sociological and public health training. As I visited and revisited the data, fresh from following theoretical leads, I then systematically began coding notes and transcripts. This coding scheme then formed the basis for the results of this paper below.

## **Results**

### ***Home Visits and the Roles of Community Health Workers***

Home visits are an integral part of primary care provision and public health prevention in the neighborhood of Bom Retiro. While nearly all CHWs live in the neighborhood, most serve in a micro-area that does not include their own residence. They often set out early in the morning to visit their micro-area after checking in first at the clinic. For CHWs whose micro-areas are at the farthest reaches of the clinic's territory, they sometimes must walk 30-40 minutes to reach their destination. The micro-areas could greatly vary from one to the next in terms of the age, occupation, socioeconomic status, and ethnicity of the residents, as well as the type and density of the housing and the presence of commercial space. One micro-area might require checking in with residents of an *oficina*: a textile workshop, sometimes known as a

sweatshop, where anywhere from 3 to 30 people do piecework with fabrics. Bolivian men and women hunched over sewing machines while children played with fabric swatches on the workshop floor were a common sight in the *oficinas*. Visitations to another area might entail enjoying pastries over a dining room table in a meticulously furnished multi-bedroom apartment with a widowed octogenarian. In part, the housing conditions and inhabitants of each micro-area dictated CHWs everyday experiences conducting home visits. CHWs affectionately described to me their micro-areas as deeply familiar terrain. They pointed out which patients gave them trouble, were dismissive or overly chatty, and those whom they visited frequently for the simple enjoyment of their company.

CHWs frequently encountered neighbors, friends, and even family members while canvassing the neighborhood. At times, the conflation of roles – moving from professional relationship to neighborly relationship – spurred discomfort or even irritation for CHWs. They frequently complained about patients who had approached them in the grocery store or the corner bar over the weekend (when the clinic was closed), asking for medical advice or to pass a note to a physician. While communicating with patients through social media was officially discouraged, many CHWs did exchange messages with certain patients over WhatsApp or Facebook Messenger. A quick exchange online could save an hour of walking across the neighborhood. Yet opening up these channels also caused headaches for CHWs, as some patients overwhelmed them with messages on nights and weekends. In these cases, CHWs had to once again carve out professional boundaries; several reported cutting off WhatsApp contact with patients altogether.

Home visits allowed CHWs the opportunity to observe and gather information from patients, in a context where they could more easily enforce the boundaries of a

professional relationship. When CHWs desired it, they could direct the flow of the visit, achieve their goals, and move on to the next home. With some patients, however, CHWs lingered to chitchat or sip coffee. In these instances, CHWs took on the role of confidante, sharing details of their own personal and professional lives. CHWs had control over their connections with patients – with whom, when, and how they allowed their “emotional side” to be present.

Being present in person permitted CHWs to assess patients’ home environments, gathering clues about how patients were managing chronic conditions and noting possible health hazards. Amanda, a veteran CHW with 18 years of experience, explained how she learned what a home visit was when the government first implemented the Family Health Strategy in Bom Retiro.

[They told us] that we were going to enter into patients’ houses, that we were going to have to find out about people’s lives, that we had to create the strongest link that we possibly could because we were there as...as a kind of “detective”, right? So that we could...because we needed to investigate, to the maximum point that we could, about those who were registered, the patients, because they told us that they wanted to investigate why people were getting sick, right? Because illness on the surface is never just illness, it also comes from stress and from the day-to-day. So I learned how to look at life, to look at people’s lives...and where I entered, I would look around – 360 degrees – and so just talking with you, I can notice if your house is dirty, if you are an unbalanced person, if your husband swears at you, or if he’s hitting your children, if you don’t treat your children well, if your food is made with enough water, if your kitchen is clean... We talk with people a lot, so that the person opens up...”

Other CHWs spoke of “conquering” patients, whereby they gained patients’ trust and gleaned information about their health over time. Júlia elaborated on this gradual process.

Drugs, alcohol, domestic violence. Right? With these things, you only discover them with time. You’re never to going to discover them the first visit. The first time, when you do the registration, “Does anyone in the house use drugs?” “Nah.” “Anyone drink?” “No.” “Anyone smoke?” “No.” “Anyone have an illness?” “No.” So, with time, you begin discovering that things aren’t

so simple....Like me, I live on a street over there. On the weekends, I see that same person at the bar. I see that person drunk on the weekend, so. I'm not on the street to see that, but I ended up seeing it because I live in the area, right? So you only end up discovering things with time. It's pretty rare that you do the registration and you ask if they use drugs and they say, "Yes, I do," the first time. That's rare.

Júlia alludes to a crucial aspect of the home visit: because CHWs live in the area, they are witness to intimate details in the lives of individuals who are not only their patients, but also their neighbors. In the sections that follow, I demonstrate how this intimacy benefits some patients, while disadvantaging others in predictable ways.

### ***"Open Arms": Visiting Older Adult Patients***

While some patients required relatively little time during a visit, those with multiple or complicated health issues could take up to an hour. Two types of patients prevalent in the neighborhood – older adults and those with limited fluency in Portuguese – demanded more time and attention from CHWs. Older adults were more likely to present multiple health conditions, along with mobility issues. Furthermore, it was not uncommon for older adults to be living alone and experiencing social isolation or loneliness. According to CHWs, older adults desired their company, a service that CHWs ordinarily felt pleased to provide. Many immigrants, on the other hand, lived and worked in *oficinas*. Visiting *oficinas* posed difficulties for CHWs, as sociolinguistic barriers often prevented smooth communication. CHWs were most likely to identify "favorite" patients as older adults, and "difficult" patients as immigrants, a pattern that I observed on home visits and confirmed with CHWs during our interviews.

In contrast to immigrants living in the *oficinas*, older adults often presented physical health issues that while complex, were understood by both CHWs and patients as a normal part of aging. CHWs listened to and empathized with their older adult patients. As I accompanied CHWs on their home visits, they would typically brief me on whom we were going to see that day. They often described older adult patients in warmly sentimental terms, noting their quirks and above all, their need for care and attention. During our interviews, I asked CHWs to tell me about their favorite patients. CHW Yuri remembered an older man who had died recently. “His way of being, always going after us, always wanting to have a conversation. Always with a “are you having a good day?” Always with a smile. As they say, there are just people who have open arms.” While some CHWs were responsible for visiting both *oficinas* and older adults, a few had areas mostly populated by elderly patients, which they viewed positively. Giovanna fell into this category and I asked her to tell me about her micro-area.

Very peaceful...I don't have any complaints. The older adults just want to know if the doctor is going to come and do a visit. They adore when you go with the nurse or the tech, they love having their blood pressure taken. “Oh, how nice that they've come to take my blood pressure.”

She then went on to describe an 88-year-old patient who was one of her “favorites.”

He is Brazilian. And he is so cute. He likes Dr. Caetano. Every time he says, “Send the doctor a kiss.” And he says the same thing to the girls. Since I started going, ever since I visited him and I was pregnant, you know, every time now he wants to see a photo of [daughter's name]. And he says, “Ah, you have to bring her, I want to meet her.” And I say, “Oh, some Saturday I will.” And he says - he's sharp - “you don't come on Saturdays.” So I really like him and I really like Dona Nilda. You've been to her house, right? She has the dog named Davi. And I think she really likes to talk, because she's very alone, you know? Her son is a priest.

CHWs expressed genuine affection for many of their older adult patients. In return, these patients lavished CHWs with gratitude and praise. Rather than being overwhelmed by insurmountable obstacles beyond their control, CHWs felt needed, useful, and fulfilled by their contacts with elderly patients.

***“It’s complicated”: CHWs Interactions with Immigrant Patients***

While older adults were sometimes themselves immigrants, they were more likely than younger immigrants to speak Portuguese fluently and to have lived in Brazil for many years. In other words, Brazilian CHWs perceived most older adult immigrants to have acculturated to a degree that made for smooth discourse. In one curious case, a CHW invited me to meet an older couple in his micro-area one morning. Sebastião, the CHW, told me on our walk to the home that he had heard that I was interested in meeting immigrant patients for my study and he immediately thought of this couple that we would soon meet. When we arrived, a man that Sebastião had told me was in his late 70s answered the door; a rotund dachshund barked at our feet with suspicion. Old black and white photos lined the wall, alongside a rosary, a crucifix, and several posters adorned with the script of an Asian language. An elderly woman in a nightdress sat wedged into the corner of the couch, a cane propped on a nearby cushion. She showed us a wound on her ankle about the size of a quarter that was emitting pus. She explained that she needed surgery on both of her knees and lamented that she has been on the waiting list for a very long time. Patients receiving care exclusively through SUS can experience wait times of years to get certain high-demand surgeries for which a low supply of specialists working in the public sector exists. CHWs voiced joyous relief when notified that a patient had reached the top of the waitlist for a specialty procedure. They spent much energy



reassuring patients during home visits that they would soon get their turn, while privately expressing frustration at the slow-moving process.

Once the woman had described her medical complaints, I steered the conversation towards the couple's life story. I came to find out, after a tortuous series of questions about their origins, that they were both born in the interior of the state of São Paulo, to Japanese parents. They had lived in this villa for 50 years and used to own a small business in the neighborhood. I looked at Sebastião in confusion, given that he had identified them to me as "immigrants," but he did not seem to notice. For Sebastião, the couple's Asian phenotype marked them indelibly as being from elsewhere. Yet similar to the United States, the racialization of Asian Brazilians is nuanced by a history of upward mobility, creating stereotypes akin to the "model minority myth" (Higa 2015). Even if Sebastião considered the elderly couple immigrants, he saw them as "the good kind."

This stereotype was starkly visible in our next visit to Dona Nemésia, a white Brazilian widow also in her 70s, who lived across the street from the Japanese Brazilian couple. She gushed about the kindness of the couple; she lived alone, and they often brought her meals and kept her company. "We take care of each other." Sebastião had stopped in to see Dona Nemesia even though she rarely visited the health clinic because she had private insurance. He wanted to ensure that she was continuing to successfully manage her diabetes. He also enjoyed chatting with her about politics, and she provided snacks and coffee at her dining room table. The conversation found its way to discussion of "the Bolivians." Dona Nemesia assured me that she would not be seen by Bolivian physicians. Her niece worked in a hospital and had warned Dona Nemesia that Bolivian physicians always misdiagnose patients (a story with no basis in fact). "I don't trust them," she declared. Thus, certain

immigrants, even those employed in a high-status occupation (i.e., physician), become the object of prejudice.

Home visits provide the context for this prejudice. Brazilian CHWs' exposure to different groups of immigrants – and in turn their home environments – occurred through home visits. As I have documented elsewhere (see Pingel, Paper One), CHWs were apt to hold prejudiced beliefs about particular groups of immigrant patients, usually younger immigrants from other South American countries, including Bolivia, Paraguay, Peru, and Ecuador. These patients had typically resided in Brazil for shorter periods of time compared to older adult immigrants from Europe or South Korea. South American immigrants in Bom Retiro were more likely to be living in poverty, working long hours in low-wage textile jobs.

One hot afternoon in February, I accompanied the CHW Júlia up to the fourth floor of an apartment building in her micro-area. A Bolivian woman named Karina opened the door, as a baby cried from a back room. A tiny gray kitten appeared at our feet. I picked it up and found its paws wet from the floor. We waited at the entrance to the apartment while Karina went to get her SUS ID so that Júlia could make sure she was registered at the correct clinic. When Karina returned, Júlia asked “Who lives here?” Karina responded, “Just the three of us – me, my husband, and the baby.” The baby was a year old and was born in Brazil. Karina told us that she was from Cochabamba. Two of her front teeth were rotting. She looked to be about 25 years old and had sleek, black hair pulled back in a ponytail. The baby continued to fuss and a stream of snot ran over her lips and down her chin. From where we stood, we could see a clogged toilet brimming with waste. A fry pan with leftover oil sat on one of the burners; an open bottle of beer adorned the windowsill. Pieces of baby bottles and rags littered the floor. As we left the building, the doorman sitting outside remarked to

us that “everyone comes streaming home at 4am.” Júlia mentioned Karina’s claim that just the three of them lived there. “Yeah right – you should see it in the middle of the night – packed.” Júlia shrugged indifferently, telling me on our walk back to the clinic that an apartment such as Karina’s would only be affordable if packed with multiple families.

Many of the problems underlying the health issues of poorer immigrants could not be fixed by the CHWs. These structural and environmental issues included underemployment, overcrowding due to lack of affordable housing, and unsanitary or poorly ventilated living spaces. CHW José described the conditions of the *oficinas* as inhumane.

**José:** You’ve been in an *oficina*. You know how it is. It’s complicated, you know? They’re kind of standoffish [the residents]. They’re not very open to you....and sometimes they understand what you’re saying but pretend that they don’t....I have more or less four *oficinas*, with a lot of people.

**Emily:** Had you ever been inside of an *oficina* before you became a CHW?

**José:** No.

**Emily:** So, what did you think, when you entered one for the first time?

**José:** I was shocked. Mostly by the hygiene. It’s difficult, because you see those children, you know? Those children without any kind of care. I don’t know if you noticed that, but it’s hard because I have a son. I have a four-year old son. So, wow, you see that child, in that state, wow, it squeezes my heart. But it’s complicated. They work in a place that’s inhumane. They work there, they have a little room to sleep in, and the conditions there are not okay. So, it really shocked me. It’s very difficult. You have to...you have to be focused. You have to go in there and be really cold. You have to see what’s going on, do what you have to do, because if you let it get to your emotional side, you won’t manage to work....

**Emily:** Can you give me an example of what exactly shocked you?

**José:** The kitchen. Whoa. Dishes, plates with food, unwashed. Man, there were even rats, passing through the kitchen. Pans with frying oil, everything thrown into the sink. The *oficina* is a mess. There's fabric everywhere. I mean, sometimes there isn't even a chair for you to sit down. Because the chairs are loaded up with fabrics. And so you've got to do registrations [of new patients] while standing. It's inhumane. Everything is all closed up [unventilated]. It's difficult.

Coupled with low or no Portuguese fluency, such precarious living and working conditions exacerbated existing gendered power dynamics among South American immigrants, resulting at times in intimate partner violence (IPV) and unwanted pregnancies.

Several providers at the clinic confided to me that Bolivian women had approached them seeking abortifacients. Abortion is illegal in Brazil under nearly all circumstances; these providers could do little for the women except hand them a prenatal workbook and encourage them to return for care. As for intimate partner violence, teams periodically discussed known or suspected cases of abuse. The city prosecutor's office held a daylong event early in my fieldwork to train CHWs from across the metropolitan area on how to respond to IPV. Yet nearly ten months later, health professionals at the clinic were still in the process of forming an IPV response group. Most CHWs admitted they were not aware of any reporting mechanism available to them.

Confronted with these complex situations, and untethered by a shared sociocultural or linguistic background, Brazilian CHWs expressed feelings of powerlessness and frustration towards some immigrant patients. CHWs wondered

openly whether patients were to blame or were merely victims of difficult circumstances. Either way, as CHW Isabel commented, being confronted repeatedly by patients' desperate living conditions while having little recourse to change the situation, took a toll on CHWs.

There needs to be a psychologist, to consult with the CHWs, you know? To get things off your chest. So that you don't take the patients' problems home with you. Because...in the day to day, there are things that shock you, things you see that you can't do anything about. Thank God, I have never gotten sick from it all. But I have colleagues who have ended up depressed, who have ended up seeking psychological treatment because of it all. Having to assimilate [patients' problems], to absorb, not knowing how to handle it all. It's bad.

At the time of my fieldwork, the clinic employed three CHWs who had emigrated from Bolivia, out of thirty CHWs total. These CHWs do not exclusively visit Bolivian or even Spanish-speaking patients, given that CHWs are assigned by street of residence. Thus, three Bolivian CHWs did not even begin to cover the 2,576 newly registered Spanish-speaking patients in 2018-2019 (UBS Bom Retiro, 2019). I interviewed all three CHWs from Bolivia and found that not surprisingly their experiences visiting the *oficinas* and homes of other South American immigrants were markedly different compared to those of Brazilian CHWs. In place of frustration, they expressed empathy for the precarious conditions in which many of these immigrants found themselves. CHW Pamela recounted her own story of hiding her birth control from her partner. Prior to becoming a CHW, she too had worked in an *oficina* and could barely make ends meet; she feared a pregnancy would make things even more difficult. She used this experience to connect with her "countrywomen (*conterrâneas*), Bolivians, Peruvians, those who speak Spanish." She viewed

educating fellow Spanish-speaking women about family planning options as a meaningful part of the home visits she conducted.

If a woman has a lot of children, I say to her...they [the providers] have all these things there [at the clinic]. You could participate in the family planning workshop. You can get these things [forms of birth control], just like I did, right? Because I did it all secretly..... So I pass this to them as well. I say, “if you want to stay with him, you can. But if you want to do something else, you can. The doctor does this, this, and that.” And I tell them about all the methods and see what they think is best. I’m talking about family planning because there are a lot of women who never manage to lift themselves up because they have a lot of children. So, I think that that part [of my job] is really important. But I have to earn their trust first, or they could close the door in my face.

Similar to Pamela, CHW Cláudia explained to me that she understood the stressful conditions in the *oficinas*, given that she herself had worked in several when she first emigrated from Bolivia. Cláudia not only interpreted spaces and occupations through a different lens, but she also more effectively engaged the patient population. Unlike her Brazilian co-workers, Cláudia displayed no hesitation as she marched into homes and *oficinas* belonging to Bolivian patients. I noted that she was warmly welcomed and maintained a joking banter with workers at their sewing stations. Cláudia’s ease in the absence of linguistic and sociocultural barriers was striking, as I watched Bolivian and Paraguayan patients laugh, converse at length, and make sustained eye contact with her – a rare sight on home visits with Brazilian CHWs.

The idea that CHWs possess a greater understanding of patients’ context within a given neighborhood is fundamental assumption of the Family Health Strategy within SUS. The municipal health secretariat maintains a separate contingent of CHWs, in a program called BomPar, to attend to the city’s large homeless population. CHWs working within BomPar must themselves have experienced homelessness at some point in their lives, the idea being that such experiences make

the CHWs better equipped to serve this particular population. Yet most CHWs at the BRPHC had never set foot inside of an *oficina* before entering one in a professional capacity. This asymmetry raises critical questions about the preparedness and training of CHWs to meet the needs of some of the neighborhood's most vulnerable patients.

### ***Attending Patients with Stigmatized Identities***

Four groups - pregnant people, children, adults with chronic illness, and older adults – utilize the majority of services provided by the BRPHC. For this majority, home visits create a crucial link between neighborhood residents and the clinic. Home visits offer a window into patients' lives outside the confines of the consultation room. This holistic view of patients' environment can, and often does, improve the clinic's ability to tailor health promotion programs and prescribe appropriate treatment based on actual need. For patients with stigmatized health conditions, behaviors, or identities, however, home visits increase their vulnerability to outside scrutiny and neighborhood gossip. More than a year of participating in everyday conversations at the clinic confirmed for me that stigma against those living with HIV or engaging in same-sex behavior remains strong, even in the city with the world's largest LGBTQ pride celebration.

A standard feature of the Family Health Strategy (FHS) is weekly team meetings between the team physician, nurse, nurse techs and six CHWs. Each week, CHWs bring cases to the team for discussion. The first mention of the case of Alicia appears in my fieldnotes in early May 2019. This case dogged the FHS team assigned to Alicia based on her residence. I never met Alicia; I made several appointments with CHW Júlia to visit the *oficina* where she lived, all of which fell through at the last minute. She was one of the “difficult patients” and her reputation among the primary

care team led me to question the benefits of patient home visits. In the end, a combination of HIV stigma and language barriers prevented Alicia from receiving the care she deserved.

Alicia was a Bolivian woman who was living with HIV and pregnant when the CHW Júlia first mentioned her. She had previously lived in an *oficina* in another section of the neighborhood and was therefore the responsibility of a different team. Júlia noted that this other team was “trying to get rid of her,” in other words, trying to fob off responsibility for Alicia to a different team. Much of the tension around Alicia’s case stemmed from the pressure (tied to financial incentives) within SUS to ensure that patients attend at least 7 prenatal visits in the course of pregnancy. The municipality examines prenatal statistics closely and will sanction management organizations whose clinics are not meeting standards. Alicia had missed multiple prenatal visits. During her first visit, she did not disclose her HIV status to the nurse; this omission rankled the team when it was discovered through a routine blood screening. The CHWs recounted that one of the physicians, a white woman who had emigrated from Bolivia, confronted Alicia about the test result, asking why she had failed to disclose. Alicia allegedly responded that she did not speak Portuguese and therefore did not understand that she had been asked her HIV status. The doctor supposedly then snapped at her that she was also Bolivian, and yet had managed to learn the language. She told Alicia that living here, she ought to also learn at least a basic level of Portuguese. The doctor added that because Alicia had not done so, any consequences, such as infection of the fetus with HIV, would be her fault.

Júlia grudgingly agreed to follow up soon with the patient via home visit. She assured everyone in the room that if Alicia did not attend her prenatal appointments, she would call the Federal Police to report her, though for what offense, she did not



specify. A few days later, Júlia had gone to the *oficina* to visit Alicia, who met her at the entrance. “She doesn’t speak. Doesn’t speak at all. Doesn’t open her mouth.” Alicia had missed her scheduled appointment the day before with the nurse, Regina. She showed up several hours after the appointed time and told the nurse that her husband had hit her. Júlia sighed, “I don’t know how Regina is going to deal with it [the case]– it’s gonna be hard. Her husband doesn’t want her to get treatment, doesn’t want her to come to the appointments. So maybe that’s why she doesn’t speak.”

At a team meeting a week later, Júlia reported to the group that it was impossible to communicate with Alicia because of her limited Portuguese. The team’s physician lamented that communication barriers were a persistent issue in the neighborhood, adding that many patients employed “selective understanding” - comprehending what they chose to and pretending not to understand what they did not want to hear. Júlia and the nurse, Regina, mentioned that Alicia *had* managed to communicate that she did not want to disclose her HIV status to her neighbors, presumably to avoid any gossip or stigma that might ensue. Yet a fellow resident of Alicia’s apartment building had arrived at the clinic and brought it up to the nurse, demonstrating the casual spread of such information. The team then discussed possibilities for getting Alicia’s husband, also HIV-positive, into treatment. He had thus far refused. According to one of the CHWs, Alicia had hit her husband at the clinic a few days earlier while waiting for her appointment. Another CHW declared, “he hits her at home, but she can hit him in public, because in their culture, they can do that.”

One afternoon, Júlia announced to the team that she had convinced one of the Bolivian CHWs, Claudia, to go visit Alicia, even though Alicia lived nowhere near Claudia’s micro-area. Júlia recounts that she said to Claudia, “I’m unable to go in, but

you, you're different." Everyone believed that Cláudia would more easily gain access to the *oficina*, where Júlia had been denied entry. (In the end, Cláudia was also denied entry into the *oficina* to speak with Alicia). The team physician pondered the case, saying "It's also hard to know if she wants to get treatment and her husband won't let her. Remember that fight they had out front?"

A few weeks later, Júlia texted the team's WhatsApp thread to announce that Alicia had given birth.

**Júlia:** Doctor and Regina [the team nurse], I passed by Alicia's today and the husband said she was at the hospital. The baby was born on Monday.

**Júlia:** A girl.

**Júlia:** I don't know if he understood the question I asked, but she will be discharged tomorrow.

**Regina:** What a good sign that everything went well! [smiling emoji]

**Dr. Caetano:** Great! And at least we hit the 7 appointments too!!!

**Dr. Caetano:** I hope the baby is HIV-negative [sad emoji]

**Dr. Caetano:** And I hope too that now they'll bug us less, lol

Having reached the minimum number of prenatal visits, the team had reached their primary goal with Alicia, and would now pass off her HIV care to a public clinic specializing in sexually transmitted infections. As I reflected on the many ways that the team might have handled Alicia's case differently, it also struck me how little institutional support the CHWs had. After all, there is no required training for CHWs providing services across sociolinguistic or cultural barriers, or for providing services to people living with HIV. No translators were available to help. No protocol for instances of IPV were initiated. It was clear that the team was unprepared for such a

challenging case. Layered upon these institutional shortcomings, the CHWs compounded the effects of stigma through their interactions with one another and at the *oficina* where Alicia lived. I recalled an exchange in my interview with two CHWs, Márcia and Eliane, in which they reflected upon knowing stigmatizing details of patients' lives through home visits.

**Eliane:** It's just like a gay person too, right? It's clear that the person is [gay]. I don't have anything against it. But he won't say it. It's obvious, from the way he acts. But he won't say it. "Oh, it's my friend who lives with me." And then we find out that it's his husband, his boyfriend. They don't say, understand?

**Márcia:** They're ashamed. I even sometimes don't agree with this idea of community health workers being from the neighborhood. I don't agree. Because sometimes....let's say there's a man, that for me, this man is a man. I see him in the street as a man. But then I become his community health worker and I see that, that in the street, for others, he's a man. But inside the home, he is not. So, I think the person must feel bad, knowing that "Jeez, that girl there, she's coming to my house, she's going to discover that I'm gay. She's going to discover that I use cocaine. I think the person becomes a little....apprehensive. I don't know. So, I disagree with that [the idea of CHWs living in the area]. Sometimes I think it should be people from other areas. Because there are people that have tongues this big [stretches out her arms wide], you know?"

**Eliane:** And then you see that they're telling the whole neighborhood.

**Márcia:** [mimicking someone speaking] "Oh, do you know what I found out? I discovered that Little Tony, who lives by the bar, he lives with a dude." Understand? "Yeah, he lives with a dude and he's married, and the three of them all live together in the house." So, it's complicated.

**Eliane:** So, they say that you can't say anything, but people do. There at the clinic, people do that. Whether you want them to or not, they're going to find out who Little Tony is. They're going to ask.

**Márcia:** I'm not going to lie. I've done that with David (her husband). "David, guess what? You know what I found out?" I'm not going to deny it [that I've done that].

**Eliane:** Sometimes I do that too.

**Márcia:** Cuz we're chatting, we're drifting off to sleep at night, and we talk. "You know what I discovered today? Wow, so and so has syphilis." Understand? I know that it's wrong. I know that I did the wrong thing.

Márcia and Eliane acknowledge how stigma is compounded by home visits. Information about one's health or identity becomes apparent to CHWs through these visits and is not guaranteed to remain private. Rather, such visits potentially expose patients to stigmatizing attitudes, which has widely documented ill effects on health (Link & Phelan, 2006). In the final section, I reflect on the implications of these findings and suggest ways to address some of the disadvantages of home visits, such that they are incorporated to the greatest advantage with the primary care system.

### **Implications and Conclusion**

Evidence suggests that tailored training and on-the-job support has the potential to increase CHWs' efficacy (Catalani et al. 2009; Cometto et al. 2018; Kane et al. 2016). As outlined in the introduction, CHWs receive very little training when they become SUS professionals. This absence of training is predicated on the idea that they already possess knowledge of the local population. My findings suggest that CHWs' experiential and local knowledge indeed aids them in attending to pregnant people, mothers, children and older adults. Such knowledge falls short, however, in extending services to immigrants and non-Portuguese speakers, reflecting a larger trend towards privileging the Portuguese language in Brazilian culture (Preuss and Alvares 2014). My work and that of others (Melo, Maksud, and Agostini 2018; Seoane and de Carvalho Fortes 2009; Zambenedetti and Both 2013) underscores the need to strengthen respect for patient privacy, particularly in the case of stigmatized health conditions. CHWs in Bom Retiro would benefit from training that normalizes such conditions, as well as multicultural and multilingual environments and interactions.

The implementation of the Family Health Strategy in Brazil the early 2000s represented a step towards health equity, in large part by growing the number of CHWs in the healthcare workforce. Given that SUS physicians and nurses have higher levels of education, income, and socioeconomic status than community health workers (Andrade et al. 2018), CHWs play a crucial role in primary care by bridging the gap between providers and patients. Typically, CHWs share a similar cultural and socioeconomic background with patients. They are therefore able to disseminate medical information through respectful and empathic communication as well as indigenous knowledge (Pinto, da Silva, and Soriano 2012). The valuable interpersonal strategies and shared life experiences of CHWs help them build trust and rapport with neighborhood residents and adhere to healthy behavior changes (Katigbak et al. 2015). Yet as I demonstrate above, these skills and attitudes do not always transfer when a CHW perceives a patient as “other” or when patients’ ethnoracial or class status does not map on to those of the CHW, resulting in misunderstanding and even discrimination. Under these circumstances, CHWs -- touted as an organizational strategy to reduce inequalities -- end up reproducing these inequalities instead.

SUS is founded on three principles: universality (access for all), integrality (a holistic approach to health and health systems), and equity (the right to health among all groups). In practice, however, public health practitioners have understood this third principle as more akin to equality, arguing that equal services must be provided to everyone (Caldwell 2017). Indeed, I heard from practitioners that “everyone should receive the same care.” Health equity, however, dictates that healthcare should be focused on the needs of each population or community, and such needs will inevitably differ. This tension – between equity and equality – shapes the provision of care in Bom Retiro. Immigrant populations, particularly those of lower socioeconomic status,

require specific interventions by the BRPHC to ensure that they are receiving equitable care. I suggest that public health scholars and administrators reevaluate how to train and integrate CHWs, particularly in contexts with diverse populations. My findings demonstrate that relying on CHWs' similarity to the population being served proved a less than effective strategy in reaching the most vulnerable patients.

The professional role of CHWs is neither well-defined nor consistent across contexts, complicating studies of efficacy at a broad scale (Arvey and Fernandez 2012). Nevertheless, strong evidence exists for CHWs' contributions to improved health outcomes (e.g., reduced hospitalization rates for chronic conditions, maternal and child health) since Brazil first implemented the Family Health Strategy in 1994 (Giugliani et al. 2011; Macinko et al. 2007; Macinko and Harris 2015). I found CHWs to be an excellent source of emotional and informational support for older adults. Future research should investigate the effects of frequency and quality of CHW attendance on the health outcomes of older adults.

Working in an under-resourced healthcare system hinders the efficacy of CHWs in Bom Retiro and elsewhere in Brazil (Rahman et al. 2017). CHWs witnessed the predictable outcomes associated with the inequitable distribution of wealth, power, and prestige in society. Poverty, un(der)employment, minimal education, and lack of affordable and adequate housing generate fundamental public health problems, including poor hygiene and sanitation. The conditions present in some of the *oficinas* and patient homes shocked CHWs. As my research indicates, the absence of institutional capacity or resources to confront these burdens can lead to feelings of hopelessness and burnout. This cascade has been documented elsewhere in Brazil and worldwide (Jatobá et al. 2020; Nxumalo, Goudge, and Manderson 2016; Ge et al., 2011). While clinical social workers at the BRPHC regularly linked patients

to resources (e.g., for food, transportation costs, employment opportunities), this information did not travel as easily among CHWs. I found that CHWs were often unaware of resources they could make available to patients. Other times, CHWs lacked either the confidence or desire to proactively provide such resources. While far from overcoming the structural barriers to health equity, strengthening CHWs' knowledge of resources available through the health system and other government entities would represent one immediate step towards remedy of this issue.

Although informal on-the-job mentoring does occur, in which seasoned CHWs accompany newly hired CHWs, I found this practice to be underutilized and inconsistently applied. The municipality of São Paulo and the management organization that oversees the clinic *does* require CHWs to complete continuing education courses. The CHWs I interviewed, however, complained bitterly about such courses because participation in them only increased their workload without corresponding financial compensation. Because they live in the neighborhood, CHWs do not receive the meal tickets (*vale refeição*) or transportation vouchers given to all other healthcare providers as part of their benefits package. Attending off-site trainings forces CHWs to pay for roundtrip transportation and to eat out in neighborhoods with few inexpensive choices. Furthermore, attendance at trainings does not exempt CHWs from their home visit quotas. Rather, work piles up in their absence. In periods of daily vaccination campaigns (in which CHWs must participate e.g., in the spring, for measles), trainings represented one more bureaucratic duty that would ultimately force them to race through home visits. While against the rules, other CHWs admitted to checking in with patients over WhatsApp, skipping the actual visit altogether when faced with mounting professional obligations. Such

barriers to job satisfaction and quality improvement must be taken into account when designing training programs.

Past research has noted how CHWs are themselves embedded in the webs of power that compound disadvantage in the first place, thus becoming entwined with the reproduction of health inequities (Nunes and Lotta 2019). Despite the belief that CHWs successfully support their communities in part through identification with and empathy for fellow residents, we must recognize that CHWs are not immune from treating patients with disrespect and harboring stigmatizing attitudes and beliefs (Maes, Closser, and Kalofonos 2014). In establishing a standardized and validated set of core competencies that undergird the CHW profession, Covert et al. (2019) found that CHWs scored some of the lowest means on competencies related to diversity and inclusion (“function without judgment, bias, or stereotype”). These findings and my own underscore the need to re-examine our assumptions about CHWs’ intrinsic ability to empathically connect with patients, and instead, invest in the strategies and approaches public health and medicine have emphasized with all other healthcare workers, such as cultural humility (Foronda et al. 2016; Tervalon and Murray-García 1998). CHWs constitute a crucial segment of the healthcare workforce; in turn, they deserve the respect that such professional development could provide.





## **Chapter 4: Virtual Aspirations: How Women in São Paulo, Brazil use WhatsApp to Communicate their Desires for Safety and Stability**

### **Introduction**

WhatsApp is a ubiquitous form of communication in Brazil, where people send daily messages, share pictures, and forward memes. While researchers and journalists have emphasized the role that political messages and fake news on WhatsApp have played in recent elections (Anita Baptista et al. 2019; Chagas, Modesto, and Magalhães 2019; Mont’Alverne and Mitozo 2019), less attention has been given to how other kinds of messaging shape people’s everyday interactions. In this paper, I consider how women in a health promotion group in São Paulo share crime alerts and inspirational messages over a WhatsApp group thread, and how these messages fit into a broader cultural narrative in Brazil that links whiteness to safety and security (see Figure One on Page 143 for examples). My findings contribute to a body of literature striving to reintroduce culture, in addition to structure, as a force shaping our health (Kagawa Singer, Dressler, and George 2016).

### ***Women’s Experiences of Uncertainty and Loss***

When I arrived at the party, the women had already filled up the room with food and chatter. Hellena invited me to this gathering at her small apartment with several other neighborhood residents, most of whom were part of a health promotion group in which I had been participating for several months as part of ethnographic fieldwork of a primary care clinic in São Paulo, Brazil. That evening, we were celebrating Hellena’s birthday and she had invited many of her friends from the group. She buzzed around the room, proffering snacks. Another woman named

Marisol balanced a plate of food on her lap, leaning slightly against a television that displayed black and white video surveillance feed, capturing scenes of the entrance and front hallway of the apartment building. I became accustomed to seeing this setup in São Paulo, allowing building residents to remain in a constant state of vigilance about their surroundings.

Perched on the edge of the sofa, Isabel leaned in to tell me how afraid she felt about scheduling a gynecological appointment. At age 76, she was distressed by the idea of the doctor examining her naked body yet had experienced some uncomfortable symptoms that warranted medical attention. She had seen a dermatologist in the past and had had to disrobe there as well, an experience she found humiliating. The dermatologist was treating a skin condition that Isabel developed soon after the murder of her brother during a mugging. “They say these patches are emotional,” she explained as she pointed to discoloration on her hands. The doctors attributed the skin condition to the acute stress she experienced in the aftermath of the crime. In other words, Isabel’s stressful experiences were written on her body.

While I had met Isabel through the health promotion group nearly a year before this conversation, she had been participating in it for a couple of years, at the recommendation of her physician. He had advised that joining one of the clinic’s health promotion groups would lessen her fear of leaving the house. I asked if she felt afraid to go out because of her brother’s murder, and she shook her head no. Rather, she was traumatized by a hospitalization several years ago for a nearly fatal heart attack. The patients on either side of her in the ward died while she huddled in her hospital bed. After she was released, she recalled feeling certain that walking even a short distance would cause another attack.

Isabel pulled out her phone to show me several real estate listings in a town a couple of hours outside the city. “I wanted to move there, because it’s getting so dangerous here. But my son says there are criminals there too.” She sighed. Isabel had three adult children with her husband of over 60 years, with whom she still lives. Like many of São Paulo’s residents, Isabel migrated as a child from Brazil’s Northeast region. The fourteenth of seventeen children, she attributed her light brown skin to her grandparents: her white European grandfather, a landowner, married and bore children with one of the Black women he had formerly enslaved on his farm. Isabel’s mother was an Indigenous woman. By 1990, she and her husband had obtained what they considered comfortable middle-class status, until currency changes under the Presidency of Fernando Collor de Mello depleted their savings almost overnight. Along with many others, Isabel and her husband claimed to have lost nearly everything. “You have to shrink [your expenses] to make enough to live. Sometimes you get worried.”

In the pages that follow, I piece together how women’s experiences of uncertainty and loss negatively affect their mental health and foster a desire for a “light and enjoyable” world. In many ways, Isabel’s life story, punctuated by migration, violence, familial strife, economic insecurity, and mental and physical health crises, exemplifies those of the women I came to know through the health promotion group. While few suffer from the intensive poverty and state-sponsored violence that mark São Paulo’s peripheral communities, the threat of loss and ensuing precarity nevertheless loom large. In this context, inspirational WhatsApp messages emerge as a cultural symbol of the desire to transcend these histories. Women in the ING sought to create an affective atmosphere (Lupton 2017), a space in which

pleasant feelings abound, feelings that in turn are meant to foster an intimacy between the women (Berlant 1998).

Back at the party, the night wound down at around 10pm and I casually mentioned that I would call an Uber to take me home since I never took the thirty-minute walk from Bom Retiro after dark. The other guests could walk home easily, as most lived within a few blocks of Hellena. The route between Hellena's residence and my own traversed Cracolândia, an area of several blocks where people congregate openly on the street and live in makeshift tents where they buy, sell, and consume drugs. While I strolled by "Crackland" nearly every morning without incident, the streets were not well-lit at night.

Mara and Hellena were shocked that I was thinking of calling an Uber, insisting that the ride service was dangerous. A few days earlier, a passenger had shot his female Uber driver to death, and while the murder had happened more than an hour south of Bom Retiro, the report had induced the customary handwringing about crime in the city<sup>2</sup>. To an outsider, the urgency of this fear feels exaggerated at times. In my 15 months in São Paulo, for example, I used Uber dozens of times without incident. Nevertheless, all of the women then strategized how I could get home safely without the Uber. Finally, I suggested the metro and Hellena agreed on the condition that her husband accompany me the two blocks to the station. For these women, the well-lit and policed metro stations in São Paulo's central neighborhoods represented the relatively safer option. We gave each other a single kiss on the cheek, agreeing

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<sup>2</sup> <https://sao-paulo.estadao.com.br/noticias/geral,motorista-de-aplicativo-e-assassinada-em-diadema,70003012036>

that we would all see one another in a few days at the next meeting of the health promotion group.

### ***The Integrative Practices and Nutrition Group (ING)***

In 2018-2019, I conducted a 15-month ethnography of the Bom Retiro Public Health Clinic (BRPHC), a primary care clinic that serves local residents through Brazil's Unified Health System (known as SUS). As part of this fieldwork, I attended many of the activities and events organized for patients of the clinic, including several health promotion groups. One such group was the ING (Integrative practices and Nutrition Group or *Grupo para Alimentação e Práticas Integrativas* in Portuguese), which met in-person weekly in a neighborhood cultural center located about a fifteen-minute walk from the clinic. The ING was nominally open to all patients. Nearly all participants, however, were middle- or working-class women, typically in their 50s or older. They were ethn racially diverse, reflecting the surrounding neighborhood, and a few were immigrants to Brazil. Most of the women were either retired or had flexible work schedules that permitted them to attend the group on a weekday afternoon. Physicians at the clinic had referred many of the women as part of a mental health regimen. A core group of about eight women were present at nearly every meeting, and five to ten others attended once or twice a month.

The stated purpose of ING is to promote “integrative practices,” which are alternative techniques and therapies that Brazil's Ministry of Health has defined as complementing biomedical approaches to primary care (e.g., acupuncture, aromatherapy, Ayurvedic medicine). Auricular therapy occurs weekly, in which the practitioner tapes seeds to the outer ear of the patient in order to diminish chronic pain. In practice, however, this therapy occupies approximately ten minutes at the end

of the group meeting. Most of the meeting is spent sitting in a circle, talking to one's neighbors or as a whole group. For birthday celebrations, everyone who is able to brings a dish or soda to pass, as feeding others constitutes a central piece of essentialized Brazilian womanhood.

The group's facilitator was a white woman named Fernanda whose background was in social services within the public health system. Her role was to manage group logistics, moderate the group's WhatsApp messaging thread, suggest future meeting topics, and give updates on events happening at the clinic, such as vaccination campaigns. At 32 years old, Fernanda was younger than most of the group's participants. She was also well-educated, possessing a professional degree in occupational therapy. As I explore in the following sections, Fernanda envisioned the ING as a space in which participants could temporarily escape everyday stress and develop long-term strategies for coping with the fears and uncertainties present in their lives. At times, however, this vision clashed with the messaging contained in the inspirational posts and crime alerts that many of the ING participants shared on the group's WhatsApp thread.

### ***Crime Alerts, Fear of Crime, and Psychological Distress***

News of crime travelled fast in Bom Retiro. Whether by word-of-mouth or alerts on social media, residents frequently warned one another about happenings near and far. Luncheonettes, which dot the corners of São Paulo's central neighborhoods, often displayed a channel devoted entirely to broadcasting reports of criminal activity. Whether stopping in for a coffee on the way to work or a beer on the way home, residents could linger in the luncheonettes, soaking up the latest atrocities.

Fear of crime looms large in Brazil's collective imagination (Caldeira 2000; Penglase 2007). Yet nearly everyone has stories of petty crime; and some, like Isabel, have had their lives directly affected by violence. How do these experiences inform our understanding of women's mental health? Dustmann and Fasani (2016) found in a study with Londoners that local area crime led to psychological distress among residents, with an increased effect among women. Whitehall II, a prospective epidemiological study also in Britain, demonstrated that fear of crime was associated with poorer mental health, reduced physical functioning, and lower quality of life (Stafford, Chandola, and Marmot 2007). Jackson and Stafford (2009) suggest a feedback loop, in which worry about crime diminishes mental and physical health, which in turn amplifies worry. Indeed, in a 2014) study, Foster et al. determined that fear of crime diminished frequency of walking among residents of Perth, Australia. Brazilian health professionals and researchers also recognize the impact of urban violence on the mental health of Brazilians (Mari, Mello, and Figueira 2008). In a 2007 study exploring experiences of depression among women in São Paulo, participants cited street and intimate partner violence as primary causes (Martin, Quirino, and Mari 2007).

Scholars distinguish, however, between the fear of crime and actual crime on mental health outcomes. In a spatial analysis of crime in the Brazilian city of Belo Horizonte, Alkimim, Clarke, and Oliveira (2013) found that fear of crime was not associated with actual reported crime. Rather, fear is a subjective experience, independent of actual crime, that can lead to psychological distress. Given this subjective quality, fear of crime can be alleviated through increased contact with one's neighbors, even when levels of actual crime remain constant (Silva and Beato Filho 2013). Thus, health promotion initiatives might focus on reducing fear of crime



by building neighborhood trust as one path to improving mental health among residents. Social connections create trust (Glanville, Andersson, and Paxton 2013), and feelings of trust and safety diminish psychological distress (Phongsavan et al. 2006).

Researchers point to troubling rates of psychological distress among women in São Paulo. In the São Paulo Megacity Mental Health Survey, Andrade et al. (2012) found that women were more likely than men to have mood and anxiety disorders, and those disorders were more likely to be moderate or severe. Meanwhile, according to data from the Brazilian Longitudinal Study of Adult Health (ELSA-Brasil), women, and specifically women of color, had the highest burden of “common mental disorders,” such as anxiety and depression, of any group surveyed (Nunes et al. 2016). These findings are consistent with past literature which suggests that women are socialized to internalize stress, which then manifests as depression and anxiety, whereas men externalize, resulting in higher rates of substance use, suicide, and antisocial behavior (Bird & Rieker, 2008).

Brazil’s Unified Health System (SUS) provides mental health care for the public through its primary care clinics. Whereas patients with severe psychiatric disorders are often treated exclusively by or in conjunction with Psychosocial Care Centers (*Centro de Atenção Psicossocial* - CAPS), those with more manageable illness or everyday psychological distress receive care through a collaboration between Family Health Strategy (*Estratégia Saúde da Família* - ESF) teams and Family Health Support Center teams (*Núcleo de Apoio à Saúde da Família* - NASF), both of which are housed in the neighborhood primary care clinic (Barros and Salles 2011). In Bom Retiro, NASF professionals facilitated neighborhood health promotion groups, several with at least a partial focus on helping patients manage their

experiences with depression and anxiety. Such groups functioned in part by bringing neighbors together to exercise, get information on healthy eating, and share everyday problems with one another. This approach is consistent with frameworks that link fear of crime and psychological distress with the surrounding social and built environment (Lorenc et al. 2012) and suggest that such distress lessens as feelings of trust and safety in one's community increase (Phongsavan et al. 2006).

### *Affective Desires*

I arrived home safely from Hellena's party that September evening, contemplating the evening's conversations. As I jotted down notes, my phone vibrated on the bedside table. Glancing over, I saw the WhatsApp banner: Isabel had sent two smiley face emojis with heart eyes, followed by an inspirational message: a pink heart covered in black lace, with a quote inscribed beneath. "When we have God in our heart, no sadness can be bigger than our hopes. Good night." The quote was attributed to Fabio de Melo, a celebrity Catholic priest whose books and CDs have sold millions of copies. Throughout my fieldwork, I received hundreds of these WhatsApp messages. I once asked Isabel what she liked about them, as she was scrolling through the images.

All this, all these messages are from the girls. My husband says, "Turn off that phone, it's gonna stop working." But then the next day, there's a new pile of messages. Everyone sends messages. I like it because many times there are things that you didn't know, like alerts. And then people send them in the morning, at night, saying "Good morning. Good night." So it's a way to stay in the loop... Sometimes you forget things. Oh, look how cute! [She interrupts herself to show me a picture of a white baby in an Anne Geddes-like pose.] She looks like she's from your country!

Isabel and the other women in the ING used the messages to stay connected to one another and share information. Yet they are also reproducing cultural messaging that presents whiteness (primarily through images of white children) with purity, safety, and Christian faith.

I participated in the group's weekly face-to-face meetings at the neighborhood cultural center at least twice a month over the year, joining in their activities and conversation. I also read and responded to the group's WhatsApp instant messaging thread. I grew familiar with the daily greetings, laced with religious references and frequently invoking pink hearts, cutesy animals, and golden-haired children. On occasion, sharp words punctured these placating images. Typically, a woman would post something that raised objections from the facilitator, Fernanda. Tensions arose time and again over which images and messages were acceptable in a group ostensibly organized around improving one's mental health. Yet no one ever mentioned the online squabbles when the group met in person.

Given this conflict, the ING's WhatsApp thread emerged organically as a site of mental health intervention. Group members used the thread to express their desires for feelings of safety and continuity by frequently posting inspirational messages and crime alerts. Though it seemed innocuous to the women, Fernanda deemed this material detrimental to the group's mental health and tried to prohibit it. To her, the messaging dichotomy of a frightening criminal world on the one hand and platitudes festooned with hearts on the other offered a narrow worldview – linked to whiteness and Christianity – that diminished possibilities for connection, and reinforced fear and mistrust.

In the sections that follow, I explore how women coped with lives marked by instability by trying to construct an online world that is both familiar and safe, and how one mental health professional resisted this solution, encouraging the women instead to embrace the unfamiliar (e.g., by welcoming neighborhood immigrants) and find strength coexisting amidst difference. Through analysis of field notes and images from online and in-person observations, as well as in-depth interviews with group members, I explore the meaning of the group's online conflict and participants' reactions to it. How does women's repetitive deployment of particular images and symbols in group texts – and the facilitator's critical response – point to competing cultural messages about how we can achieve safety and well-being?

## **Methods**

In this study, I use culture and affect as a lens through which to analyze images, discourse, and everyday practices of health promotion. Moving between face-to-face meetings of the ING and the text and images posted on the WhatsApp thread allowed me to examine how both symbols *and* practices comprise culture (Sewell 2005). Through this data triangulation, I was able to investigate how online and offline interactional spaces inform one another (Lane, 2016). According to Sewell, “to engage in cultural practice is to make use of a semiotic code to do something in the world” (p.167, 2005). Small groups constitute a rich space in which to explore how culture shapes healthcare provision. Within small groups, culture, structure, and interaction come together to form the “building blocks of society” (Fine 2012, pg. 19). The women in this study used cultural practices and symbols including the inspirational memes, to generate feelings of belonging and safety with varying degrees of success.

The analysis presented in this paper originates in an ethnography of the Bom Retiro Public Health Clinic (BRPHC) that I conducted from August 2018 to November 2019. During these months, I engaged in participant observation of weekly meetings of various health promotion groups offered by professionals from the Family Health Core Support Team (*NASF – Núcleo de Apoio à Saúde da Família*), including the Integrative practices and Nutrition Group (ING). In addition to my fieldnotes from the weekly meetings of both of these groups, I also actively participated in and observed the WhatsApp thread that team/group members used to communicate with one another. The dataset consisted of 989 written messages, 670 images/memes, and 97 videos, averaging 146 posts per month. Finally, I conducted semi-structured in-depth interviews with the facilitator of the ING, and five of the patients who were core participants in the ING. These data form the basis for the analyses presented below.

The BRPHC serves a coverage area specified by the municipal government as the subprefecture of Bom Retiro. The coverage area encompasses both commercial, industrial, and residential blocks; housing varies between taller, larger apartment buildings to the east of the clinic to three-story buildings to much of the south, west and north. These buildings often house a retail shop on the first floor, workshop areas for sewing, ironing, folding and packaging on the second floor and third floor, interspersed with makeshift living areas for the sweatshop workers.

My primary role in the field was that of participant observer. I attended over a dozen of the ING sessions and formed relationships with group members. As I got to know several of the core group of women who regularly showed up at ING meetings, they invited me to gatherings in their homes and at neighborhood cafés. These outings gave us the opportunity to gain some mutual understanding about one another beyond

the context of regular group communications. Meanwhile, my training as a sociologist and an ethnographer augmented my observational sensibilities (Pachirat 2017), in which I am attuned to how power, often deployed through race/ethnicity, class, and gender, shape social interactions. In-depth interviews allowed me to further pursue particular topics of interest and compare what people said about their experiences to their everyday actions (Jerolmack and Khan 2014).

From February through October 2019, I continued these participation observation activities and augmented them with semi-structured in-depth interviews with healthcare professionals and patients. The interview topics ranged from experiences working in or getting care at the clinic, relationship to the neighborhood, history of health issues, and participation in health promotion groups. Prior to each interview, I collected basic demographic information and asked the participant to choose a pseudonym. Of 28 total patients interviewed, 5 of them were regular participants in the ING. All five identified as woman/feminine (*mulher/feminina*) when asked their gender. All of the women were in their sixties with the exception of Isabel (age 76). Interviews lasted between one and three hours. When asked “what is your race or color?” – the standard question asked of patients during registration into the health system – two women identified as white, one as Bolivian, one as Black, and one as Brown. Fernanda, the facilitator, was 32 years old at the time of the interview; she identified as a white woman.

I conducted and audio recorded in-depth interviews, then uploaded the recordings to a password-protected laptop and Emory University’s firewall protected server. All of the interviews were conducted in Brazilian Portuguese. I obtained IRB approval for all research-related materials in English, Portuguese, and Spanish. I maintained the confidentiality of all interview participants; we met at a neighborhood

location outside of the clinic. As part of the informed consent, I frequently reminded participants that their participation had no bearing on their medical care at the clinic, nor their professional status (in the case of healthcare professionals). I communicated at the time of scheduling the interview and during consent that they were under no obligation to participate or to answer any questions that made them uncomfortable. I compensated each patient participant for their time and expertise with R\$60, approximately \$15 US dollars.

While in the field, I frequently read over past fieldnotes and devised analytic memos to document my theoretical hunches. The salience of small group culture in the everyday practice of community health demanded my attention. I developed my theoretical framework in tandem with analysis of three empirical datasets: audio recordings of the in-depth interviews, fieldnotes, and WhatsApp threads. This abductive analysis allowed me to solidify my research questions. Listening again to the interviews, I marked and transcribed portions that were responsive to my questions. I turned to my fieldnotes and developed a corpus of notes in which I had observed the ING in session and interacted with its members at social gatherings. I entered these notes, the interview excerpts, and the Whatsapp threads into MaxQDA and coded them, then triangulated the codes from each data source. Continuing my iterative process, I structured my results based on the codes and further refined my theoretical framework.

## **Results**

In the analysis that follows, I explore how women's fears of crime and uncertainty became manifest over the health promotion group's WhatsApp thread, through the sharing of alerts and inspirational memes. The group's facilitator resisted

these postings, opting instead to encourage learning from one another and in-person connection as an approach to managing psychological distress. I delve into the cultural imaginaries upon which the women rely to construct an online affective space that they deem “light and enjoyable,” while Fernanda, the facilitator, draws on a mindfulness approach that emphasizes the material present. I conclude by showing how this tension between the cultural imaginary (who one could be) and the material (who one is) opens up a third space (Soja 1996). The group and facilitator reached a respectful resolution and the women reported improvements in their mental health as a result of group participation.

### ***Convivência through the ING***

The ING constituted space for interpersonal connection, talk of everyday troubles, and what Brazilians refer to as “*convivência*” translated as “coexistence.” *Convivência* in the ING ranged from eating food together and amiably chatting about one’s day to sharing experiences of physical or emotional pain. Soon after I arrived in Bom Retiro in August 2018, one of the clinic’s occupational therapists, Fernanda, assumed the role of facilitator for the ING.

At the end of most weekly sessions, Fernanda administered auricular therapy, a form of acupuncture in which the practitioner tapes small seeds to a patient’s ear in order to diminish chronic pain. This “integrative practice” is one of 29 recognized by SUS as a supplemental intervention or alternative to biomedical treatment (Ministry of Health, 2015). As part of her training to be an occupational therapist, Fernanda visited other public health clinics throughout São Paulo that were engaged in various integrative practices, including herbalism, anthroposophic medicine, and acupuncture. While she appreciated SUS’s efforts to implement such practices, she found that



many of these public health clinics lacked the resources and personnel to optimize this kind of programming. Through the BRPHC, at least three separate health education and promotion groups offered auricular therapy. I frequently noticed health professionals and patients alike at the clinic sporting the little taped seeds on one ear and decided to try it out. In so doing, I recognized a more subtle, but nonetheless powerful effect of the practice: that of being attended to, and gently touched with consent, by a person performing the role of a healer.

ING participants typically joined the group on the recommendation of their physician at the BRPHC. Most of the women that I interacted with over the year had a diagnosed mental health condition (e.g., anxiety, depression, panic disorder). Mara's comments about how she ended up in ING reflect typical sentiments among participants:

“When I began [to attend the group], last year, I was beginning to take the medicine again and was still having panic attacks. So the doctor told me to participate in the occupational therapy group [ING]. So I went..and I kept going, and I started to feel better. Because we could talk, we could participate. She did, or does, auricular [therapy] too, you know [i.e., Fernanda, the facilitator]. So, that really helped me a lot.” (Mara, age 61)

Fernanda explained what she felt that women gained from participation in ING.

I think the first gain is social interaction, this question of always having human contact, of permitting yourself to be linked to others. I think that's the principal gain. And then there's the gain that's more individual, more familiar, which is to share one's anxieties, right? One's pains. And another step is understanding their own importance in society. Like, they end up passing on information, that which they learned in group that day, and end up bringing it to their neighbors. So that's the principal gain. To be able to chat, to sit, and perceive that someone else's pain is important, and how you approach others...To listen, to be allowed to speak, to be heard.

When I first began attending the group, I expected the sessions to either focus heavily on delivering health information or to mimic group therapy, with individuals sharing one at a time. Rather, they consisted of about ten minutes of updates about events happening at the clinic or in the neighborhood, followed by an hour of unstructured socializing, in which participants ate and joked around as a whole group, or sometimes camped out in pairs or trios to chit chat. Occasionally an invited guest would arrive and offer additional information on health topics, such as how to manage diabetes. Mostly, however, the ING functioned simply a space where women gathered to socialize: a social network organized by the clinic.

### *Threats of Precarity*

The first time I walked into an ING meeting, I sat down next to a woman who looked to me like she was in her mid-sixties, with long jet-black hair elegantly swept up into a ponytail. She introduced herself as Renata and within moments, was lamenting to me how much she missed her old neighborhood. “There weren’t as many homeless people there. You’d see people begging here and there, but not flat out sleeping on the sidewalk.” She had relocated to Bom Retiro so that her son’s family could take over the apartment in the old neighborhood, where they deemed the schools to be superior.

The ING participants who were long-term residents of the neighborhood routinely fretted over the decline of Bom Retiro. They wistfully described the safe streets of their youth (Halbwachs 2020), sighing over the seemingly recent influx of vagrants from nearby Crackland. This worry took another form when residents discussed shrinking opportunities in the neighborhood textile industry. They pointed to Korean and Chinese immigrants as responsible for importing cheap goods and

undercutting prices, forcing Brazilian businesses to close. Omitted from this discourse was the fact that many of these “Brazilian” businesses were themselves established by immigrants, first from Southern and later from Eastern Europe. As with Isabel, whom we met in the introduction, the women of ING had experienced personal traumas (e.g., intimate partner violence and neglect, the sudden death of a loved one), alongside everyday economic insecurities (e.g., fluctuating currencies, unstable labor markets). The majority of them were working or middle-class, which in São Paulo functionally means that one is neither living on the streets, nor free from financial uncertainty.

These threats of precarity – social and economic – may feel particularly acute for working and middle-class women balancing on the narrow straits between Brazil’s rich and poor. The vast inequalities at the heart of Brazilian society are very much present in Bom Retiro, where merchants and sidewalk sleepers occupy the same street, and squalor lives next door to luxury. Reminders of downward mobility linger on every street corner. Meanwhile, the media landscape provides no shortage of escapist visions of elites commanding skyscrapers and beach-hopping by boat. Thus, it is not surprising that women’s psychic uncertainties manifest themselves in two primary forms: the discourse of terrible events, (both past and possible), and the circulation of images via WhatsApp depicting a hegemonic white, Christian femininity, packaged as inspirational memes. Could engaging in the latter save one from the former?

### *Messages of Fear*

Fernanda, the ING facilitator, joked that she had been coerced into creating a WhatsApp thread for the group. ING participants had insisted upon it. Indeed, I found

that both patients and providers at the post typically belonged to many WhatsApp group threads – with family, friends, coworkers, and through formal and informal organizations. Months later during my interview with her, I asked Fernanda about the ING’s WhatsApp thread.

I fought against creating it, but there’s no way, so I ended up creating it. (...). I instituted norms. I described what you could post, what the goal was, and what you couldn’t post. It didn’t make any difference. (Interviewer laughs). There have already been fights, and even so, people feel the need to...send daily send prayers, pictures, and good mornings, good afternoons, and good nights.

One of Fernanda’s “rules” when she established the ING thread was to prohibit postings depicting violence, abuse, or crime. Nevertheless, participants did occasionally post crime alerts, accounts of violent crime in the city, or warnings of schemes being perpetrated upon unsuspecting citizens. For example, the following exchange occurred in late 2018, warning group members about prisoners on temporary reprieve for the Christmas holiday.

**Hellena (participant):** Guys [*“Galera”*], Christmas pardon starting today ... so pay more attention on the streets! Be careful at traffic lights when entering and leaving parking lots, sitting in the car, fiddling with your cell phone or talking on the street. 27 THOUSAND prisoners coming out of prisons full of love at heart for society and their belongings! Caution! [police emoji].

**Júlia (participant):** God help us that one day this will end. Why do they arrest them if on special dates they are on the street doing the same thing. It is very sad because many families lose their loved ones in these times [i.e., at the holidays]. If it were the other way around, we would be arrested for taking the life of an offender. [sad emoji]

The next morning, Fernanda responded to the alert.

**Fernanda (facilitator):** I asked you not to talk about these "controversial" issues. I don't agree with your opinion but the only way to keep the group from getting upset is not to talk about it here. Thanks. See you Wednesday when we'll do our Secret Santa! [heart emoji]

**Hellena (participant):** Good morning girls! People, it’s just an alert, I don’t see any reason to get upset, I’m sorry!

In another incident that took place at the weekly in-person meeting, a participant began talking about a man in the neighborhood who had killed himself by jumping off a building near to where she lived.<sup>3</sup> Fernanda used the conversation as an opportunity to warn of “the naturalization of violence.” She noted that when humans talk about violence, like that which we see on the news, it raises our cortisol levels. “Even if we don’t perceive it, it’s stressing us out.” The participant ignored Fernanda and kept talking about the suicide to her neighbor and one of the community health workers. Fernanda reiterated that ING was meant to be a space in which “we don’t talk about violence and instead we try to laugh and share and give each other affection.” She then reminded everyone that one of the rules of ING was to put away phones upon entering, so as to avoid distraction and create a space in daily life that was not dominated by screens. Fernanda’s rationale for discouraging talk of violence, especially over WhatsApp, was plain:

It’s one of the issues in the group that I always work on, of “turn off your phone, I don’t want phones ringing, I don’t want anyone on WhatsApp.” We lose what’s real, what’s happening in the moment, what’s happening now, to have these virtual conversations, and those messages, motivational messages, there’s some of it that has gotten into the group, and there’s a lot of fake news too, and that, I nip in the bud right away. When people send images of accidents, sensational events, or chain letters, I exclude it. And I have to tell them about the importance of not doing this. As much because it’s bad for us to see these kinds of images of accidents and all, as it is about disseminating false information, so....

Ultimately, no one left the group over these disputes. Rather, such tensions would arise and dissipate periodically while the in-person group meetings continued, complete with baked cakes, icebreakers, and the exchange of health information.

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<sup>3</sup> I was unable to find any evidence that this event actually occurred.

In her professional role, Fernanda sought to create boundaries around shared content that she believed promoted group health. This task was easier to accomplish in person than online; face-to-face interactions allowed her to communicate her supportive intentions in a tone that could be construed otherwise on a group thread. “Health promotion” precluded allusions to crime and violence. In person, she could remind group participants of these rules with a supplicating tone that invited agreement, rather than resistance. In the online space, however, group participants expressed irritation and a suspicion that they were being censored when Fernanda asked that they refrain from posting what she termed “controversial” material.

For some of the women, alerting others to potential threats signaled protection and loyalty. After all, many had experienced interpersonal and/or street violence firsthand, as I learned through my interviews with them. Danger was not an abstract concept; the binary of “good” vs. “bad” people loomed large. At the same time, calls for heightened security and “pacification” hold political currency in Brazil, undergirding routine killings by police (Alves 2018). This public discourse of state-sponsored violence, symbolized by the phrase “a good criminal is a dead criminal” (Bueno Nunes, 2014) was on display all throughout my fieldwork, as conservative President Jair Bolsonaro was elected in October 2018 in part by warning of the increasing and constant threat of violence (Cioccarri and Persichetti 2018). As a young, white, urban, middle-class health professional, Fernanda likely perceived the ING’s habit of posting crime alerts as an extension of the political right-wing’s call for increased surveillance and policing. Anthropologist Teresa Caldeira (2000) has written extensively about how discourses of fear and crime pervade daily life in Brazil, and how such discourses serve to strengthen the security apparatus and undermine democracy. Fernanda believed that these same discourses also generated a

biological response that heightened the participants' experiences of psychological distress, as evidenced by her frequent mentions of stress, cortisol levels, and poor health outcomes.

### ***“Light and Enjoyable”***

In contrast to the sinister quality of the crime alerts, the ING participants sent daily inspirational memes and greetings. I asked people in interviews and everyday conversations for their perspective on what motivated people to send the inspirational messages. Most of my interlocutors shrugged and gave an explanation similar to that of Isabel: “I send the greetings because my friends like to send them.”

Over the course of 11 months, the women participating in the ING posted 617 inspirational messages and videos, averaging more 56 a month. As shown in the Introduction, this material typically offered a greeting or an inspirational or religious message (e.g., “Good morning, beautiful people! May our day be peaceful, watered with love and many blessings!”; for further examples, see Appendix A). The text of the message was frequently overlaid on an either an image (most often of a white child) or a computer graphic of hearts or flowers. The white children include both boys and girls and display a reverence for the innocence and purity of (white) children. Flowers and hearts symbolize ideals of femininity and romantic or devotional love. The messages were nearly always overtly or subtly religious; many also used the language of positive thinking (e.g., “Spread good things! People deserve them and the world needs them!”). The women did not create the content; rather, they received a daily digest from one of many meme generating websites and Facebook pages. Participants also simply forwarded to the group inspirational messages that they received from elsewhere. In my experience, the circulation of such messages was

commonplace. In addition to the ING thread, I received them from health professionals at the clinic, family members from other parts of Brazil, and acquaintances with whom I had exchanged phone numbers. While the messages were most often shared by women, exceptions existed, such as the doormen in our apartment building who sent these messages daily.

On the surface, we might interpret the automaticity of circulating these seemingly benign messages as a way of sustaining weak ties (Granovetter, 1973), the virtual equivalent of waving to a neighbor on the street. Such greetings reinforced a sense of predictability and normalcy, of lives anchored by the rhythm of good morning and good night. Markers of stability prove powerful in a place where many have known otherwise. What then made them so inevitably rankle Fernanda, the group's facilitator? As she articulated in her interview with me, conducted nine months after I had begun frequenting the group, Fernanda perceived the content of the inspirational messages as inimical to her work aimed at improving the overall mental health and well-being of the women of ING.

One group specifically that I, that I do lead, it's really mixed. There are as many immigrants as there are people from the Northeast, who arrive in Bom Retiro. The people who were born, the people raised in Bom Retiro, who have lived their whole lives here, without being of any other origin, the majority of times they have a better financial condition. So we have to do some very basic work with them, to say that we're all equal, that everyone has the right to health. But these residents of Bom Retiro, who are really from the neighborhood, they think that the immigrants, for example, come to disrupt things, that they fill up the health post, and that they shouldn't have the same rights. That if it was just Brazilians, if it was just people from São Paulo, the health system would function better, because there would be fewer people. So there's some of that feeling. And so it ends up that there are comparisons made [by long-term residents], by social class, by profession. So we have to break down these prejudices. The work in this group went along, and today the people feel better, but in that closed group (little core – nucleo). When you think about outside of the group, where there isn't already those kind of close



relationships, these prejudices appear. So it's the Korean, the Bolivian, the Peruvian, the Paraguayan, is taking their spot [at the clinic]. This discourse is present among the people.

Her efforts with the group were grounded in the idea that some of the women experienced stress because they were erecting symbolic boundaries based on class and place of origin (Lamont and Molnár 2002). From Fernanda's perspective, such boundaries prejudiced the women's mental health; breaching them, within the confines of ING, was a path to well-being.

I suggest that the inspirational messages constituted the other side of the coin to the discourse mentioned by Fernanda above in which fear of the Other was central. They conveyed a hegemonic aspiration to whiteness and profession of Christian belief: the human image is represented by blonde, blue-eyed children; the message promises salvation from earthly peril. These messages are particularly potent in the present era, in which the ascendancy of conservative figures like President Bolsonaro was made possible in part by the strong support of Evangelical leaders (Almeida and Almeida 2019). While Brazilians have adopted Evangelical Christianity at an accelerated pace in the past several decades, populating churches and electing prominent Evangelical leaders to office, (Burdick 2005; Martin, 1994; Reich and Santos 2013) aspirational whiteness has a long history in Brazil (Bailey 2009; Davila 2000). Paired with symbols of Brazilian nationalism and militarism, as they have been since Bolsonaro's tenure began in 2018, aspirational whiteness and Christianity stand in for promises of public safety. In this vision, if one is willing to accept its terms (i.e., white Christian male dominance), the threat of difference can be traded for security and prosperity.

To my initial surprise, given her emphasis on creating a “light and enjoyable” space, Fernanda resisted the inspirational messages. Instead, she reiterated the thread’s ostensible purpose and emphasizing that “important” messages could get lost amidst the frivolity.

Girls, I created the thread in order to have a communication channel for ING. Before creating it, I said we were not going to send chain messages and memes and prayers, etc. Let’s focus on this, please!!! If someone has something important to say, we won’t be able to see it. (12/20/2018)

Hellena, the participant who had posted the material that Fernanda had deemed extraneous, responded heatedly, using Fernanda’s own words against her by pointing out that the “rules” for the thread encouraged “a useful, light and enjoyable” group. “If we aren’t allowed to have a good laugh, how is this group supposed to be light and enjoyable?” Hellena asked sharply.

Fernanda sensed the temptation of the inspirational messages’ facile imaginary. She sought to root it out by diminishing the importance of the WhatsApp thread and offering up healing through a mindful appreciation of our coexistence (*convivência*) each week at the in-person meetings. At one such meeting, she broached the subject of immigration, telling the women that “Bom Retiro is a neighborhood of immigrants and language can be a barrier, so it’s important to ‘*acolher as pessoas*’” – or welcome them. According to Fernanda, connection to others improved one’s health because “the emotional and physical are not separate. Sometimes, people suffering from depression are missing something sweet in their lives.” She asked the group what else provided sweetness. They shouted out answers, including sex, happiness, friendship, laughter and eating an actual sweet, like chocolate. Fernanda agreed, chiming in “we don’t say *never* to chocolate.” One of the women pointed out that being healthy was hard in São Paulo because of the *correria*,

or hustle and bustle, of the city. Fernanda nodded and reminded everyone to “stop and meditate when we eat, and pay attention.”

This focus on “paying attention” and recognizing the entanglement of body and mind stood in marked contrast to the extremes escapism and high alert circulating on the WhatsApp thread. Given the arguments over fear messages and inspirational memes, I felt uncertain as to how receptive the women would be to Fernanda’s framework. In later interviews, however, some women intimated that being pushed beyond one’s preconceptions was precisely the benefit they derived from participation.

They filled me up [the health promotion groups], filled up the emptiness. Something was lacking, I think, something different in my life. Ummm...I got to know different people, you know? **I was able to see life in a different way, that wasn’t just my little world.** To see that out there, there was more. (Júlia, age 62).

Despite defending their right to send the inspirational messages, no one extolled the benefits of sending them or questioned their ubiquity. Instead, when asked directly about the benefits of the ING, participants emphasized being physically present with others and having space to both listen and be heard. As Hellena summed up in her interview, the group was an escape from the heaviness of everyday life.

I like the togetherness (*convive*) of the group. I like...to interact with the girls. It was through the group that we formed our [friendship] group, going to each other’s houses, getting together here for some tea, getting together there for a snack...I love that - to converse, to play around, to distract myself. We get distracted a lot that way, chatting, laughing. I feel good, I like it. **I think less about things, about what’s happening in the day to day, about heavy things.** I’m lighter, I let go more, when I’m with them, chatting. You don’t think so much about your problems. It softens your problems, when you have a problem.

Júlia cast aspersions on the possibility of online relationships without a face-to-face component.

Sometimes you're so distant from people, and this [the technology] brought warmth again. Except that I don't really agree with it. Ok? I don't agree. Why? I think that the lack of conversation these days, of opening up with one another, for the other person to know how I'm doing, me looking at you and saying "Look, today I'm feeling this way...." And you looking in my eyes and saying "I'll help you." The Internet disrupted that. Knowing one another. So I think it brings people to you, but in a way that's cold. It's a cold knowing.

As I watched Júlia at an ING meeting one afternoon, I admired how mutual presence – through touch, through the sharing of food and sorrows, *and* through exposure to difference - held untold significance for these women. Júlia complained loudly about a painful blackhead on her back. "Show it to us!" demanded several of the women. Júlia obliged, lifting up her shirt, and a couple of the women stood up to take turns squeezing it. Finally, Fernanda shuffled over and said calmly, "Let me get it out." Júlia flinched and yelped in pain several times, but eventually Fernanda managed to remove it. Júlia spun around smiling; everyone cheered and laughed.

## **Conclusion**

Women in the ING attempted to create an affective space, engendering positive emotions, to counterbalance the difficult life events they had experienced. Yet I argue that the cultural symbols attached to this desired space - those of a white Christian femininity – are intimately entwined with a politics of fear and state-sponsored police violence against impoverished Brown and Black Brazilians (Alves 2018; Gomes 2017). The group messaging thread thus reflects what feminist scholar Lauren Berlant has termed cruel optimism, the "condition of maintaining an attachment to a significantly problematic object" (Berlant 2011, pg. 24). In such

circumstances, the very objects of desire become obstacles to one's flourishing (Keyes 2002). The women in the ING paradoxically built a "safe space" online whose corollary in everyday Brazilian life exemplifies an exclusionary and violent agenda, in turn threatening true *convivência*. In contrast, the group's facilitator resisted this form of intimacy, urging instead for social connections derived from in-person interaction, unmediated by the problematic digital imagery. Her aspiration for these women's well-being was an amplification of the sphere of belonging, an acknowledgement and acceptance of difference.

The case of the ING group demonstrates how societal structures (e.g., racism, heteropatriarchy) bleed into clinical spaces through communications between health professionals and patients. Small group settings within public health become a place in which individuals use culture expressions to wrestle with the structures enabling and constraining their behaviors and beliefs. Rather than passively absorbing information legitimated within biomedicine, patients create their own spheres of meaning, employing cultural symbols as grounding for their virtual aspirations. Yet such aspirations are necessarily complicated, as desires for security bump up against possibilities for liberation. In this case, the health professional nudged patients towards a vision in which the politics of inclusion are synonymous with health. Health promotion thus moves beyond its initial conception as a unidirectional push towards behavior change and emerges as a complicated coexistence – a true *convivência*.

## **Chapter 5: Conclusion**

This dissertation examines how cultural imaginaries, particularly around race, shape primary care service provision. Whereas much prior research has focused specifically on interactions between physicians and patients within a clinical setting, I approach the topic from perspective of community health workers as they attend to patients throughout the neighborhood. I also explore how macrosocial structures shape labor regimes, which in turn order occupation and housing, providing the material for the racialization of various groups in the neighborhood.

This dissertation contributes to research on neighborhood health through its emphasis on the role of culture, space, local and global histories. Furthermore, it is methodologically innovative in its triangulation of digital and face-to-face data analysis. In the following pages, I focus on each of these topics in turn, in addition to discussing implications of this research for public health practice and avenues of future inquiry.

### **Race, Racism, Immigration and Health**

The social determinants of health approach posits that macro-level social conditions result in disparate health outcomes by race/ethnicity, socioeconomic status, gender, sexuality, nationality, disability status, and other social categories (Braveman and Gottlieb 2014). For example, structural racism – rather than race itself – is largely responsible for observable Black-white differences in rates of chronic health conditions (e.g., hypertension, diabetes). One might imagine a trajectory that is rooted in sociohistorical processes of settler colonialism in the Americas, and extends to epidemiological data on racial health disparities today. The social determinants of

health approach goes beyond individual-level explanations for differences in health status. Prior to the turn in public health scholarship towards social determinants, researchers typically investigated lack of access to healthcare or poor quality of services as drivers of health disparities (Baum et al. 2009). Too often, race is incorporated into studies of racial health disparities as a static demographic variable, rather than a fluid social process embedded in deep histories of oppression. I sought to do otherwise in these three papers.

In preparation for writing this dissertation, I read and incorporated histories of race, racial categorization, immigration, and racism in Brazil. Given my prior coursework on these topics in the United States, I was prepared to see certain patterns repeat themselves, as well as to note important differences. I observed that racial categorization and identification tend to be much more fluid in Brazil than in the United States, particularly among individuals in the middle of the color spectrum (e.g., those who are neither very dark-skinned or very pale). Interracial relationships resulting in children have always been more common in Brazil as well, meaning that we see many more “mixed-race” families. As a result of these two trends, elites have successfully downplayed the role of racism in maintaining societal inequalities, arguing that the nation escaped the worst excesses of racism in the United States. Individuals that I met throughout my fieldwork were about equally likely to characterize racism in Brazil as “less severe” than in the United States or about the same. A glance at nearly any social indicator, however, reveals racial disparities in employment, income, education, and health (Lima and Prates 2019). Furthermore, Brazilians of younger generations have embraced the messages of the Black Lives Matter movement, identifying with the anguish stemming from police brutality towards Black and Brown citizens.

I extend studies of racism and migration in Brazil by incorporating immigration into examination of Brazilian racial dynamics. By examining these processes of racialization – asking how certain groups come to be racialized – my analyses necessarily travel from spatial and labor regimes to attributions of particular characteristics. I thus investigate *how race happens* by exploring: spatial schemas (who belongs where in the neighborhood); how much space bodies typically take up (Bolivians are crammed in apartments, Koreans and older immigrants live in more spacious apartments); the division of labor (who sews and who owns the sewing shops); characterizations of health conditions (who gets pregnant, who has strokes, who gets syphilis); the gaze upon the other (who is permitted to be beautiful, how bodies look and smell); and everyday behaviors (inviting in community health workers or asking them to wait on the threshold). I observed how Brazilian health professionals develop schemas about immigrants, migrants, and Paulistanos, as well as narratives about themselves, drawing on racial scripts (Molina 2014) that have been recycled by those in the neighborhood for over a century. Sociohistorical processes are responsible for the way that people occupy space in the neighborhood, yet within these micro-spaces of homes, businesses, and the clinic, health professionals draw on cultural schemas to interpret these structural processes. Health professionals try to make sense of people's presence: by looking at their bodies, the spaces that they occupy for both living and working, and their behavior.

Finally, we must also consider that these schemas emerge in a political context in which Brazil's leader encourages particular kinds of discourse. Jair Bolsonaro was elected president in October 2018, two months into my fieldwork. Mimicking the brashness of Donald Trump, he appealed to a desire among some Brazilians for global status equal to that of the United States. Bolsonaro too has constructed his populist



image via Twitter, emphasizing increased security, policing, and a reverence for the former civil-military dictatorship (Cioccarri and Persichetti 2018; Tamaki and Fuks 2020).

### **Culture, Affect, and Space in the Context of Health**

Public health scholars and sociologists alike have long been interested in the relationship between neighborhoods and health. Whereas epidemiologists and behavioral scientists have sought to identify the individual and census-level features of neighborhoods that determine specific health outcomes (Diez-Roux 2016), sociologists have tended to focus on how larger structures and institutions, such as racial residential segregation, play a role in health inequities (Williams and Sternthal 2010). This dissertation seeks to bridge these two traditions by arguing that the health of neighborhood residents is contingent upon 1) micro-level interactions between patients and providers, mediated by primary care as an institution; 2) the material configurations of public *and* private neighborhood spaces such as homes, sweatshops, churches and schools; and 3) the cultural imaginaries at hand among neighborhood residents and health professionals.

I define culture in my dissertation as both a system of symbolic meanings and a collection of practices and beliefs (Jung 2015; Sewell 2005). How actors deploy, reproduce and alter such meanings and practices colors patient-provider interactions. Physically, the post itself is a small building whose needs far outstrip the available space. The contention over space became an apt metaphor in my fieldwork for exploring how health inequity is both materially and symbolically determined by space (Lipsitz 2011; Soja 2010). Furthermore, I explore how racial ideologies exist in relation to space in the urban Brazilian context. This spatial perspective is informed

by the scholarship on space, race/ethnicity, and health in Brazil (Caldeira 2000; Caldwell 2017; Guimarães 2019; Holston 2009; Perry 2013; Santos 1982; Vargas Costa 2006).

My focus on women's affective desires and mental health stems from my exploration of a Whatsapp text thread corresponding to a health promotion group. I sought to piece together how women's experiences of uncertainty and loss negatively affected their mental health and fostered a desire for a "light and enjoyable" world. I came to understand the inspirational WhatsApp messages that the women sent as a cultural symbol of this desire. Women in the health promotion group used instant group messaging to communicate their aspirations for psychological well-being and physical safety. The messages circulated in the group messaging thread, however, reflect what feminist scholar Lauren Berlant has termed "cruel optimism." "Cruel optimism is the condition of maintaining an attachment to a significantly problematic object (Berlant, p.24, 2011). I analyze how the group navigates this affective terrain and the implications of this process for women's mental health.

In exploring racialized geographies, as I did in Paper One, I wanted to understand how a global capitalist system orders labor such that peoples occupy particular residential and occupational spaces, spaces whose attributes then become attached to their ethnoracial identities, as perceived by health professionals. In other words, part of what it means to be "Bolivian" is to work and perhaps live in an *oficina*. Global capital flows thus draw people into cultural scripts in seeking to explain what they observe before them. Spatial capital also becomes important, shaping decisions about migration, the spaces in which people live and work, how people make use of public spaces and commercial spaces, and how particular spaces are policed. Through home visits (Paper Two), the State attempts to make visible

spaces that are otherwise private or hidden, while simultaneously laying bare the power of those who can refuse such visits.

### **Public Health Implications**

Transitioning from the applied focus of public health to the more theoretically oriented discipline of sociology expanded my intellectual vision. Sociological training in patterns of structural inequalities, stigma, culture, and institutional logics deepened my critical stance towards the shortcomings of public health and medicine. At the same time, the applied work in which public health and medical practitioners engage makes the theoretical insights a tangible reality in the lives of everyday people. Therefore, as I wrote this dissertation, I frequently reflected on how my findings might be translated into public health programs and interventions, as well as how we might avoid the pitfall of creating programs that do more harm than good. Indeed, one of the primary findings of this dissertation is that sometimes public health measures instituted to reduce inequalities end up reproducing them. This issue necessitates critical reassessment of policies and programs.

During my fieldwork in São Paulo, I identified how status inequalities translate into uneven health service provision. For example, Brazilian providers sometimes characterized Bolivian patients as lacking a “culture of health.” They used this stereotype to explain poorer health outcomes among Bolivians, while discounting or ignoring altogether the effects of many Bolivians’ grueling work hours, substandard living conditions, and limited Portuguese fluency. One might be tempted to conclude the research at this point, attribute bias to the providers, and lament the inequity baked into the patient-provider relationship. Nearly all providers I encountered in Bom Retiro, however, wish to do their best on behalf of patients; the

patients, in turn, try to balance the demands of their lives with their health needs. Fostering these intentions, while far from eliminating structural constraints, does offer patients and providers a chance to collaborate, shifting the grounds of inequality and suggesting new possibilities in community health practice.

Brazil's Unified Health System (SUS) reflects both its status as an institution of the State and as a site of resistance. Its roots in social activism, proclamation of health as a human right, and emergence coinciding with the end of Brazil's civil-military dictatorship have generally made it a progressive institution within Brazilian society (Paim et al. 2011). At the same time, because the Brazilian middle-class has largely fled from public institutions, preferring in the case of health to rely heavily on the private sector, SUS has also suffered under its designation as an institution for "the poor." Patients frequently experience long wait times to see specialists. Healthcare professionals are commonly underpaid, overworked and burnt out. Attempts to improve the system under progressive governments (e.g., the *Mais Médicos* program that brought Cuban doctors to underserved communities throughout Brazil) have been rolled back by the current administration.

In the specific case of the Bom Retiro Public Health Clinic, the opportunity exists to more equitably serve the various populations present in the neighborhood. SUS is built upon democratic principles and the policies that are written into its constitution at the national health conference occurring every four years begin at the local level. Indeed, each primary care clinic, including the BRPHC, has a *Conselho Gestor*, a kind of advisory board made up of patients, health professionals, and administrators. Representatives from the Conselho Gestor attend citywide meetings that often end up shaping health policy at the municipal level, and influencing the state and federal level. Yet the Conselho Gestor in Bom Retiro is not as influential as

it could be, nor does it represent all of the constituencies of the neighborhood. While its patient members are democratically elected, many patients have no knowledge that the group exists. This reality stands in contrast to other neighborhood advisory boards that I met at a citywide conference, with active and representative membership. Ensuring more widespread involvement is one way that a greater diversity of voices could be heard within the clinic.

### **Future Research**

The framework of racialized geographies can be applied in global contexts outside of Bom Retiro where particular regimes of labor and migration determine to a large extent the spatial configurations of ethnoracial groups. Identifying and understanding these geographies gives scholars the tools to see beyond surface-level everyday discrimination and mine the deeper historical and political economic trajectories that inform how prejudice, discrimination, and structural racism are inevitably tied together in a vicious feedback loop. Furthermore, putting this knowledge in the hands of policymakers may lead to creative solutions to enduring urban problems, such as poverty and affordable housing.

Future research must investigate further how WhatsApp and other social media platforms shape the fabric of everyday life, but within and outside of Brazil. We have seen the past few years how our democratic processes have been altered by these online spaces. Greater attention must be given to how such technologies differentially affect various populations, given what we know about the built-in biases of algorithms (Noble 2018; O'Neil 2016). Such technologies are not merely benign or neutral digital tools, rather they are powerful conduits of content, both true and false.

The COVID-19 pandemic has presented scholars of race and healthcare systems with questions to be entangled over the next decade. How and why did Brazil and the United States fail so spectacularly in their response to the pandemic? How did politics and media shape the response? SUS is responsible for vaccinating nearly all Brazilians – not only at clinics, but in schools, metro stations, workplaces, and even sometimes patient homes. And while far from perfect, Brazil’s healthcare system offers a safety net to the most vulnerable that does not exist in the United States. I admit that at moments in Brazil, I wondered if the continued heavy emphasis on prevention of infectious disease was occurring at the expense of less visible yet more deadly chronic illnesses such as diabetes and heart disease. I now see that Brazil’s public health plight will increasingly be that of the world: needing to fight both fronts, infectious and chronic, at the same time. Climate change will only amplify this urgency.

Here in the United States, the federal government plays a small centralized role in public health; I believe that we have paid an extremely high price for meager involvement. The United States is a country predicated on individualism. This trait has inspired many entrepreneurs, activists, immigrants, and politicians to dream big and accomplish incredible feats. I would argue that it also left many of our public institutions immobilized during the COVID-19 crisis. The United States healthcare system is fragmented. Many Americans do not have a regular doctor that they see or place that they go to get healthcare services. The number of Americans without health insurance remains too high, even after the passage of Obamacare (Sofer 2019).

Both Brazil and the United States contend with extreme economic inequality to a degree that threatens the life expectancy of all citizens. Furthermore, both nations continue to wrestle with centuries of racism, embedded into our structures and daily

lives. Given these circumstances, it is no surprise that COVID-19 has disproportionately affected the morbidity and mortality of Black and Brown Americans (as those from Brazil and the United States are both Americans; (Anyane-Yeboah, Sato, and Sakuraba 2020; Kalache et al. 2020; Santos et al. 2020)). We have also witnessed the tearing down of expert opinion, the proliferation of fake news, and a population that mistrusts our leaders and media in equal measure. Some say that nobody saw this pandemic coming. In fact, many scientists had been predicting it for years. We see now that a lack of investment in public health has dire consequences, as do the actions and words of our leaders. Hopefully, we use this tragedy as an opportunity, to strengthen our health systems and recommit to addressing inequalities, in both the United States and Brazil.

I spent many hours of fieldwork observing and participating in vaccine campaigns. A measles outbreak occurred in the city while I was there, and the community health workers were responsible for going door-to-door and setting up shop in the metro stations nearby in order to get as many people vaccinated as possible. While I saw little resistance to vaccination among the patients seeking care at the Bom Retiro Public Health Clinic, I did see multiple journalistic reports in the city about a rising anti-vaxxer movement, linked to supporters of President Bolsonaro. Communication from the federal government has been murky throughout the pandemic, as Bolsonaro has played down the consequences and fake news about vaccines has spread (Vasconcellos-Silva and Castiel 2020). Future research ought to investigate who benefits (and who is disadvantaged) by this movement, as well as the connections between right-wing political movements in the United States and Brazil that inform vaccine opinions.

A satirical video circulated on WhatsApp among my Brazilian relatives in December that portrays in which two women on a video chat discuss the possibility of a COVID-19 vaccine. Watching the clip, entitled “Lucy, Helena, and the Vaccine,” I felt like laughing to keep from crying, as I was reminded of how public health information can become twisted in the hands of politicians, and then circulated by digital technologies. At the same time, the level of distrust can feel warranted at times, given past behaviors of powerful elites. Here is an excerpt that I have paraphrased:

**Lucy:** There’s gonna be a vaccine!

**Helena:** Vaccine! Do you think I’m gonna take a vaccine? Are you crazy [sneering]? The vaccine just came out of the oven. No one know if it works. I spent I don’t know how many months in the well [i.e., social distancing], putting hand sanitizer everywhere, even my soul. And now I’m going to go out and get this crappy ass vaccine, that they put a bunch of microchips inside?

**Lucy:** What bunch of microchips, if there’s even one, at the most?

**Helena:** No, you don’t understand these technologies. They’re trying to put microchips in us to capture our information....

**Lucy:** Why? For what? What information would they want to capture? Who wants to know how to make corn cake? [an everyday Brazilian dessert]

**Helena:** Look, all I know is that I’m not obligated to be part of all this “hubub” about the vaccine, ok? This vaccine is very weird because it comes from the same place as the virus! [The Brazilian vaccine was developed in collaboration with Chinese scientists]. First comes the virus, then comes the vaccine. It’s a pyramid scheme!

Helena (the skeptical one) goes on to say that she received a video over WhatsApp that shows what the vaccine is going to do to people. Lucy receives it and remarks that it appears to be a clip from the U.S. television program *The Walking Dead*.

Helena dismisses this, lamenting how hard it is talking to people who just don’t want to hear the truth. They devolve into accusing one another of being “communists,” a



common discrediting epithet since at least the civil-military dictatorship (1964-1985) that has recently been revived by the right-wing in Brazil (Levy and Sarmiento 2020).

### **Concluding Remarks**

Writing this dissertation in the midst of the pandemic was both painful and invigorating. Talking with a group of public health colleagues in February 2020, having just spent 15 months in São Paulo, I worried openly that Brazil's public health system would not be up to the challenge posed by a global pandemic, in no small part because of the absence of political will from the president. Seeing the nation ravaged from thousands of miles away proved excruciating, knowing that the health professionals I had worked alongside for months were in the midst of such terrifying and exhausting work. At the same time, the analyses that I was conducting each day as I wrote my dissertation had never felt more relevant. The world's eyes were turned upon public health; everyone was searching for answers to some of the fundamental puzzles of human health that I have been wrestling with for over a decade. As I embark on the next chapter of my professional career as a public health research, and now as a sociologist, I will draw on the momentum of the valuable theoretical and practical lessons learned in Brazil with the hopes of improving public health for decades to come.



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## Appendix I: Patient Interview Guide

### IN-DEPTH INTERVIEW GUIDE - PATIENTS

#### INTRODUCTION

Before we start, I want to thank you again for your participation in this study. Your participation may contribute to better understanding how primary care is delivered in São Paulo. As you know, the UBS Bom Retiro provides healthcare to most of the residents in the neighborhood of Bom Retiro through SUS. But less is known about what it is like to be a patient at the post and to receive treatment for chronic illness. Furthermore, by learning about the patients' experiences, we can contribute to our understanding of health systems around the world. It is for these reasons that I want to conduct this interview with you today and learn more about your experiences as a patient with [chronic condition(s)] in Bom Retiro.

I want to remind you that everything we talk about today will be completely confidential. That means that I will not share what we talk about with any of the other people who work at the post or live in the neighborhood – including your doctor. I hope to publish the results of this study one day, but any part of your story that I use will be under the pseudonym that you have chosen and will not include information that could identify you. As part of my job, I have conducted many interviews on health topics in the past. The interview is about your experience, so there are no right or wrong answers. I say this so that you know that you are in an environment where you are free to share your story, ask questions, and take a break whenever you need one. Do you have any questions before we begin?  
[ANSWER ANY QUESTIONS]

#### A. Life History

I would like to begin by hearing about the story of your life. Can you tell me how you came to be sitting in front of me today?

[PROBE THE FOLLOWING TOPICS FOR LIFE HISTORY]:

1. **Childhood** – [Sample probes]:
  - a. Where did you grow up?
  - b. What do you remember about your childhood?
  - c. Who raised you?
  - d. Who (else) did you live with?
  - e. What was your neighborhood(s) like?
  - f. What was your school(s) like?
  - g. How far along did you go in school?
  
2. **Significant Relationships** – [Sample probes]:

- a. Are there people in your life that you would call your family? [If yes] Can you tell me about your family?
  - b. Have you ever been married or with the same person for a long time? [If yes] Can you tell me about that person? How would you describe your relationship?
  - c. Do you have children? [If yes] Can you tell me about your children?
  - d. Who else beyond those people you've mentioned has played an important role in your life?
3. **Immigration/Migration** [for those not raised in São Paulo]
- a. When did you arrive in São Paulo?
  - b. With whom?
  - c. What do you remember about moving?
  - d. What was it like to leave [home state or country]?
  - e. Have you returned to [home state/country] to visit?
  - f. What was that like?
  - g. Can you tell me about your most recent visit?
4. **Employment**
- a. How old were you when you began working?
  - b. What kinds of jobs have you had? [Probe for both formal and informal work experiences].
  - c. Which was your favorite/least favorite? Why?
  - d. What is your current work situation?
  - e. Some people feel like they have plenty of money to cover their expenses while others are just trying to make ends meet. How would you describe your current situation in relation to money?
5. **Current Living Situation**
- a. Where are you currently living in Bom Retiro?
  - b. What is it like?
  - c. How long have you lived there?
  - d. Who else lives with you?
6. What else is important for me to know about your life that we haven't talked about yet?

Thank you for sharing all of that with me. If it's okay with you, I'd like to move on now, to talking about stress and support.

## **B. Stress and Support**

- 7. What, if any, are the major sources of stress in your life?
- 8. Who do you turn to for support when you need it? [PROBE: How do you feel that this person/people support you?]
- 9. How would you describe your religious or spiritual beliefs?
  - a. In what ways, if any, are you involved with a religious organization?
  - b. How, if at all, have your beliefs changed over the course of your life?

[IF PATIENT HAS NOT ALREADY BROUGHT UP CHRONIC CONDITION(S), SAY:] Overall, how would you describe your health?

### **C. Illness History and Explanatory Model**

10. Can you tell me more about the health issues you've experienced?
  - a. When did you first begin to experience symptoms?
  - b. What was going on in your life at that time?
11. What do you think caused the illness?
12. What kinds of symptoms do you experience?
  - a. What kinds of situations or events can make the symptoms worsen?
13. [If patient experiences chronic pain] Tell me about your pain.
  - a. Where does it hurt? When?
  - b. How has your pain changed over time?
  - c. Is there anything that alleviates your pain?
14. What kinds of treatment, if any, have you gone through?
  - a. How, if at all, has the treatment helped?
15. How has your family [or the important people in your life] responded to your illness?
16. How has living with [condition(s)] affected your life?
  - a. What have you lost as a result of having [condition]?
  - b. What have you learned about yourself in the course of your illness?
17. What do you fear the most about living with this illness?

### **D. Interactions with the Health Care System**

18. How do you feel about the care that you have received?
  - a. What kinds of services have you used outside of the UBS?
19. How would you describe your experience as a patient at the post?
  - a. Can you remember a consultation you've had at the post and tell me about it?
20. How would you describe your experiences with Dr. [name]?
21. Do you know your Community Health Worker is? What is (s)he like?

Well, that's the end of the interview! Anything that you feel is missing or should have been asked about in a different way? Any other questions or comments?

**THANK THE PARTICIPANT**

## Appendix II: Health Professional Interview Guide

### IN-DEPTH INTERVIEW GUIDE WITH HEALTH PROFESSIONALS

NOTE: TEXT IN BRACKETS SERVES TO GUIDE THE INTERVIEWER, NOT TO BE READ TO PARTICIPANT.

#### INTRODUCTION

Before we start, I want to thank you again for your participation in this study. Your participation may contribute to better understanding how primary care is delivered in São Paulo. As you know, the UBS Bom Retiro provides healthcare to most of the residents in the neighborhood of Bom Retiro. Community health workers, doctors, nurses and all others who work at the post make this possible. But less is known about what it is like to actually work at the post, and what that can teach us about health in Brazil overall. It is for these reasons that I want to conduct this interview with you today and learn more about your experiences as a [insert position] in Bom Retiro.

I want to remind you that everything we talk about today will be completely confidential. That means that I will not share what we talk about with any of the other people who work at the post or live in the neighborhood – not the director [name] nor [doctor that leads participant's team, if applicable]. I want to emphasize that I take this promise of confidentiality very seriously. I also want you to know that, as part of my job, I have conducted many interviews on health topics in the past. I say all of this so that you know that you are in an environment where you are free to share experiences, ask questions, and take a break whenever you need one. Do you have any questions before we begin?  
[ANSWER ANY QUESTIONS]

#### A. Work Experiences

- 1) Why don't you begin by telling me how you became a health care worker?
  - a. How did you end up working at the UBS?
  - b. [If applicable] What made you want to apply for a position?
  - c. What kind of process did you go through to get the position?
  - d. Did you know anyone at the post before you began working there?
    - i. Who/how?
    - ii. What did they tell you about the post?



- e. [For CHWs] Living in the neighborhood, what kind of contact did you have with the post before working there?
  - f. What did you do for work before coming to the post?
- 2) What kind of training did you receive as a [position]?
- 3) Walk me through what a typical day of work looks like for you.
- a. How do you decide who to see during your home visits?
  - b. What are some of your other responsibilities as a (nurse, doc, CHW)?
- 4) **[For CHWs only]** What is your area like?
- a. How would you describe the patients in your area?
  - b. What does it look like?
  - c. How does it compare to the rest of the neighborhood?
  - d. Have you always covered that area?
    - i. [If not] Where were located before? When?
    - ii. How would you compare the two (or more) areas?
    - iii. How did you feel about the change?
  - e. How has it been using the tablets?
- 5) How would you describe the patients you interact with in Bom Retiro?
- a. Can you tell me about one of your favorite patients?
  - b. Which patients are the most difficult (and why)?
  - c. What does it mean for a patient to collaborate?
  - d. Have you ever experienced mistreatment from a patient or family? (Elaborate...)
  - e. Have you ever felt unsafe, whether in the clinic or out on a visit? (Elaborate...)
  - f. [For direct care providers] What has your experience using What's App with patients been like?

## **B. Institutional Culture**

- 6) **[For staff who ARE part of a color team]** What's it like to be part of the (color) team?
- a. **[For docs]** What is it like for you to manage the team?
    - i. What, if anything, have you learned over time about how to do it better?
  - b. [For non-docs] What is it like to be on a team led by Dr. [Name]?
  - c. Have you always been a part of the (color) team since you began working here?
    - i. [If not] What team were you on before?
    - ii. How would you compare the two?
  - d. How would you describe your relationship with other members of the team?
    - i. What about with people not on your team?
  - e. What are your team meetings like?
  - f. Does your team have a What's App group? What kinds of messages do people send on it?
  - g. Some people have talked about how their team is like any other, while others have said that there are little things that make their team unique. What would you say about the (color) team?
- 7) **[For staff who are NOT part of a color team]** How would you describe the role of [the pharmacy, reception, NASF, etc.] in the functioning of the post?
- a. How would you describe your relationship with other members of the [pharmacy, NASF, etc.]?
    - i. What about with people not on your team?

- b. Does your team have a What's App group? What kinds of messages do people send on it?
- 8) What is the role of IABAS at the post?
- a. [If participant has been at post long-term] What was the post like before IABAS took over?
- 9) How, if at all, have things changed at the post since you began working here?
- 10) What, if anything, sets UBS Bom Retiro apart from other UBSs?
- a. How do you think the post is seen by patients in the neighborhood?
- 11) [If participant has worked in another part of SUS/other clinic] How would you describe working in Bom Retiro compared to your past work at x?
- a. What was the leadership like there?

### **C. Professional Outlook**

- 12) What do you enjoy most about your work?
- 13) What is most difficult?
- 14) What would you change about your job? About the post?
- 15) How would you describe the ideal (participant's position, e.g., nurse)?
- 16) Part of a being a healthcare worker is providing care. What other kinds of care do you provide outside of work (e.g., for family members or neighbors)?
- a. How would you compare caring for a loved one with the work that you do as a (participant's position)?

### **D. Conclusion**

I just have a few more questions for you before we end the interview.

- 17) How would you describe your own health?
- a. Are you a patient at the post?
    - i. [if yes] What has it been like to be a patient there?
      - 1. Do you have family members who receive care at the post?
    - ii. [if no] Where do you get primary care services?
- 18) What kinds of alternative medicine do you use/have you used in the past?

Well, that's the end of the interview! Anything that you feel is missing or should have been asked about in a different way? Any other questions or comments?

**THANK THE PARTICIPANT**





