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Doris Cikopana March 26, 2018

A Case Study of a São Paulo Health Clinic: Accessibility to Health Services by Patients Who Do Not Speak Portuguese as a First Language

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Abstract

A Case Study of a São Paulo Health Clinic: Accessibility to Health Services by Patients Who Do Not Speak Portuguese as a First Language

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This honors thesis explores the topic of accessibility to health services in Brazil. The thesis is a case study of the UBS Bom Retiro, a health post/clinic in the neighborhood of Bom Retiro located in São Paulo, Brazil. The neighborhood is home to multiple immigrant groups such as the Bolivians, Koreans and Paraguayans. This thesis aims to better understand how accessibility barriers work in this neighborhood and what initiatives has the staff taken to reduce these barriers. Another aim of this thesis is to analyze the level of access to health services by patients who do not speak Portuguese as a first language. Lastly, this thesis contains possible health policy suggestions that could provide solutions to accessibility barriers in UBSs that are located in neighborhoods with a similar demographic profile as Bom Retiro.

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DISCLAIMER: All of the names used are fictitious in order to protect the identity of the patients, doctors, community agents and any other person that participated in the research project.

Introduction:

During my stay in Brazil, one of the medical staff members of the UBS Bom Retiro invited me to join him on his daily home visits. While walking through the streets of Bom Retiro with Santiago, one of the community agents[1] at the *Sistema Único de Saúde(SUS)*, or the Unified Healthcare System of Brazil, I met a Paraguayan patient who frequented the UBS[2] Bom Retiro. Pedro, who was very polite and friendly, allowed me to be present during his consultation with Santiago. Santiago asked Pedro if he would mind answering a few questions regarding his thoughts on the UBS, and he agreed without hesitation. I was caught off guard, as many of the other patients had been reluctant even to acknowledge my presence at first. Before even having the chance to get to the questions, Pedro began telling me the "miracle" story of his brother-in-law, Mário. I found this spontaneous conversation interesting and quite surprising at first, so I kept listening. Pedro explained that a few years back, Mário suffered from tuberculosis when he was still living in Paraguay. Pedro's wife (and Mário's sister) had traveled to Paraguay to visit her family and had found Mário on what Pedro described as his deathbed. Scared and worried for her brother, she called Pedro. Without hesitation, he told her to bring her brother to Brazil.. Pedro described that when Mário arrived at their home, he could barely breathe, stand or speak. Alarmed and not knowing what to do, Pedro sought out Santiago to discuss Mario's case.

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[1] A community agent is someone who works at a primary health clinic. Community agents do not have any specific medical training.

[2] UBS (*Unidade Básica de Saúde*) - Primary Health Clinic. I will discuss the way an UBS works in more detail in the second chapter of the thesis

Although Pedro did not speak Portuguese fluently, he was able to communicate with the health team through Santiago, who was Bolivian and spoke Spanish. After Pedro explained the case to Santiago, he then talked to Dr. Maria, the doctor in charge of his medical team at the time. After she finished her work at the UBS, Dr. Maria rushed to Pedro's home, to examine Mário. She checked his symptoms, wrote a prescription with the necessary medication, and also made sure that he was sent to a specialized hospital. Throughout the following weeks, as Mario's health started to improve, Dr. Maria continued to visit him to make sure that he was taking the necessary precautions and that the disease was being treated appropriately. After Pedro finished telling me the story, he invited us to head over to the factory where Mário was working. Pedro and Santiago wanted to show me this "miracle" story in action.

When we entered, I saw multiple men and women working on the second floor of the sweatshop. Pedro immediately called his brother-in-law to talk to us. As he approached, it was clear that he was a different Mário from the dying man that Pedro had described. Máriowas standing and working quietly, still looking a little pale but strong enough to work at the sewing machine and to cut the fabric. When he heard Pedro call him, Mário approached us immediately. Of course, he was still recovering and under treatment, but he was able to work and take care of himself. He now felt capable of providing for himself and his family. Although he spoke in a low volume, which was a constant reminder of his illness, I had the opportunity to talk to Mário about his serious health condition. The entire family was also present working at the sweatshop and told me about how grateful they were to Dr. Maria and the medical staff at the UBS. This medical team ultimately saved Mário's life - the life of someone who came to Brazil as an immigrant - with healthcare services provided by a country that was not his own. Mário was able to receive these services that had not been available to him, at least not free of charge, in his own

country. This is a miracle story, one of the many real-life miracle cases that were presented to me, that demonstrates the significance of the UBS Bom Retiro healthcare initiatives to decrease inequality of access to healthcare for immigrants or people who do not speak Portuguese as a first language. This story was a success thanks to Santiago who eliminated any communication barrier that existed between the patient and the medical team. Dr. Maria's dedication also ensured that Mário received treatment for his condition and that his health improved.

Although Santiago, Mário and his family presented this story as a "miracle", other people in Brazil would not portray or introduce the healthcare services the same way. A middle class Brazilian might interpret this story as a common service provided by the medical system. While many immigrants and Brazilians belonging to the lower class appreciated and were thankful to the UBS staff for all of their assistance, others felt entitled to these services and saw all the efforts put in by the medical professionals as merely part of their jobs. It was common for people who had private insurance to continue using SUS services. In one case, I visited an elderly Brazilian Jewish woman on a home visit along with Dr. Alessandro and one of the community agents. The lady lived with another woman whom she had employed so she could take care of her. On that visit, I thought that she was very nice and appreciative of all of the UBS efforts. She seemed to really get along with Dr. Alessandro and the community agent. She welcomed all of our research team (I, along with my professor and another researcher) as well as the doctor and the community agent.

During one of the following team meetings, I heard a different story about the elderly lady. When the community agent had returned to visit her, she was upset because they had placed her employee's name on the same folder as hers. In the UBS, folders were organized based on living accomodations. Since her employee lived with her, the staff had created one

folder for both of them. She considered this to be beneath her and that she should not be receiving the same type of treatment as someone from a lower class. As a result, she had asked the agent to remove her own name from the folder, while commenting that the "poor people" should be the ones using SUS. Since SUS services are free of charge and available to everyone in Brazil, they are often associated with the lower classes. Although the lady had private insurance, she continued using SUS because it was convenient to have a doctor visit her at home. I believe that if this lady had experienced a similar situation as Mário's, she would not have seen or presented it to me as a "miracle" story but rather as the duty of the health team to ensure that she was cured and received all of the necessary treatments for her condition.

Mário's story is one of the success stories of the UBS Bom Retiro in regards to the immigrant population, but there are other stories and cases that do not have the same ending as this one. Although Santiago was very proud to display this success story and show me the wonderful job that they carried out at the UBS, I learned that there were other instances in which the UBS was unable to provide the best treatment for patients who did not speak Portuguese as a first language. Throughout my research stay, I encountered cases that were not always solved through the best approach. One of these stories was that of an elderly Korean lady who did not understand the doctor's recommendations and struggled through kidney stone pain. Although the UBS learned about this misunderstanding later on and found a way to communicate with the patient, the solution does not make up for the limited communication between the patient and the staff during the first consult. This was not a case mentioned to me by the UBS staff, but by another member of our research team who happened to be present during a home visit with a community agent. Thanks to the researcher, who spoke Korean, the community agent had been able to communicate with the patient and correct this misunderstanding. Throughout the time

that I spent in Bom Retiro, the staff always showed me success stories, but only rarely introduced me to cases that had not always gone smoothly. They were proud to show their successes and I do think that they also thought I would be impressed by examining such cases. Every time I asked a UBS staff member whether they remembered a time when they had not been able to communicate with a patient or address their concerns effectively, I would always receive vague answers or no answer at all. Although the UBS Bom Retiro does a great job helping patients, there are instances in which services can be further improved.

This honors thesis explores the topic of accessibility of healthcare for immigrants or people who do not speak Portuguese as a first language in Brazil. It examines Bom Retiro as a case study of a health post that provides services to patients who do not speak Portuguese as a first language. The word accessibility has many definitions, but in the context of my thesis, 'accessibility' is defined as the ability to have full access to a specific benefit such as health services. In the case of healthcare, access means that a patient is able to receive medical care and have all of his/her health concerns addressed, and if possible, solved during consults with the doctor or other medical professionals. A patient who has full access to healthcare is able to travel to a clinic, schedule a consult with a medical professional, and fully understand and participate in the consult. According to the Brazilian Constitution, access to healthcare is a right of everyone residing in Brazil (Constitution of Brazil, 112). However, in my thesis I aim to explain and analyze the idea that being able to get to a clinic is not equivalent to having access to healthcare, if the visit is unsuccessful (ex: the patient is not able to communicate with the medical professionals), and the patient does not receive the proper medical care that he/she needs and deserves.

Inequality of access to social services is a pressing issue in many countries in Latin America, including Brazil. The factors that contribute to this inequality include social class, gender, race, and citizenship status. The areas in which accessibility is unequal range from employment and housing to education and healthcare. This research project aims to explain how the inequality of healthcare access for patients who do not speak Portuguese as a first language in Bom Retiro affects the quality of patient care. The project also proposes ways in which this inequality can be reduced in the field of healthcare. In this thesis, I provide policy suggestions on improving communication and accessibility to medical services for patients who do not speak Portuguese. Communication barriers in the context of healthcare in Brazil have been under-researched; throughout my thesis, I attempt to better understand how such barriers affect access to health services and provide solutions on reducing the existence of barriers to accessibility.

As a researcher, I am particularly interested in the nexus between issues of inequality of access, communication barriers, and immigration in the field of public health. The multicultural and multilingual nature of Bom Retiro inspired my project and led me to ask questions such as: How can inequality be reduced in a highly unequal country? Is accessibility of healthcare by immigrants an issue at the UBS Bom Retiro? If so, how is it an issue? If not, how has inequality to accessibility been reduced in the neighborhood? What programs and initiatives have been taken to reduce inequality in access to healthcare services? What are the key points that ensure accessibility of healthcare by patients who do not speak Portuguese as a first language? Can these initiatives be applied to other settings to reduce inequality? By specifically conducting this research in the UBS Bom Retiro in São Paulo, I was able to explore a variety of issues that comprise and challenge access to medical care. Through this thesis, I make an attempt to address

all of these questions in my project by analyzing the data I obtained during my research as well as primary and secondary sources.

The idea of this proposal first came to mind during my study abroad trip to São Paulo, Brazil in the summer of 2016. We often had discussions about the healthcare system in Brazil as part of the program activities and during our class time. Given my interests in medicine, I immediately wanted to know more about this healthcare system that provided medical services to everyone at no cost. During our stay, we visited the UBS Bom Retiro, which later became my research site the following summer. The first time I visited the neighborhood, my professors and the rest of the people that I met in Bom Retiro told me about its multicultural and multilingual nature. I also had the opportunity to witness this multiculturalism myself during the various visits to the neighborhood. Throughout those visits, I had the chance to get to know the UBS Bom Retiro as well as the Museum of Public Health, Emilio Ribas. Later on, I was given the opportunity to carry out a research project specifically in the neighborhood of Bom Retiro and in the UBS, and it was its multicultural and multilingual nature that inspired this honors thesis.

My project shifted and developed after that first visit to Brazil , especially after I started my research internship at the UBS Bom Retiro during the summer of 2017. At first, I intended to specifically research communication barriers in the field of public health, and how they affect the quality of patient care. After spending numerous hours in consults, walking around the neighborhood, and attending a variety of health activities at the UBS, I realized that my project had expanded beyond the topic of communication barriers to exploring patients' (especially patients who do not speak Portuguese as a first language) access to health services in an unequal country such as Brazil. Researchers of inequalities in healthcare list Brazil as one of the top twelve countries that have a large income inequality (Yazbeck, 2009). Brazil is also a very

unequal country when it comes to access to healthcare. While the *Sistema Único de Saúde* (SUS) is free of charge and *available to* everyone regardless of citizenship status, that does not always mean that it is *accessible by* everyone. For example, according to a 2013 research article, significant income-related inequalities and disparities in accessibility to medical and dental services exist in Brazil (Almeida et. al., 95). Although these inequalities have declined in recent years, they remain a prominent feature of everyday life for many poor Brazilians.

In addition to income-related inequalities, regional inequalities in access to health services exist in Brazil, particularly in the Northern and Northeastern regions of Brazil. These inequalities are closely associated. In many occasions, people who live in the poorest or most remote areas do not have access to proper and necessary health services. This explains why geography plays an important role in the distribution of inequality. The same concept of inequality of access to healthcare can be applied to patients who do not speak Portuguese as a first language and have a difficult time approaching medical professionals and seeking medical care. In order for these patients to have access to medical services, they need to have the adequate skills and programs that facilitate communication and ensure that they can access public health services. The staff of the UBS Bom Retiro works hard to develop innovative and helpful ways to reduce these disparities. I will address and analyze some of these initiatives in the second chapter.

I executed this research project during the summer of 2017, sponsored by a research grant I obtained as part of the Lesser/Kitron research team. For approximately five weeks, I worked along with one of the medical teams at the UBS Bom Retiro. As a member of the team, I was a participant-observer and interacted with a variety of people, including patients, community

agents, nurses, doctors, and other residents of the neighborhood. These experiences allowed me to collect primary data for my research in the form of interviews and observations.

My research methods ranged from attending consultations with patients to reviewing secondary sources on accessibility in Brazil. I recorded observations of doctor-patient consults at the UBS Bom Retiro, during which I paid particular attention to the interaction between doctors and patients and the type of language used (including but not limited to spoken language whether it was in Portuguese or a mix of two languages, body language and gestures). I also observed doctor-patient consults at the patients' residences. These consults usually required the presence of a doctor and a community agent. The doctor always brought a community agent along with him since he/she was closer to the patient and also served as a witness. In certain cases, the nurse or nurse technician came along to draw blood or carry out other exams, if necessary. During these consults, I compared interactions between the different medical professionals. I also observed the living conditions and other details about the patients such as interaction within the families, the language spoken by them, social status, and ethnicity. In addition to these consults, I also participated in home visits with the community agents.[3] I will explain the role of community agents more in detail in the second chapter.

I also conducted interviews to obtain data on the perceptions of medical professionals and patients on topics such as SUS, patient and doctor/community agent interactions, and their opinions on communication barriers in a healthcare setting. Throughout the time that I spent in Brazil, I carried out informal, unstructured interviews with patients and semi-formal, semi-structured interviews with medical professionals (community agents and doctors). During my

[3] Home visits with the community agents - Usually the visits consisted of the agent talking with the patient about doctor recommendations, medications and other medical topics. The agents would also check the overall health of the patient/s and make sure that everything was well at home. Then the community agents would discuss this with the doctor during team meetings.

home visits with the community agents, I carried out mostly informal interviews with the patients. Most of them happened either at the patient's home or workplace, or on the street where we met, as was the case with Mário. In total, I conducted approximately eight informal interviews with patients and a total of ten interviews with medical professionals. Lastly I obtained and analyzed primary and secondary sources that covered a range of different topics, such as accessibility, inequality, and immigration. I have included a more detailed methodology section in Appendix 4.

As I finished my research and returned to the United States, I started analyzing the data collected and began writing my thesis. The first chapter contextualizes the topic of accessibility within Brazilian historym from the colonization period, through the slave trade, to the military dictatorship. I also provide data on the demographics of Brazil, and then more specifically, demographics of São Paulo and Bom Retiro, and analyze how the demographics can lead to accessibility problems. To conclude the first chapter, I include background information of the Brazilian healthcare system (SUS) and some of its challenges and problems. Lastly I explain how the existence of SUS can still lead to improved access to medical services by making healthcare universal and free of charge.

The second chapter of my thesis provides a closer examination of the current situation in Brazil in regards to access to health services and the research that I conducted in São Paulo during the summer. The beginning of the chapter explains SUS policies on healthcare and the way it functions throughout each level of care. I explain the different types of clinics that I visited while I was in São Paulo and I compare the different ways in which they operate, analyzing how these differences can lead to different levels of access to public health services for patients. Then, I analyze the data obtained during interviews with community agents and doctors

on their perceptions of SUS. Some of the information they provided includes their opinions on the benefits and problems of the Brazilian healthcare system. The universal and free of charge nature of SUS was one of the main positive aspects that the medical professionals mentioned during the interviews. The next topic I explore is the existence of communication barriers in the field of healthcare and the opinions of the medical professionals on this topic. The chapter concludes with several proposed solutions to minimizing communication barriers and accessibility problems, which I obtained through interviews and identified through my own observations.

Chapter 1: Contextualizing Accessibility

Section 1: Accessibility in Brazil

Brazil, the biggest country in Latin America, is also the fifth largest country in the world. Many times called a country of the future by journalists and scholars, Brazil is filled with different cultures and great potential for economic expansion. Being the largest country in South America both in terms of territory and population, Brazil is highly diverse in terms of racial, ethnic and cultural demographics. Brazil's demography has changed significantly over the years as immigration has expanded and continued throughout the years.

Walking down on Avenida Paulista in São Paulo, the country's economic hub, I encountered people from many different races, cultures, religions and ethnicities. I saw a Brazilian or a Bolivian immigrant, a Japanese descendant or an Afro-Brazilian. Although they are often automatically labeled as Japanese or Bolivians or African descendants, all of these groups are part of a collective Brazilian national identity and are in fact Brazilian. Simultaneously, I was also able to observe how there is a mix between people belonging to contrasting socioeconomic classes. Although they share the same physical space, many of these groups never interact with each other. As the homeless people begged on the streets, business executives rushed to return to their office after lunch. In Brazil, and specifically in São Paulo, it is easy to observe the cohabitation of different socioeconomic classes, races and ethnicities in the same physical space. While it might almost look as if these groups are mixing, they are usually segregated from each other. The people from the higher classes rarely interact with those from the lower classes.

As I walked down on *Rua Jose Paulino*[4] in Bom Retiro to get to work every day, I saw people from many different backgrounds walking around the neighborhood. Many residents were of European descent such as the Jewish coming from Poland or other European countries or the Italians or the Greeks. Surprisingly, as an Albanian-American, I felt that I fit in perfectly in the neighborhood. No one paid special attention or treated me as a foreigner. Other immigrant groups in the neighborhood were Peruvian, Bolivian or Korean. Some worked in the sweatshops and others owned the clothing stores. Although they usually seemed completely different based on their appearance and the languages they spoke, I learned to see how all of them displayed the many faces of the Brazilian identity. As I started traveling up to Northern Brazil, I was able to see a significant African influence. Once I arrived in Salvador, Bahia, I could already see a shift in racial and ethnic characteristics. It was impossible not to love the famous *moqueca de camarão* [5] and the colorful streets of Pelourinho showcasing the huge African influence.

Brazil is a very diverse and yet a highly unequal country with many disparities in fields such as healthcare. Significant gaps exist between the rich and the poor, the blacks and the whites, the Brazilians and the immigrants. Inequality is present in many different areas such as employment, living places and healthcare. During the time I was in São Paulo, I had the opportunity to visit different places where I witnessed this inequality first hand. As I visited different homes in Bom Retiro with one of the health teams, I could already see people that came from completely different social classes, economic backgrounds and ethnicities. On a single block, one home would be spacious and full of art pieces, and relatively luxurious furniture, and another down the street would be situated in a parking lot used as a place to house textile factory

[4] *Rua Jose Paulino* - The main street filled with shops (typically formal dresses stores) in the neighborhood of Bom Retiro

[5] *moqueca de camarão* - shrimp stew (a dish made with shrimp (or other types of fish), tomatoes, onions, and other ingredients brought to Brazilian cuisine by the African slaves in the 1600s)

workers . I also visited a tenement, known as a *cortiço* in Portuguese, where Brazilian northeastern immigrants were living. Children of immigrants of European descent generally owned these luxurious apartments, and those who lived in the parking lot accommodations were in large part recently arrived Bolivians or immigrants coming from other Latin American countries such as Paraguay or Peru. Their lack of Portuguese skills and unfamiliarity with Brazil led them to accept these conditions for relatively high prices.While the housing conditions for the price may not appear as a reasonable deal to me or a Brazilian person, such accomodations are often the only option for these immigrants These conditions sometimes automatically lead to a decreased level of living and healthcare accessibility for immigrants.

My research focuses specifically on the topic of accessibility to healthcare by those who do not speak Portuguese as a first language. The research I conducted was based in the UBS of the neighborhood of Bom Retiro in São Paulo. Although inequality is still present in the neighborhood, the staff members of the UBS work hard to increase accessibility to healthcare for all the residents of Bom Retiro. The issue of accessibility in Brazil has existed for over five centuries, dating back to its colonization by the Portuguese in the 1500s through the slave trade and the civil-military dictatorship until present day.

Brazil as a colony of Portugal (1500 – 1830)

The discovery of Brazil dates back to the year 1500 when the Portuguese ships first arrived in Bahia and colonized the territory that is now known as Brazil. The Portuguese wanted to expand their territory and extract goods and services from the colonies. In the process, they took control of the territory and turned many of the locals, the indigenous people, into slaves. Although the Portuguese wanted to use the indigenous people as a source of labor, the

indigenous were hunters and gatherers and not really trained to work on the sugar fields or in other industries (Skidmore, 14). The number of indigenous people, or Indians, living in Brazil at the beginning of the 16th century was large but there is a debate between scholars about the exact value. With the arrival of the Portuguese, the indigenous population decimated significantly as a result of forced labor and disease contagion.

Accessibility problems were prominent and common during this period. As slaves and non-speakers of Portuguese, indigenous people had limited access to communication, food, housing and healthcare. Although, the idea of healthcare and accessibility then were not topics such as we understand them to be today, indigenous people had very limited access to any kind of health services, except for traditional herbs and remedies that they created or collected. The Portuguese relied on the indigenous community for slave labor at the beginning of the 16th century. Although the Portuguese continued to enslave the indigenous people, they soon realized that they could not rely on the Indians as a primary source of labor, as the number of indigenous people decimated drastically (Maggi, 15). Their immune system was not strong enough to fight off all of the foreign diseases brought by the Portuguese. The diseases brought by the Europeans, malnutrition, slave labor and mistreatment led to negative health outcomes for these indigenous people. These outcomes automatically point out to a lack of access to proper nutrition, freedom, and medical care. The indigenous people have been discriminated against and mistreated throughout Brazilian history. Throughout the years they have decimated in numbers for many of these reasons, demonstrating that inequality of access for the indigenous groups continues to remain a problem in Brazil. To combat these disparities, the Brazilian government created organizations such as the Indian Protection Service (SPI)[6] in 1910, the Aerial Sanitary Units

[6] SPI - Organization that protects the rights of indigenous people and protects them against violence, persecution and discrimination (Indian Protection Service (SPI)).

Service (SUSA)[7] in the 1950s, and the National Indian Foundation (FUNAI)[8] in 1967 (Maggi, 15). Other organizations and government branches that protect the rights of the indigenous people are the Special Indigenous Health Department(SESAI) created in 2010 and the Instituto de Medicina Integral Prof. Fernando Figueira (IMIP). These organizations serve to protect the rights of the indigenous people, and consequently reduce barriers to accessibility for this group of people.

Slavery in Brazil

Like many other countries in the Americas, Brazil has a long history of the slave trade. Brazil received the highest number of slaves in the world, and it is the last country to abolish slavery in the Americas (Hébranrd, 48). It is impossible not to address the topic of accessibility to health services, food, housing and freedoms when discussing slavery. Slavery officially started in Brazil by the settlement of the Portuguese in 1530, but different forms of slavery had existed beforehand as members of indigenous tribes enslaved representatives of other tribes (Hébrard, 48). The Portuguese first enslaved people from the local population, but they soon realized that many of the indigenous people could not survive the diseases brought to Brazil by the European colonists. Because of the continuous deaths of the indigenous people as a result of diseases and the consequent reduction in the labor force, the Portuguese started bringing African slaves to Brazil.

The Portuguese colonizers initially relied on slaves who were brought from West Africa, who usually came through the Bahia bay on ships (Skidmore, 17). Hence, there is a significant African influence in Bahia and the entire Northern and Northeastern parts of Brazil. By the

[7] SUSA - An organization created in the 1950s that was linked to the Ministry of Health and provided care in remote areas (Maggi, 15).
[8] FUNAI - This is a branch of the Brazilian government responsible for setting up the policies in relation to indigenous people (FUNAI - National Indian Foundation (Brazil)).

1580s, the Portuguese were bringing large numbers of slaves to Brazil, which is how the slave trade, which would last until the 1850s, began. Just like the indigenous people, the slaves faced a lot of health problems; half of the slaves would already die en route to Brazil because of the horrible sanitation and living conditions on slave ships (Skidmore, 17). Once the survivors arrived in Brazil, they were sold to the highest bidders. In their new "homes", they lived in very harsh conditions and were often mistreated, which affected their health negatively. Imprisonment, the terrible conditions in the traveling ships, mistreatment and separation from their families led to the poor health of the slaves (Kenny, 1). Other factors that led to declining health for these individuals were sexual abuse, forced breastfeeding for female slaves, and living life as a captive. Accessibility to health services or any cures for these conditions were non-existent or very limited for the slaves throughout the slave trade.

The slave trade lasted for over 300 years, with the 19th century being the period in which the highest number of slaves were brought to Brazil (Pôrto, 1019). There were very few laws that protected the slaves, and most owners did not respect the laws that existed. Slaves did not have direct access to health services. During epidemics when they did not want to lose slaves, the owners would reduce violence or the amount of labor assigned to slaves, since slaves were their only source of labor. They often relied on "*curandeiros, quimbandeiros*[9]*, feiticeiros* " (healers, magicians, witchdoctors) as providers of healthcare (Pôrto, 1022). Slaves believed that disease and health were something of a supernatural nature, which explains their beliefs in the medical practitioners mentioned above that had no official medical training. The slaves relied on traditional remedies and non-licensed medical professionals such as the healers, and they also believed in wearing amulets that were supposed to protect them against disease. Slaves also used African medicine which was often utilized by the whites (Pôrto, 1023). Although the slaves who

[9] *Quimbandeiros* - magicians that are part of an African religion called Quimbanda

practiced African medicine were seen as impostors, many people, including slave-owners, continued to use their services (Pôrto, 1023). Slaves found a way around the issue of accessibility to healthcare as best as they could but of course their high mortality rates show that hindrance to accessing medical services affected the Afro-Brazilian population greatly. Slavery was finally abolished on May 13, 1888 in Brazil (Skidmore, 70). As seen in the history of the indigenous and the slaves, both groups were compelled to find ways around accessibility barriers. Something that groups had in common was that they did not speak Portuguese. Communication could have been an impediment to accessibility for these groups of people. While the Indians, received protection against discrimination when accessing government services later on, slaves did not. Regardless, indigenous people and Afro-Brazilians continue to be treated unequally and face challenges in regards to accessing government and health services.

	Spain / Uruguay	Portugal / Brazil	Great Britain	Netherlands	U.S.A.	France	Denmark / Baltic	Totals
1501-1600	119,962	154,191	1,922	1,365	0	66	0	277,506
1601-1700	146,270	1,011,192	428,262	219,931	4,151	38,435	27,391	1,875,632
1701-1800	10,654	2,213,003	2,545,297	330,014	189,304	1,139,013	67,334	6,494,619
1801-1900	784,639	2,469,879	283,959	3,026	111,871	203,890	16,316	3,873,580
Totals	1,061,525	5,848,265	3,259,440	554,336	305,326	1,381,404	111,041	12,521,337

Table 1: Slave Trade Estimates[10]

Abolition of Slavery and Immigration to Brazil

The 1800s were years of turmoil and important changes in Brazil. In 1864, Brazil and Paraguay went to a war that lasted for about six years and ended in 1870 (Skidmore, 43). After the war, Brazil underwent important changes such as the abolition of slavery and received huge

[10]"Assessing the Slave Trade: Estimates." *Voyages,* Voyages, http://www.slavevoyages.org/assessment/estimates.

waves of immigration from Europe and Asia. As I mentioned in the section above, accessibility to health and government services was a huge problem for slaves who were mistreated and were not offered any legal protection. The abolition of slavery led to more opportunities for increased accessibility for liberated slaves. Abolitionists had existed for years and had been fighting for the liberation of the slaves in Brazil.However, the abolitionist movement only became popular and obtained support in the 1860s and 1870s (Skidmore, 68). The work of abolitionists such as Joaquim Nabuco, André Rebouças and Luis de Gama and criticism from abroad led to the passing of landmark laws like the "Law of the Free Womb"[11] and "the Sexagerian Law"[12] that eventually led to the abolition of slavery (Skidmore, 69). Abolition was finally achieved on May 13, 1888. This led to a huge inflow of immigrants from different European countries. Right after the abolition of slavery, the previous slave-owners needed new sources of labor, which they sought to obtain from immigrants. Simultaneously, the elites wanted to "whiten" Brazil. By receiving a large influx of immigrants from European countries and through miscegenation, Brazil would have increased numbers of non-blacks. The largest numbers of immigrants came from Italy, Portugal, and Spain respectively (Skidmore, 71). The majority of them went to São Paulo. In 1908 the Japanese immigration to Brazil began. Some of the children of these immigrants nowadays live in Bom Retiro, the neighborhood where I conducted my research. There is a large number of Italian, Portuguese and Japanese descendants in today's São Paulo. Brazil continues to receive many immigrants from other countries such as Bolivia and Paraguay.

Civil-Military dictatorship (1964-1985)

[11] Law of the Free Womb - Law that was passed in 1871 in Brazil that stated that all of the children that were born from slave mothers were automatically free, however they had to serve the owner of the mother until they turned twenty-one years old (Skidmore, 69).

[12] Sexagenarian Law - Law that was passed in 1885 in Brazil that stated that all slaves over sixty-five years old were free (Skidmore, 69).

The civil-military dictatorship in Brazil, which overthrew President João Goulart from power, started in 1964 with a coup d'etat led by the military generals (Skidmore, 159). The military took control of the country and placed General Humberto de Alencar Castelo Branco as the first President of Brazil under the civil-military dictatorship. In comparison to other Latin American countries that had a single leader who ruled throughout the entire length of the dictatorship, the Brazilian military maintained a more democratic façade by rotating power between the military generals. Elections were maintained and Congress continued to function, even though the elections were always altered or rigged to suit the interests of the military leadership. The civil-military dictatorship is usually described in three stages. The first period, lasted from 1964 to 1968 and it is considered to be the lightest phase of the dictatorship. The numbers of torture, killings and forced disappearance cases are a lot lower compared to those of the second stage of the dictatorship, which started in 1968 and ended in 1974. The second period was characterized by high numbers of torture cases, forced disappearances and political killings. This stage was also the harshest phase of the civil-military dictatorship and it was known as *anos de chumbo*[13]. The harsh and repressive nature of the dictatorship during this stage caused the most accessibility problems. The last stage of the Brazilian dictatorship which lasted from 1974 to 1985, served as the political opening that led to the democratization of Brazil. About three years after democratization, the national Brazilian healthcare system, SUS, that still exists today and made healthcare universal, was created as part of the new 1988 Constitution.

The issue of accessibility continued to exist throughout the civil-military dictatorship in many aspects of life including personal rights, healthcare, information and freedom. In 1968, Congress passed the harshest institutional act known as *Ato Institucional 5* (AI-5), which

[13] *Anos de chumbo* - Years of lead; Refers to a period of high levels of censorship and oppression during the Brazilian civil-military dictatorship

restricted individual rights and even suspended habeas corpus in the case of political crimes (Skidmore, 164). This automatically restricted people's access to freedoms and rights, particularly for the militants who were active in armed organizations. The harsh censorship of the media restricted the public's access to information on what was happening in the country. Many Brazilians did not know that some of the activities such as torture and killings were taking place in Brazil at the time. The majority of political prisoners were tortured with the purpose of obtaining information. They did not have access to medical services during their imprisonment.. In multiple torture cases, a doctor would be present for the sole purpose of ensuring that the prisoner did not pass out or die too early without sharing any useful information. Some of these activities still take place today, as Brazilian police often violate the law by torturing and mistreating individuals who live in the poorest areas such as slums and tenements.

Throughout the civil-military dictatorship, accessibility to healthcare, freedoms, and information, was restricted and not available for many people such as the political prisoners and anyone who did not support the regime at the time. Healthcare in Brazil was very different from what it is today and SUS still did not exist. The democratization after the military dictatorship contributed to the creation of SUS.

Section 2: Demography of Brazil

Geography and demographics are two important topics to keep in mind when studying accessibility in Brazil. Based on its geography and demographics, it is possible to analyze where decreased levels of accessibility to healthcare and government services are concentrated and why. Brazil has a total area of 8,515,770 sq. km and is divided into five different regions: the north, the northeast, the center-west, the southeast and the south (The World Factbook: Brazil, 2017). This separation has various implications for the inequality of access to healthcare and

other government services. The most recent population estimation of Brazil for 2017 is 207.353.391 people (The World Factbook: Brazil, 2017). Roughly forty-eight percent of the population is white, forty-three percent is mulatto (mixed), and eight percent is black and one percent is Asian and then a very small percentage is comprised of the indigenous people. As this data demonstrates, Brazil is a racially and ethnically highly diverse country. This high level of diversity, as a result of the language and cultural differences and differing social classes, unfortunately leads to inequality of access in many spheres of life such as education, employment, and healthcare.

The diverse demography of Brazil is a result of the different immigration patterns in the country. The first people to live in Brazil were the indigenous; then arrived the Portuguese, who later on brought the Africans. The poorest areas of Brazil, in which a very low level of accessibility is observed, are in the north and northeast regions. Many people are unemployed because of the frequent droughts that lead to the bankruptcy of the rural workers. As a result of this, a large number of people migrate to the southeastern region of Brazil to look for new job opportunities, making the region one of the most populated sections of the country. Accessibility to healthcare in the northern and northeastern areas is very limited because there is a lack of doctors and medical resources. The people who live in these areas often do not have any access to health services. Dr. Victor, who had worked in the northeast in the past, stated during an interview that he often faced more communication barriers with Portuguese speakers with a lower education than with immigrants who did not speak Portuguese fluently but had higher levels of education. Dr. Victor shared that he had a hard time communicating with people with a lower level of education, because they often would not understand his instructions, which consequently led to a failure in the following the directions. Many people in the Northeast and in

other parts of the country face accessibility problems when it comes to education, which can result in lowered access to health services in certain cases.

While I was in Brazil, I learned more about the problems related to physician shortage and unequal doctor placement across the different regions of Brazil. I was also introduced to a program called *Mais Médicos*[14] by Dr. Alessandro and some of the other doctors that I met. Dr. Alessandro, although he was Brazilian, was actually a part of this program. Some Brazilian doctors can take a test and enter a competition to be able to work as part of the program. Dr. Alessandro had benefits that other doctors at the UBS did not have, such as a four-day work week and the ability to dedicate the remaining one day to doing research and keeping up to date with new medical innovations. There are different opinions in Brazil regarding the program. The people who receive treatment thanks to the existence of this program really appreciate it and are thankful to the doctors. Other people such as doctors who have studied medicine in Brazil, often do not support the program because they believe that the foreign doctors are taking their jobs. Doctor placement in Brazil is a problem because there is a large discrepancy between the high demand for medical professionals and the low availability of doctors (Kirk et. al., 468). Another issue is that many of the professionals who were educated in Brazil want to work in city centers or in the southeastern areas of the country. Since areas in the northeast of Brazil are not as convenient as those in the southeastern part, many doctors do not want to move to the northeast. When I use the word "convenient", I am referring to location, proximity to different services and the availability of the necessary health resources needed for the doctors to perform their job. In response to this, the government under Dilma Rousseff, the President at the time, created the program *Mais Médicos* to bring doctors from abroad, especially Cuba, who could work in these

[14] *Mais Médicos* - More Doctors; A Brazilian program intended to bring international doctors to Brazil to work in underserved areas. However, there are opportunities for Brazilian doctors to work as a part of this program.

less popular regions (Kirk et. al., 467). When I visited the UBS where Cuban doctors worked, I witnessed the impact of this program firsthand. I will explore my interactions with these doctors in the second chapter of my thesis.

Bom Retiro was very conveniently located in the center of São Paulo, while the health post where the Cuban doctors worked was in the periphery of the city, in a hill. Getting to the Bom Retiro health post on a daily basis was an easy task. All I had to do was get on the metro from my apartment on Avenida Paulista and I would reach the clinic in less than twenty minutes. Traveling to the other health post, which was located in Vila Maggi, was quite the opposite experience. The neighborhood was inaccesible by metro and the only way to get there was via bus or car. The relative difficulty of access and the physical location of the clinic explain why some Brazilian doctors may not prefer working there. Without these Cuban doctors, the residents of the neighborhood would possibly be left without a neighborhood physician. I was able to witness the impact of these doctors firsthand. One of the consults that I shadowed involved a newborn child. The medical team made sure to visit mothers of newborn children in their homes to check in and to teach the mothers how to lactate and take care of the newborns. This would have not been possible without this program. *Mais Médicos* is the Brazilian government's attempt to decrease inequality of access to healthcare in remote areas. Although there are problems with the program and many people do not agree with it, the program is highly appreciated by families that have been able to gain access to medical services thanks to these Cuban doctors. This is one of the various programs and initiatives taken to increase access to health services.

Section 3: São Paulo

São Paulo is a state in the southeastern region of Brazil. Although it is not one of the biggest states in terms of size, São Paulo has the largest population in the country. It is a huge and very diverse state where it is possible to observe the nature of Brazil's diversity. As I spent weeks walking through its streets, I encountered people from various backgrounds and everyday was different. The nature of the city has changed a lot over the years from what it used to be. São Paulo used to be a coffee-producing state, therefore an agricultural society, which was a characteristic that attracted immigrants in the late 1800s and early 1900s (Lesser, 65). As a result, it was the state of São Paulo that received the largest immigrant influx in the entire country. The presence of immigrants and the mixing of different races, ethnicities, languages and cultures led to inequality.

Right after the abolition of slavery in 1888, Brazil needed to find more laborers to work in the coffee production industry in São Paulo. Since at the time there were efforts to "whiten" the population, the government created policies that opened the doors of Brazil, and especially São Paulo towards immigration. São Paulo received immigrants not only from out of Brazil but also from the northeastern part of the country. The government doubled its spending on immigration in 1891, which reached more than eleven percent of the government's total expenditures (Lesser, 70). São Paulo received more than two million immigrants in the period between 1890 and 1930. These immigrants were mostly European such as Italians and Portuguese, and other immigrants were the Japanese (Lesser, 73). The influence of these immigrant groups is still present today in São Paulo. Many of the people who currently live in the neighborhood of Bom Retiro, for example, are descendants of Italian, Eastern European and other European immigrants.

After the Europeans, came the Japanese and the Koreans. Korean immigration to Brazil, which was mostly focused in São Paulo, began unofficially in 1910 (Choi, 234). Many of these Korean immigrants entered Brazil as naturalized Japanese citizens. The official Korean immigration to Brazil began in the 1960s (Choi, 235). While the Korean immigrants today work mostly in commercial businesses such as sweatshops, they initially came to Brazil to work in agriculture. Since most of them came from the middle or upper classes in Korea, they were not able to adapt to a rural lifestyle. This inability to adapt pushed the Koreans to move to the city of São Paulo so they could work in the industrial field. The city housed many immigrants, which gave the Korean immigrants hopes to achieve better living conditions (Choi, 235). They tried to move to the neighborhood of Liberdade where many Japanese immigrants were located. Not knowing the language and unfamiliar with the city of São Paulo, it was important for the new Korean immigrants to have people from a similar culture to help them integrate into this new life. The Koreans initially began working in sweatshops, and they later started to own these spaces. Recently, I observed that São Paulo is receiving a numerous amount of Bolivian, Peruvian and Paraguayan immigrants. They now occupy the jobs previously held by the Koreans in the textile factories. It is possible to argue that, in São Paulo, immigrants have the ability to ascend the socioeconomic ladder throughout generations. I observed this ascendance in status daily in Bom Retiro as I met children of immigrants who now lived in nice houses and owned sweatshops, while the newly arrived immigrants worked for them. Throughout immigrant generations, the lack of access to specific services decreases as they ascend in social status, while the new immigrants face more challenges in accessing specific services such as healthcare.

The multicultural, multilingual and multiracial nature of São Paulo ultimately renders the city a prime location for accessibility issues to arise because of communication barriers and

socio-economic disparities. Socioeconomic class and language, among other factors, influence accessibility to employment, social services, and especially healthcare. Immigrants who do not speak Portuguese as a first language face challenges finding jobs, good places to live and receiving medical care because of communication barriers. As I visited different housing accomodations with the community agents, I witnessed these challenges myself. Once, we visited a parking lot that was located in the neighborhood of Bom Retiro. On top of the parking lot were "apartments" built from very thin wood planks where many Bolivian and Paraguayan immigrants lived. The community agent told me that many of these immigrants paid very high rents to share that space with other families. This is one example of the immigrants' limited access to proper living spaces, especially when they first arrive in Brazil. It is also another demonstration of how people of different socioeconomic backgrounds often share the same space but never actually interact. While people who could afford cars parked there everyday, they did not even know of the existence of these "apartments" and did not interact with any of the people who lived there.

This is not unique to São Paulo, but immigrants, especially those who did not speak the language, worked in labor intensive jobs such as those in sweatshops. They worked long hours for a small amount of money. As part of my research, I visited some sweatshops and met the workers there. Everyone that I met was a Paraguayan or a Bolivian immigrant. In many cases, they worked and lived in the sweatshops. One floor or one room in the building was where they worked; next door, they had a small room where they lived. In one instance, I went with the medical team to a sweatshop to offer consultations with the doctor and the rest of the UBS staff (physical educator, psychologist, nurses, etc).

These visits were common for the UBS Bom Retiro. The medical professionals would have one day a month to visit a textile factory and provide consults and other medical services to the workers. Since the majority of these laborers work the entire day, they do not have the time to visit the clinic. At one sweatshop I visited, I saw an entire family that worked and lived in the same place. The workers even had their little children with them, who were maybe around two or three years old. While they were sewing on the machines, the children would play around the room with each other or sit on their parents' laps while they worked. Without the initiative of the health team, these children and their parents might not be able to access medical services. This is a perfect example where, even though the medical services are free of charge, the lack of time and maybe even language skills, hinder the patients from complete access to healthcare. By not being able to communicate or not having time to visit a primary care clinic because of long work hours, a patient may have a hard time registering for a SUS card, scheduling a medical appointment, and understanding the consult.

Section 4: Bom Retiro

Bom Retiro is a culturally and linguistically diverse neighborhood located in the center of the city of São Paulo. At the moment, the neighborhood is a highly frequented shopping space. Bom Retiro's textile industry has attracted and still attracts a lot of immigrants who are looking for jobs to the neighborhood. As I walked on the Jose Paulino street on a daily basis, I never ceased to look at the beautiful bridesmaid dresses displayed on the shop windows. The clothes on display were often sewn by immigrants who worked in the sweatshops located on the second floor of the stores. On a weekday or a weekend, the streets of Bom Retiro were crowded with shoppers, workers and residents of the neighborhood. I experienced rush hour in Bom Retiro

almost every day throughout my research stay. The narrow streets were always filled with people walking around, rushing to get on the metro or to return home. The workers would rush to close the stores and prepare them for the next day.

Bom Retiro is a busy commercial and urban neighborhood in the city of São Paulo. However, Bom Retiro was not always an urban center such as it is today. In the 19th century, Bom Retiro contained mostly farms, especially because of its prime location in between the Tamanduei and the Tietê River (De Oliveira, 2016). These farms were used as weekend getaways or "*retiros*", which translates to retreat in English, for the elite class who spent their busy weeks in the city of São Paulo and went to Bom Retiro on the weekends to rest (Muniz Pires, 1). The inauguration of the São Paulo Railway in 1867 is what led to the start of the development of the neighborhood to what we see today. The construction of the *Estação da Luz*[15] followed right after (De Oliveira, 2016). A beautiful station and right in the center of São Paulo, *Estação da Luz* continues to be a very important landmark in the city. It contains a metro (CPTM) and a train station that people use everyday to travel to other parts of the city. As I used the metro station every day to travel from my apartment on Avenida Paulista to Bom Retiro, I noticed that the Luz station was always packed. People kept running from the metro to the train or from the street to the metro. The station offers connections to the *Linha Rubi e Coral* [16]of the CPTM and has access to the *Linha Amarela*[17] of the metro. Rush hour was very crowded but also an eye-opening experience, because it was a perfect place to see the shared space between people coming from completely different backgrounds. The station is a beautiful showcase of the São Paulo diversity. The station led to the development of Bom Retiro into the center of commerce

[15] *Estação da Luz* - Luz Station. A busy metro station in the center of São Paulo that is located close to the Bom Retiro neighborhood. One of the most important metro and train stations of São Paulo
[16] *Linha Rubi e Coral* - Rubi and Coral lines. Train lines in São Paulo
[17] *Linha Amarela* - Yellow line. Metro line in São Paulo. It is one of the busiest lines because it provides connections to all the other lines of the metro.

for the city of São Paulo. The São Paulo railway and the Luz station allowed for the movement of people and materials, and, by the second half of the 19th century, the neighborhood started attracting many workers and developing different industries.

The first *Hospedaria dos Imigrantes*[18] was also built in Bom Retiro, which attracted a large number of immigrants who would later become crucial for the neighborhood as well as for the city of São Paulo (Muniz Pires, 1). In the beginning of the 20th century, the first immigrant groups started arriving in Bom Retiro; the majority of them were of European descent, such as the Italians and the Portuguese. At the time, Bom Retiro came to be known as a working-class neighborhood. In the 1920s and 1930s, as the Italians started to move out of the neighborhood to live in more residential areas, Bom Retiro received an influx of Jewish immigrants from countries such as Russia, Lithuania and Poland (Muniz Pires, 1).

Although Korean immigrants had arrived in Brazil earlier on, Korean immigration to Bom Retiro was the largest in number in the 1990s (De Oliveira, 2016). At first, the Koreans worked as textile factory workers. Later they started to buy these factories and turned Bom Retiro into the nucleus of their community. Their previous professions as sweatshop workers are now occupied by Paraguayan and Bolivian immigrants. I had the opportunity of seeing this while I was in Bom Retiro. I visited a sweatshop with the health team where the owner was Korean and her employees were Bolivians. A common phenomenon that I observed in the neighborhood was the ascendance of immigrants to a higher socioeconomic status. The European descendants and the Koreans now owned the more luxurious homes or the businesses, while the newly arrived immigrants worked in sweatshops. Of course, most of the immigrants that faced inequality of access were the newer immigrants who did not speak Portuguese and belonged to a lower socioeconomic status.

[18] *Hospedaria dos Imigrantes* - Immigrant Receiving Center

Although the population of the neighborhood continues to change throughout the years in terms of ethnicity and nationality, the majority of those who live in Bom Retiro are still immigrants or children of immigrants. The main immigrant groups in the neighborhood today are the Koreans and the Bolivians. However, there are still Jewish, Italian, Portuguese and other immigrant groups living in the neighborhood. Two big groups are the Paraguayans and the Peruvians. Accessibility to healthcare can be an issue for these immigrant groups as they learn Portuguese and start to adapt to a new country. It is important to create programs that help immigrants integrate into Brazilian society. The Brazilian healthcare system was built to promote equal access to healthcare by everyone who lives in Brazil, whether they are immigrants or people who were born in Brazil. The UBS Bom Retiro has devised initiatives to uphold this promise of equal access to everyone in the neighborhood.

Section 5: The Creation of SUS

Brazil's current healthcare system offers medical services free of charge to everyone who resides in Brazil. This system is called *Sistema Único de Saúde,* or Unified Health System, and is most commonly known as SUS. It was created as part of the Brazil 1988 Constitution (Gragnolati et. al., 15). The creation of SUS was the result of various health reforms undertaken in the past, especially in the 1980s. Before the creation of SUS, the main source of healthcare for citizens in Brazil was the Social Security System. One of the most successful movements in reaching health system reforms was the sanitary movement (Gragnolati et. al., 17). The movement identified the main problems with the health system at the time, which were underfunding, inefficiency, and most importantly, unequal access to healthcare by the population. Therefore, the movement asked for a better healthcare system that would treat more people than just workers or those present in target zones. It also focused on personal care rather

than collective care. In the past, the Ministry of Health had prioritized providing healthcare services to large groups of people, such as worker unions, in order to treat large-scale epidemics. The focus in the health of the country was the main goal of the Ministry of Health, which subsequently drove the attention away from the health of the individual.

Article 196 of the 1988 Constitution states that "Health is a right of all and a duty of the State and shall be guaranteed by means of social and economic policies aimed at reducing the risk of illness and other hazards and at the universal and equal access to actions and services for its promotion, protection and recovery" (Constitution of Brazil, 112). The Constitution also states that the funds used for health provision should be provided by the Union, the Brazilian states and the Federal district. Nonetheless the SUS contractors do not have to be public officials. Oftentimes, SUS contracts with doctors and hospitals from the private sector to provide public healthcare. While SUS was created as a universal healthcare scheme, the universality in access does not always happen in reality. Even though everyone should have the same opportunities to access healthcare in theory, there are multiple factors that impede access by some and advantage others.

Some of the problems noted with the new health system are long wait lines for diagnostic and specialist services, poor quality of care and patient dissatisfaction (Gragnolati et. al, 16). During one of the informal interviews that I conducted with patients in Bom Retiro, I heard the same complaints. The patients, Julia, Nelson and Paulina, were part of a Bolivian immigrant family residing in the Bom Retiro neighborhood. I met them on a home visit with Santiago. After Santiago made sure that everything was well with the family and finished his duties, I asked them about their experiences with SUS and specifically with the UBS Bom Retiro. At first, they were reluctant to answer. As they talked about the UBS, they had minimal complaints. They

admired their doctor and the entire team. All of a sudden, once they were referring to the system of SUS in general, they told me about the challenges they faced such as the long waits at the specialist's office.

Nelson needed an appointment with the ophthalmologist and he had been waiting more than two months for one. His vision continued to grow worse but he had not been able to schedule an appointment yet. Nelson and his family said that the doctors and medical professionals at the hospital seemed to not care about them as patients. They would usually prescribe something and never double checked whether the patients understood the instructions. Paulina, Nelson's mother, was elderly and did not speak any Portuguese. Although she spoke some Spanish, her native language was Quechua, an indigenous language. She said that during her consults with specialists, she always had a hard time communicating and understanding what they said, because of their rushed speech of the medical professionals. Another problem they encountered was a lack of time and available transportation to travel to the hospital. Even though these patients had the opportunity to receive medical care free of charge, other obstacles such as transportation, communication barriers and the disinterest of medical professionals led to limited access to public health services. The details of the operation of SUS and specific policies will be further discussed in the second chapter.

Chapter 2: SUS and Accessibility to Healthcare: Field Experience with SUS

Section 1: SUS policies on accessibility to healthcare and reality of access

The Constitution of 1988 guarantees the legal right of access to healthcare to everyone who resides in Brazil (Constitution of Brazil, 112). SUS was created to abide by this provision of the Constitution, i.e. provide this legal right. The medical services offered by SUS are available to residents of Brazil at no cost. Legally, any person that resides in the country, whether the person is a visitor, an immigrant or a Brazilian citizen, has the right to obtain a SUS card. Once the patient has obtained a SUS card, he or she can start scheduling medical consultations and accessing other health services. Although this is part of the law and it is written in the Constitution, sometimes barriers to accessibility to healthcare arise for those who reside in Brazil.

Some of these barriers are related to citizenship status, social separations, economic disparities and communication differences. In the case of immigrants or other people for whom Portuguese is not a first language, there is a possibility that they may be unaware of these services. As I will discuss later in the chapter, even though there are clinics that have devised initiatives to reach these residents, sometimes immigrants might not be aware of the existence of SUS. I only met patient who visited the health post, therefore I did not have the opportunity to meet any of the residents who were not users of SUS or the UBS Bom Retiro. Similarly, the patients that know of the existence of SUS do not always know how it functions. There are no classes offered regarding the operation of SUS for patients. Unless a medical professional explains how SUS works or they read SUS-related information on their own, the patients most likely will not know how SUS functions. I had the opportunity to learn more about SUS and its operations through personal exposure and observations. By the end of my first week in São

Paulo, I had already learned a significant amount of information on SUS, starting with the levels of care, up to how a specific clinic worked. While I was shadowing Dr. Alessandro and some of the community agents, they explained many aspects of SUS to me. During our lunch breaks or when we would go on house visits, the medical professionals would teach me new information about the SUS program and how the system operated. Since I learned so much about SUS in a very short time, I expected patients to know or at least be familiar with the same information. However, this was not always the case. My presence in Brazil was related to my purpose of researching the healthcare system, hence the reason I was able to learn so much about SUS. The patients, on the other hand, had busy schedules that did not allow them to attend doctor consultations and learn about SUS. During my interviews and home visits, the patients were not always fully aware of the services offered by SUS or how it actually worked. This is an example which calls for the need for increased patient education on SUS and how it works. In order to reach and educate the most patients, the Ministry of Health needs to create classes or hand out pamphlets about the operation of SUS. Medical professionals also need to explain to patients how the system works in workshops organized by the UBS or during home visits.

Another barrier to access healthcare or other social services was socio-economic status. Although a patient may know that SUS exists and that they were entintled to obtain health services at no charge, the patient did not always have the time or the means to get to an UBS or an AMA. Depending on their socioeconomic status, patients might work long hours and not be able to get to an UBS during its operating hours. For example, the UBS Bom Retiro opens at seven in the morning and closes at seven at night. These are the typical working hours for UBSs in São Paulo. At a glance, it might look as a flexible time schedule but in reality it does not allow for sweatshop workers who spend more than 12 hours at work to visit the UBS. Later in the

chapter, I will talk about the initiatives that the UBS Bom Retiro staff has taken to attempt to ensure that these patients have access to medical services despite their busy time schedules.

Section 2: Functioning/Operation of SUS

The three main principles of SUS are universality, equality and integrity (SUS: Princípios e diretrizes, 2013). These principles, especially universality, came up frequently in my interviews, which I will discuss further in this chapter. By looking at these principles, ostensibly, it can be concluded that there are no accessibility problems since healthcare is supposed to be universal, equal and integral. However these principles are not always ensured as mentioned above.

When I was shadowing, I had conversations with the doctors regarding the operation of SUS. On one of these occasions, Dr. Alessandro explained that SUS has four levels of care: primary, secondary, tertiary and quaternary. The primary level of care could compare to primary basic care in the United States even though it operates very differently. This level focuses more on the prevention and detection of diseases as well as the treatment of simple conditions and testing for various illnesses. I had the most exposure to this level of care since I spent the majority of my time in an UBS, which is part of the the primary level. The secondary level is more specialized and treats more serious conditions and usually occurs in hospitals or in AMEs (*Ambulatórios Médicos de Especialidades*) - Medical Ambulatories of Specialties. It focuses on conditions that require to be treated by a doctor trained in specific specialties. Specializations such as cardiology, neurology, among others, are part of the secondary level. The tertiary level of care focuses more on surgical and nonsurgical procedures such as childbirth, appendix removal, etc. The quaternary and last level of care takes place in *Hospitais de Excelência* (Hospitals of

Excellence). This level usually treats more complex conditions and focuses on complicated and long procedures such as transplants.

Since my research has a direct focus on the primary level of care (however, I did have indirect and very little direct exposure to the three other levels), I will provide a more detailed explanation of this specific level. The primary level is made up of different health institutions which are AMA (*Assistência Médica Ambulatorial*), UPA (*Unidade de Pronto Atendimento*), and UBS (*Unidade Básica de Saúde*). Each of these centers functions differently and offers specific types of health services and treatments. While I did spend the majority of my time in Brazil doing research in an UBS in Bom Retiro, I had the opportunity to visit two AMAs and three other UBSs. During my informal interviews with patients and some of the medical professionals, I learned more about the other levels of care, especially the secondary and the tertiary levels. Since the doctors at the UBS direct patients to AMEs and hospitals, the UBS is closely related to these other levels.

An UBS is the most similar Brazilian institution to a primary health clinic in the United States. However, a Brazilian UBS and a US primary health clinic function very differently, given that both countries have different healthcare systems. Some of the most common medical services offered at an UBS are a doctor's appointment, a nurse's appointment, laboratory tests (the samples of blood are taken at the UBS and sent to an independent laboratory to examine them), vaccinations, free medications (pick up happens at the pharmacy), and wound curatives. A doctor's consultation in Brazil differs from a typical appointment with a general practitioner in the United States . During the consultations that I shadowed, the doctor had to check the patient's physical condition, talk with the patient about their problems whether they were physical, psychological or emotional, and then fill out all of the paperwork. The doctor spent a full fifteen

minutes with each patient. Since most of the time fifteen minutes were not enough to do carry out all of these procedures, the doctor would prioritize the most important aspects of the consultation, such as completing the physical examination and having a conversation with the patient.

In Brazil, every neighborhood is expected to have a functioning UBS. According to the way SUS works, patients have to use services at the UBS located in their neighborhood. However, the medical staff at an UBS is required to provide urgent medical care to anyone during an emergency. When accessing a service at an UBS for the first time, patients need a SUS card. It order to obtain a SUS card, the patient needs to provide the UBS with an identification card, which does not necessarily have to be issued by a Brazilian institution, a proof of address, such as a lease contract, and a gas or electricity bill or a certificate of ownership. While I was in Bom Retiro, there were patients who went to the reception to get registered, and others that had a community agent complete their registration at home. In cases in which communication barriers existed, registration resulted to be difficult.

On one specific occasion, I went to a patient's home along with a community agent to register the patient for services at the UBS. A community agent is a resident of the neighborhood who works at the UBS. Community agents do not have any official medical training. The only required education for a community agent is that she/he has completed high school. After they are hired, community agents are expected to take courses and receive training on the functioning of SUS. Since community agents usually live in the area of the neighborhood for which they are responsible, they can find out about any changes happening in their area. This is very important when discussing accessibility. Community agents play a crucial role in improving access to healthcare services by always being informed of new residents in the neighborhood, maintaining

close contact with their patients and preserving the link between the patients and the UBS. They are the medical professionals that interact with the patients the most since they visit them on a monthly basis. In the case of the patient that we visited, the community agent was told that a new Paraguayan family had moved to Bom Retiro. The family was part of her territory, therefore as part of her responsibilities she had to go to the patient's house and register her and her family for services at the UBS. This is an example of how the presence of community agents reduces accessibility issues. Community agents ensure that any resident who lives in the neighborhood is registered at the UBS so they can access medical services. In this specific case, communication barriers were not a huge problem, since the mother spoke Portuguese. Although she was the only one in her family that spoke Portuguese, that really helped the medical professionals.

All of the UBSs that I visited had multiple medical teams that worked on different areas of the neighborhood. Each team generally has a doctor, a nurse, two nurse technicians, and six community agents. The team has assigned streets and territories for which they are responsible. The way in which areas of coverage are distributed amongst the medical teams can be better understood by looking at the maps of the areas covered by the UBS Bom Retiro, which I have included in the appendix. The professionals in every medical team work closely with each other to treat individual patients. All of the UBSs treat a large number of patients, for example the UBS Bom Retiro treats about 6789 families (UBS Bom Retiro, 2017). Then each team treats roughly about 1200 families, which means about 4800 people per team. Since there is no possible way for one doctor to see these many people in a month or possibly even every six months, there are community agents that facilitate the link between the UBS and the patients.

Every community agent is responsible for about roughly 200 families (UBS Bom Retiro, 2017). As part of their responsibilities the community agents have to visit each family every

month and ensure that everything is fine. Community agents work remotely from the UBS everyday by visiting different homes and work-place locations where they confirm that their patients are following the doctor's recommendations and are feeling well. During a home visit, community agents look at different aspects that might affect a patient's health such as the conditions in which they live, the relationships between the family members and the emotional stability of patients. Each team at the UBS has a weekly team meeting in which the doctor, the nurse, the nurse technicians and the community agents all meet to discuss their patients' cases. I was able to participate in multiple team meetings at the UBS Bom Retiro and in one team meeting at the UBS Vila Piaui. In these meetings, the community agents discuss their home visits with patients with the other medical professionasl of the team. This ensures that there is proper communication within the team and that the doctor of each team knows everything necessary about their patients. By having this information, they can try to make sure that the patients have proper access to medical services and are provided with the best treatment.

Another SUS program is the *Programa da Saúde da Escola* (PSE) - the Program of the Health in School, which promotes communication between the schools in a neighborhood and the UBS (Weber et al., 124). For example, if a teacher perceives that a student is struggling with his/her homework and learning process they may refer the child to the doctor of the UBS and communicate with the staff there. By doing this, the teachers ensure that the child is seen by a doctor and properly treated by the appropriate professionals. Although in principle, this is a great program and can improve access to healthcare for children through communication with the school, sometimes there are schools which are not as involved in these programs. While I was researching at the UBS Bom Retiro, I heard about certain cases of children who were referred to the UBS by the school because they had an alphabetization problem. One of the doctors and

some of the community agents mentioned that one of the schools was not very cooperative and they would not help children with their problems. All of these children were Bolivian or Paraguayan immigrants who had issues with alphabetization because of the similarities between Spanish and Portuguese. The children were mixing up the languages because they were exposed to both and were not able to differentiate between the two. The doctor worked closely with the families to explain that while the children were still young, they needed to be spoken to in only one of the languages so they would not get confused. This would not always prove to be the best solution. In cases in which parents only spoke Spanish, they could only communicate in that language with the child. Then when the children went to school, the teacher would speak to them in Portuguese. He would also ask about whether the child was having any emotional problems at home or at school. This could sometimes affect the child's intellectual development and their behavior in school.

During the time I was shadowing doctors and community agents, I learned that when talking about health in Brazil, it is comprised of emotional, social and psychological aspects. The UBSs follow a program called *Programa da Saúde da Família* (The Program of the Health of the Family), because it is important to assess health inside of the family to ensure that all of the aspects mentioned above are met. In addition to the different medical teams, an UBS also has a specialized team called *Núcleo de Apoio a Saúde da Família* (NASF) - The Nucleus of Support of the Health of the Family, that is comprised of different health professionals. The size of this team usually varies depending on the size and location of the UBS. In general, NASF includes professionals such as a physical educator, a physical therapist, a phonoaudiologist, a nutritionist, a social worker, a psychiatrist and a psychologist (Núcleo De Apoio a Saúde Da Família (NASF)). In UBSs that are bigger or have more resources, the NASF team also includes a

pediatrician, an ophthalmologist and/or a dentist. The NASF team is expected to have meetings with each of the medical teams weekly or biweekly to discuss different patient cases.

In certain occasions in the UBS Bom Retiro, a patient would be seeing the doctor as well as a psychologist and a nutritionist. I was able to participate in a few of these consults, and I understood why it was important to have all of the professionals present. In the case of a patient who suffered from a mental disorder, the doctor usually held consults with her along with the psychiatrist. While the doctor knew the patient, the psychiatrist had a closer relationship to her and was better trained to help her calm down and focus on what the doctor was saying. The doctor was explaining to the patient how to use a specific medication but she was drifting off into other topics. She said that the medications were not good for her and that she had bought other medication. The doctor alone was not able to convince her to use the medications, but the psychiatrist helped her focus and eventually convinced her to take the medications and leave.

During the meetings between NASF and the medical teams, they discuss the cases to ensure the best care for each patient. The patients that are discussed during these cases are those who need the support of at least one of the NASF professionals. For example, a patient who was struggling with weight problems had the support of the psychologist, the nutritionist and the doctor. In this way, the doctor could take the best route to treat the patient. By maintaining constant communication between the teams, usually there were no misunderstandings. This is very crucial when discussing accessibility. Patients had increased access to a wide range of medical services close to their homes at their local UBS. By having all of these services nearby, several accessibility problems such as transportation costs and low proximity with the medical professionals could be reduced.

Consults and any other services at the UBS are generally offered by appointment only. The doctor and the nurse usually have an occupied schedule so sometimes it might take a month or more to obtain an appointment for a routine check. This is one of the problems that usually came up at UBSs according to the individuals that I interviewed. The lines are long and the wait times as well. This was also one of the main negative aspects of SUS mentioned in interviews with doctors, community agents and patients. However, there are other medical institutions available to treat emergencies or any other type of condition that require immediate attention such as AMAs and UPAs.

An AMA is a medical center that treats patients in emergencies that can range from something as light as a simple cold to something more serious such as fainting or another medical problem. AMAs usually treat conditions of low to middle complexity but can also receive more complex cases. In these occasions, the doctors try to treat the patient in an emergency and sometimes transfer them to more specialized and trained centers that deal with higher complexity emergencies such as UPAs or other emergency rooms at hospitals. In comparison to UBSs, AMAs do not require nor offer appointments. A patient can just visit the AMA and ask the receptionist to see a doctor. The patient will then be asked to wait depending on the seriousness of the condition and will be seen by a doctor based on the order in which they came to the AMA. Something that AMAs have in common with an UBS, is that they also are based on the place of residence of the patient. For example, one AMA might pertain to four different neighborhoods. Sometimes AMAs can be in the same building as an UBS, in a separate building or inside of a hospital. While UBSs usually are not open on weekends, AMAs are open to treat patients even on weekends. The AMA that I visited in Boracea operated on Saturdays and Sundays.

The existence of AMAs allows for increased access to medical services in a shorter amount of wait time. If a person needs immediate assistance, they are more likely to receive it quicker at an AMA. If the person has a headache that is bothering them and cannot wait to get an appointment with the doctor at the UBS, they can attend an AMA. While it might take a month or more to schedule a doctor's appointment at an UBS, a patient can be seen within that same day at an AMA. Some of the problems that exist with AMAs are long wait lines on certain days or the bad usage of AMAs. One of the issues that I heard doctors working at an AMA mention was the case of patients who go to the AMA just so they will receive a justification of not having to go to work. The doctor has to give it to the patient if they complain of pain or something else such as nausea and vomiting. In some cases, the patients will alter the documents given by the doctor so they can obtain more hours/days off. I visited an AMA on two different days, and I heard both of the doctors complain about this issue on both occasions. They called this type of patient, "the typical Brazilian patient" that always finds a way to dodge the rules. Another type of clinic that treats emergencies is an UPA.

An UPA is similar to emergency rooms in the United States. They treat more serious cases such as car crash victims, gunshot wounds, heart attacks, etc. There are two different types of UPAs: *Pronto Socorro* (PS) and *Pronto Atendimento* (PA). Usually the *Pronto Socorro(*Emergency Room*)* treats more complex cases than the Pronto Atendimento but they both serve the same purpose. Having all these different types of clinics can lead to increased accessibility to health services by patients. I did not have a chance to visit an UPA while I was in Brazil, therefore I cannot give a proper evaluation of these services.

Section 3: Observations from UBS and AMA visits

Visiting four different UBSs and two AMAs afforded me the opportunity to compare these different clinics based on their type and location. The four UBSs I visited were the UBS Bom Retiro, the UBS Vila Maggi, the UBS Barrafunda, and the UBS Vila Piaui. I also visited the AMA Boracea and the AMA Vila Piaui. Each of these clinics were located in different parts of the city. In this thesis, I will explore the UBS Bom Retiro more closely, since that is the focus of this project as well as the health post where I spent the majority of my time. I visited the other UBSs and AMAs to observe the functioning of SUS in different settings and compare it to that of the UBS Bom Retiro. I also wanted to identify if some of the accessibility problems or solutions to these issues seen in the UBS Bom Retiro were also present in these other institutions. One of the other UBSs that I visited was the UBS Vila Piaui.

The UBS Vila Piaui is located in the periphery of São Paulo. I had the opportunity to visit the UBS along with an odontologist and his students during one of their projects in the USP School of Dentistry. As part of their program, the students had to visit different UBSs and learn more about the way they functioned. Although a large part of these students would choose to work in the private system after graduation, learning more about SUS and how it functions was part of their curriculum with the hopes that some of them would want to work in the public sphere. This is very important in terms of access to health services. If more doctors are willing to work on the public sphere, then there will be more medical professionals available to treat patients in remote areas. This would increase healthcare accessibility for people who live in less privileged areas as well as people from a lower socioeconomic background. The students that I spoke with enjoyed this part of the curriculum, however they thought it was hypocritical since they saw it as a way for their professors to teach them “how the poor people live”, which was usually not the case of their professors. Although these initiatives to introduce students to the

public sphere of healthcare are a good idea and could reduce accessibility problems, sometimes they are not always carried out in the best manner. Some of these students came from lower socioeconomic classes and found the way in which life in slums and poorer areas was portrayed to be offensive. The day I visited the UBS Vila Piaui, the students offered me a ride back home. During the ride back, they were telling me about a time in which they had to visit a slum and how the professor had criticized one of the families living there by making a comment on the items that they kept in the fridge.

While going to the UBS Bom Retiro was relatively easy and safe for people living in the center of the city, getting to the UBS Vila Piaui was more challenging and complicated. In order to get there, I needed to catch the metro, the train and the bus. Luckily, I was able to obtain a ride with the odontologist. The UBS was located in the border of the municipality of São Paulo and a slum called *Os Ascos*. One of the main accessibility problems that I learned about in this location was the fact that the residents of *Os Ascos* did not have access to the UBS. Since placement to UBSs is based on regionality, *Os Ascos* was part of another municipality therefore every resident needed to attend another UBS that pertained to that area. The problem with this was that for many of the people who lived across the street, it was more convenient to visit the UBS Vila Piaui since it was a lot closer than the UBS that was assigned to the *Os Ascos* neighborhood. While the students, the odontologist and I all agreed that this did not make sense, it was in fact a huge problem for the UBS and the municipality. However, nothing was being done to fix the problem. Although this was an evident issue, the Ministry of Health had not taken any steps to improve the situation. Even if medical professionals sometimes want to improve accessibility of access, they cannot achieve it without the assistance of the government.

The AMA Vila Piaui was located in the same building as the UBS Vila Piaui. The AMA Vila Piaui was receiving a large influx of patients from *Os Ascos* who did not have time or did not want to visit the UBS for the area of *Os Ascos*. This caused long lines at the AMA as well as overcrowding of the building space. This was one of those cases in which the AMA was not being used the way it was supposed to by the patients. Since an AMA cannot send patients away and is required to attend all of those who require medical attention, they had to see and treat all of the patients. The AMA Vila Piaui and the UBS Vila Piaui functioned completely separately although they were located in the same building and covered the same area, therefore the AMA did not have any extra help from the UBS to treat the large influx of patients from *Os Ascos* and the residents of Vila Piaui. In this case, although the patients could see a doctor at the AMA, they had limited accessibility to healthcare because of the issue of regionality that limited their use of the UBS Vila Piaui.

Another clinic that I visited that was also located in the periphery of São Paulo was the UBS Vila Maggi. Traveling to this UBS was as complicated as going to the UBS Vila Piaui. It took about an hour or an hour and a half to arrive from the center of São Paulo to Vila Maggi via car. If I had taken the train and the bus it would have taken a lot longer, maybe even up to two or three hours. This UBS was in the outskirts of the city, therefore the majority of the doctors working there were Cuban and part of the program *Mais Médicos* which I mentioned earlier in the first chapter. A large part of the area for which the UBS was responsible was located on a hill. It was very similar to a slum. While I was visiting the UBS, I had the opportunity to go on a home visit along with the nurse and a community agent. It was raining and we all went to the house of a newborn baby so the nurse could teach the mother how to wash the child, breastfeed him, etc. Since I only spent a few hours at the UBS I did not have a chance to observe more

cases. Some of the issues that I heard relating to accessibility at the UBS was the fact that some of the Cuban doctors did not speak Portuguese fluently prior to arriving at the UBS. However, these doctors were expected to have taken some Portuguese courses before starting their work at the UBSs in Brazil. They would usually take this class while they were in Cuba and would go through basic training before they started working in an UBS in Brazil. While in the case of Bom Retiro, the patients were non-Portuguese speakers and faced communication barriers, the situation was reversed in this UBS. The Cuban doctors did not fully speak Portuguese so that could sometimes lead to communication barriers between them and the Brazilian patients. I had very limited conversations with these doctors, but I was able to communicate with them in Portuguese without any problems. I also had the opportunity to witness a meeting with a Brazilian doctor who was responsible for evaluating the performance of the doctors working there and he mentioned that they had received very high ratings. The patients were thankful for the presence of these doctors at the neighborhood. Although minor communication problems could arise, the patients preferred having access to a doctor than none at all.

The last UBS I visited was located near the center of São Paulo. This was the *Centro de Saúde Escola Barra Funda* - Center of Health and School Barra Funda. This UBS was a little different from all of the other ones. It served as a health post but it also functioned as a place for doctors in training. There were several residents and students who were doing their rounds and practicals there. This UBS had more resources compared to the other three that I visited. I had the opportunity to learn about all of the programs and services they offered, and they even had a research study for a ZIKA vaccine happening at the UBS at the time. The UBS communicated with experts in other countries to consult on and solve complicated cases. All of these additional services were supposed to increase accessibility for patients. The UBS had multiple medical

teams that served on three different territories. The first team mostly treated immigrants who worked in sweatshops or other Brazilian families, the second territory had a large number of elderly couples and the last one was located in a slum. I had the opportunity to visit the slum along with two community agents who worked at the UBS Barrafunda.

The UBS Bom Retiro was where I spent the majority of my time doing research. The UBS was located in the neighborhood of Bom Retiro in the center of São Paulo. Although the UBS treated a large number of patients and was located in the center of the city, the size of the building was relatively smaller compared to two out of the three other UBSs that I visited. The doctors mentioned that they had tried to ask for expansions multiple times but it had not been possible. The UBS had a total of five consultation rooms, one of which was mostly used by the nurses and the rest were used by the doctors. The rooms were many times used by different doctors and nurses throughout the day. Although there were five nurses and five doctors, not all of them had access to a consultation space during the time they were working, therefore they could not see as many patients. In addition to the consultation rooms, the UBS had a reception where the patients first went to when they arrived at the UBS. The reception staff checked the patients in and directed them to the proper locations inside the UBS. Then the UBS had a room for meetings, offices for the administration staff, another room for procedures/a nurses' area, a waiting room, a pharmacy and a small room for vaccinations. Compared to the UBS Barrafunda, the building of the UBS Bom Retiro was a lot smaller. The UBS Barrafunda in addition to having all of the areas mentioned above, also included a room that was used for research projects, for medical records, and specific areas for treating children and pregnant women. The number of patients treated by each UBS did not differ significantly.

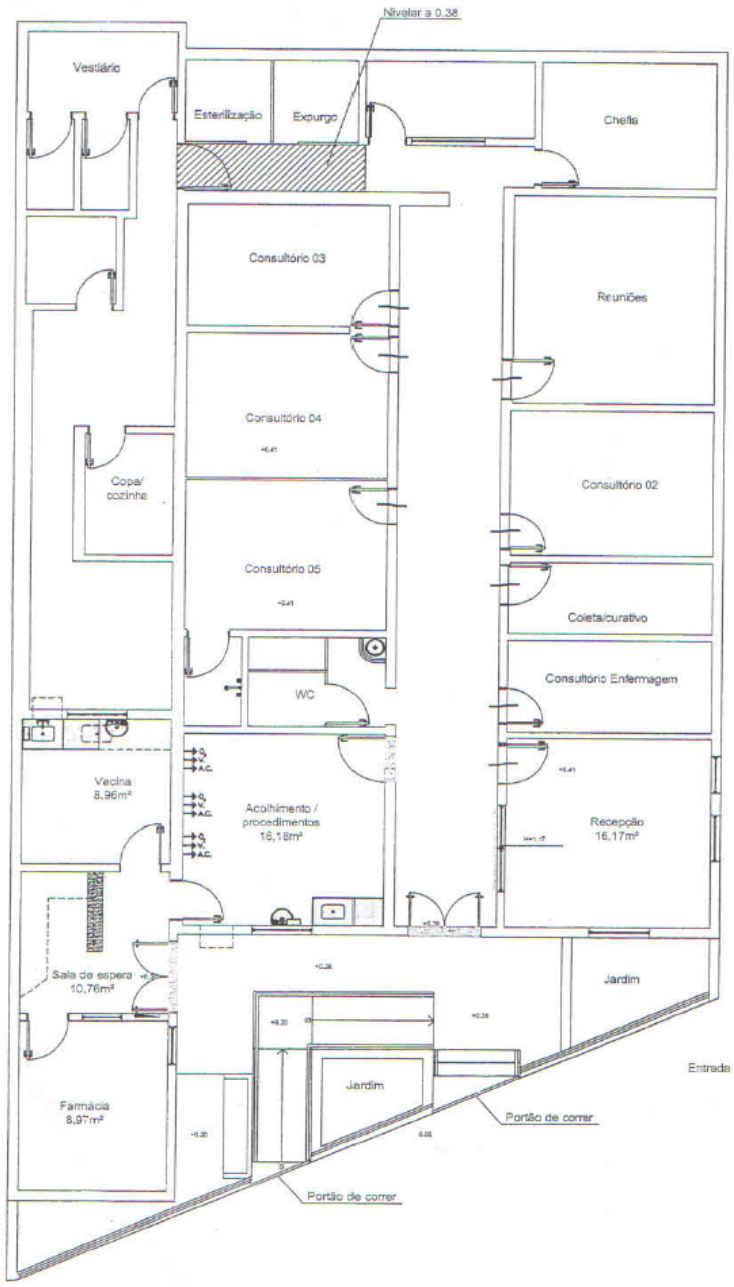

Figure 1: Floor plan of the UBS Bom Retiro (Source: UBS Bom Retiro)

Something unique to the UBS Bom Retiro due to the neighborhood in which it was located, was the large number of immigrants that the UBS treated. This was also one of the main aspects about the UBS that inspired my research. This UBS treated the largest number of immigrants/ non Portuguese speakers compared to the other places that I visited. This can be

seen in Appendix 3 where I included information on the number of immigrants and refugees treated by the UBS Bom Retiro (UBS Bom Retiro, 2017). For instance, 13.9 percent of the individuals treated by the Red (vermelha) team at the UBS Bom Retiro are immigrants. That is a significant percentage of patients that do not speak Portuguese. This unique attribute of the UBS led to the creation of different initiatives to decrease accessibility problems for immigrants. The UBS had hired community agents and doctors from different communities that spoke languages other than Portuguese, such as Spanish. Recently, I learned from Dr. Alessandro that the UBS Bom Retiro has also hired a Korean doctor. I believe that this will help greatly in reducing communication and accessibility barriers for Korean patients. The staff at the UBS also created signs in different languages to attract more patients to get vaccinated and use the services at the UBS. These are only a few of the solutions that the staff had created to increase access to healthcare services for patients of the neighborhood.

Section 4: Current Perspectives on SUS: Interviews with Community Agents and Doctors

As part of the interviews that I conducted, I asked five community agents and five doctors to express their opinions on SUS. I started by asking questions about their opinion on how SUS functions based on their profession, and then moved on to ask about the positive and negative aspects of SUS. All of the community agents and three of the doctors that I interviewed worked at the UBS Bom Retiro. One of the remaining two doctors, Dr. Victor, worked at the AMA Boracea which I visited on two occasions. Then during the week he also worked at an UBS and an UPA. The other doctor, Dr. Emiliano, was Korean and actually had his own clinic which focused on acupuncture. Dr. Emiliano had lived in Brazil for 27 years and mentioned that he had never used SUS except for one time when his son had needed surgery. He was the only

medical professional that I interviewed that worked on the private system and was not related to SUS in any way. Dr. Emiliano believed that SUS was very important for Brazilian citizens as well as immigrants. In comparison to the other doctors I interviewed, Dr. Emiliano was very serious and quite strict. When I went in along with a Korean researcher who introduced us, he had already prepared a drink that he offered us and pointed to where specifically we should sit. In the other occasions, the doctors had been a lot more informal. Although he complimented SUS, he had only used it in one instance for his son's surgery. As a Korean immigrant and a doctor of traditional medicine, he chose not to use the Brazilian healthcare system but instead had purchased private insurance. When he spoke about SUS, he seemed genuine in believing that it helped a lot of people, however he himself did not want to use it unless he had no other option. He talked about how SUS had helped a lot of Korean immigrants that were his acquiantances. Dr. Emiliano prefered using the private system when it came to him and his family. The fact that he had only used SUS in one specific occasion was a proof of this. He said that some of his Korean friends had used SUS and were satisfied with the medical services, especially childbirth. His experiences with SUS had mostly been indirect and through acquaintances who had used it.

I received multiple answers, some of which overlapped at times and others did not. I noticed some overlap in the doctor's responses in relation to the positive and negative aspects of SUS. In some occasions, each individual interpreted the question differently and focused on specific aspects of SUS. Just like I had expected from the beginning, the one main positive aspect of SUS on which everyone agreed was the universality and gratuity of SUS. Every single person that I interviewed mentioned this as one of the positive aspects of SUS. They believed that SUS was available to everyone no matter the social class, race, citizenship or economic status at no cost. However, it was interesting to see that some of the doctors almost contradicted

themselves on this when they mentioned SUS's inability to reach everyone as one of the negative aspects of SUS. Dr. Victor, for instance, mentioned universality as one of the most positive aspects of SUS, and then a few minutes later, he talked about how SUS could not reach everyone because of the different social classes and regional inequalities. Although according to the law, healthcare is available to all of the people in Brazil, it is not always accessible by everyone.

One of the doctors working at the UBS Bom Retiro, Dr. Alessandro, mentioned universality, integrity, distribution of territory, priority of cases based on the seriousness of the condition, and gratuity as positive aspects of SUS. On the other side, he acknowledged that even though SUS works well in general, it has its problems, such as the bad administration of the system and resources, long wait times for specialty consults and exams, lack of medication, increased levels of bureaucracy in certain cases, and unequal distribution throughout the country. This last problem of SUS is very important when thinking about accessibility. Although SUS is universal, it is not equally distributed throughout the country. Those who live in the cities and in the center have increased access to health services compared to those who live in small villages or in the periphery. Dr. Victor and Dr. Gabriel also mentioned unequal distribution and coverage throughout the country as one of the main problems of SUS.

According to Dr. Victor, SUS is not able to reach the entire population because of long wait times. In many occasions, patients either do not have time to wait in line and decide to not go to the doctor or they give up after trying to see a specialist for months and not succeeding. Another reason for this unequal coverage is the fact that there are very few medical professionals in Brazil to care for a large population. In cases in which patients have to work and cannot take a day off, they might miss a consult and not be able to schedule or obtain another one. Other problems include lack of medication in certain UBSs or pharmacies. One of the examples that

Dr. Victor mentioned, was the case of a patient who needed antibiotics. He said that the pharmacy at the health post had amoxicillin which can treat the illness but does not work the same for all patients. A more appropriate medication would be clarithromycin, but this medication was only available for purchase by patients. Since many patients could not afford the medication, they did not have access to the proper treatment for their condition. In these cases, Dr. Victor said that he prescribes amoxicillin for the patients which can improve their condition slighly, but does not cure it completely. The lack of and limited access to medication was one of the negative aspects that was mentioned by all of the community agents and the majority of the doctors.

All of the community agents expressed that in their opinion SUS is a great program. However they also pointed out that it has several problems. Out of the five community agents interviewed, only one of them, Catalina, did not mention any specific negative aspects of SUS other than the lack of resources. She said that she thinks that there are a lot of problems with SUS but if she started talking about them she would say more than she should. Catalina said that she preferred not to talk about the negative aspects of SUS and I accepted that and continued with the rest of the interview. I found this interesting and intriguing since all of the other community agents expressed their opinion on some of the negative aspects of SUS. Catalina had worked for SUS for a long time and had been at the UBS through several transitions. She did mention that she used to like working for the UBS better when it was run by another company. That could have influenced her view on SUS. Catalina, in her interview, also mentioned that if she would describe SUS based on what she had learned previously it would be "*lindo e maravilhoso*" (beautiful and wonderful) but in reality it needed a lot more improvements. She

said that she didn't know whether it was the fault of the people, of the system itself or the politicians.

Throughout the interviews I received some ambiguous answers and silences. These answers and silences showed that there is still a lot of work left for SUS to be fully accessible by different types of patients. All of the community agents were also patients at the UBS and users of SUS. This could put a bias on my results since the agents were also patients and needed services from the UBS so their answers might not be completely objective.

Section 5: Communication Barriers in the UBS Bom Retiro

Other factors that greatly affect accessibility to health services are language and communication barriers. There has been very little research done on the field of language and cultural barriers in Brazil. Some of the areas that need to be explored further are the effects of cultural and linguistic barriers and how to overcome these effects. There are gaps in literature relating to these topics in Brazil, however, a significant amount of research has been carried out in relation to linguistic and cultural barriers in the field of public health in other countries such as the United States and Europe.

Language barriers are widespread in the healthcare system in the United States due to its multicultural nature. Existing research on linguistics and patient care shows that in the United States patients who have limited English proficiency (LEP) receive inferior quality care compared to patients who are proficient in English (Green and Nze, 264). Also, non-English speakers are more likely to suffer adverse effects and permanent harm when receiving care than those who speak English fluently (Oliva, 73). One study that examined care for children whose parents were non-English proficient, found that the mothers of these children go through a lot of struggles in healthcare settings (Steinberg et. al, 1320). These mothers described their

experiences with healthcare professionals as “battles” (Steinberg et. al, 1320). They often were not offered interpretation services and had to ask consistently to receive one. This was also very common when I was working in Brazil. In fact, there were no interpreters employed at any of the UBSs or AMAs that I visited. Although having an interpreter could be helpful and was better than not having one in the United States context, mothers preferred bilingual healthcare providers, instead of having an interpreter present. Communication with the provider was a lot easier and clearer in that way. These mothers also felt that they had been discriminated several times because of the language barriers that existed between them and the healthcare staff. The article about children whose parents are not proficient in English also proposes different solutions to decrease language barriers such as having more Latino physicians and offering patients or their parents access to Spanish-speaking physicians (Steinberg et. al, 1324). In general, having more bilingual and multilingual physicians would help greatly in decreasing language barriers in healthcare. This would make patients from other countries feel more comfortable as well as be able to better communicate with the medical professionals.

The Brazilian healthcare system, SUS, does not have any specific programs in which translators are available for those who do not speak Portuguese. Based on a research project conducted by Mylene Queiroz, the only available interpreters for patients who face language barriers are volunteer interpreters (Queiroz, 194). These volunteers do not have any specific training in the area of interpretation. This could be a particularly dangerous and delicate matter in the context of healthcare and public health because of the difficult medical activities carried out by the professionals (Queiroz, 201). I was able to witness this at the UBS Bom Retiro. The UBS did not rely on any translators or interpreters. In consults with patients who did not speak Portuguese, the doctor or the nurse or the community agent had to find a way on their own to

communicate with the patients. This affected the quality of care received by the patients. One example would be that of the elderly Korean lady who went through kidney stone pain as a result of not understanding the doctor's instructions. Since the doctors and agents had to spend more time on trying to enable communication, often they did not have time to address everything that was needed in the consult. The time allocated to each doctor appointment was fifteen minutes per patient. Non-Portuguese speakers did not receive any extra time although it took longer for them to communicate with the doctor. The lack of additional time allocated to each consult decreases the level of access to health services by patients who do not speak Portuguese as a first language. The use of interpreters/translators would improve communication and accessibility to health services for those who do not speak Portuguese as a first language.

As Brazil's population of immigrants increases, there is a need for programs that focus on helping these individuals to better communicate in healthcare settings. Although there are certain clinics that have small programs that focus on the health of the immigrant, such as the *Centro de Saúde Escola Barrafunda*, based on my observations, the medical professionals usually try to find a way on their own to decrease linguistic and cultural barriers. Sometimes that works, and in others it does not. Since health is such a delicate topic, it is important that proper communication is achieved between the patients and medical professionals. In the case of the UBS Bom Retiro, even though the staff treats a significant number of non-Portuguese speakers, there are no professional translators employed. However, two Bolivian community agents, a Bolivian doctor and a Colombian doctor work there. The medical professionals at the UBS did find ways on their own to minimize language and cultural barriers that might exist between them and the patients. There are times in which they are successful and others in which they are not.

I had the opportunity of learning about a case in which an elderly Korean patient had attended a consultatio and did not understand what the doctor had recommended. The doctor had thought that the patient had understood everything, so he had sent her home. Then, when the community agent visited the lady with a researcher from our team that spoke Korean, they discovered that the old lady had felt a lot of pain and had not known what to do. Without the presence of the researcher, the medical professionals most likely would not have found out about this miscommunication. The miscommunication between the doctor and the patient could result in negative health outcomes for the elderly lady. This is a case in which I witnessed limited access to healthcare services. Although the lady was able to go to the UBS and meet a doctor as well as other medical professionals, she was not able to receive the proper medical care that she had needed because of communication barriers. When being offered medical care, non-speakers of Portuguese also need to be provided with the option of having an interpreter who can translate and mediate between the doctor and the patient.

In other cases, the staff at the UBS Bom Retiro was able to get through these communication barriers and achieve treating the patient properly. Communication was a lot easier with patients who spoke Spanish due to language similarities between Spanish and Portuguese. Although the staff was able to avoid or minimize language and cultural barriers in most cases, there still existed occasions in which communication was very difficult or impossible such as the case I mentioned above. Throughout the time I was there, I observed some consults or home visits with the community agents in which there was very limited communication between the patients and the medical professionals. The majority of these patients were Chinese or Korean and they did not speak Portuguese. One specific case was a middle-aged Korean man who only knew how to say very basic expressions in Portuguese. The staff was not able to

communicate with him unless his wife was present. However, the community agent or the doctor would speak slowly and use mimicry to ask him where his wife was or to try to interact with him. Sometimes, this would not work but on other occasions the man would understand what the doctor said and would try to communicate using body language and his limited Portuguese vocabulary. In the interviews that were carried out, the medical professionals described some of these communication barriers and shared their opinions on how they could be minimized even more and what tools could be used to help doing that. I will mention these solutions in the next section of this chapter.

There were multiple cultural differences that existed between the health professionals and the patients. At the UBS, the majority of the staff was from Brazil and only spoke Portuguese. An aspect that really helped with the Bolivian and Paraguayan communities was the presence of two Bolivian community agents. There were also two other doctors that spoke Spanish as their first language, one of them from Colombia and the other from Bolivia. One of the Bolivian community agents, Santiago, was very involved in the Bolivian community and played a very important role in the relationship between the UBS and the Bolivian patients. Santiago had a radio station and a newspaper that targeted specifically the Bolivian community. Other patients that listened to his radio station and read the newspaper were the Paraguayans. Some of the medical professionals in the UBS mentioned that before he joined the team, the Bolivian patients did not come to the UBS, they would not open the door to the doctor or the agents because they were scared to interact with the medical professionals out of fear related to immigration concerns and lack of trust. This is one example of how the UBS Bom Retiro has reduced accessibility problems through the initiative of employing professionals that are part of the different groups in the neighborhood.

After Santiago joined the UBS team, the Bolivian patients began to trust the medical professionals and started using the medical services offered at the UBS. Everyone talked about how these patients changed and allowed the health team to enter their homes. Then, they started attending doctor consultations at the UBS. This community agent was able to get his message across to the Bolivian patients because he was a part of their community. Also, his radio station and newspaper helped him communicate and maintain his connections with the patients. Santiago spoke Spanish, and a little bit of Aymara and Quechua which are two indigenous languages spoken by Bolivians and Paraguayans. Santiago was very involved with the Bolivian community and participated in many cultural events organized by the community. In the interview that I conducted with him, he said that he had worked with other communities in the past to create Portuguese classes for the Bolivian immigrants in the neighborhood. Having these types of programs and employing community agents who spoke different languages and were considered a part of the different immigrant groups, had really helped attract more patients to the UBS. By offering language classes, the patients would learn some Portuguese and be able to better communicate with the medical professionals. In this way, they could understand the doctor and have increased access to medical services.

During my time observing, there was a large number of Bolivian patients frequenting the UBS on a daily basis. The presence of Santiago decreased the existence of cultural and linguistic barriers between Bolivian and Paraguyan patients and the UBS, at least in terms of visiting the UBS and using the medical services offered there. The fact that he spoke Spanish, Quechua and Aymara helped a lot, but the most important thing was that Santiago was seen as a part of the community and had gained the trust of the Bolivians. The languages that they shared in common and his participation and engagement in these activities had created this relationship between the

agent and the patients. During the home visits that I attended with Santiago, the patients showed a lot of respect towards him and always asked Santiago for advice on solving their problems. As we walked around the neighborhood doing home visits, many patients stopped Santiago to ask him medical questions and address their problems. Then, Santiago checked that everything was going well and reported that information to their doctor. This was another instance where I saw the importance of the work of the community agents at the UBS, who ensured that patients had access to medical services and sometimes facilitated communication between them and the other medical professionals.

Some of the cultural differences that existed between Brazilians and other Spanish-speaking patients such as Bolivians and Paraguayans, were the frequency of going to the doctor, following up with the UBS during and after pregnancy, alimentation, and hygiene. As these immigrants moved to Brazil, they had to adapt to new ways of living and follow the doctor's instructions. As mentioned by a community agent in one of the interviews, the medical professionals often had a hard time convincing pregnant women to always come to consults and make sure that they were getting all of their vaccines. As far as hygiene, there were a lot of cases in which the children had cavities or other dental problems because they did not receive proper mouth hygiene. Although the doctors emphasized the importance of maintaining mouth hygiene of the children, in a lot of cases the parents would not follow through with the instructions. In some occasions, it could be because the parents did not grow up with those expectations and did not understand its importance and in others because they did not understand or ever learned how to do it. The agent stated that they always tried to convince the patients to come to consults regularly and follow the doctor's instructions but they always do it in such a way that they do not disrespect the patient's culture. For example, although maintaining proper mouth hygiene was a

problem in the Bolivian community, the agents explained the importance of the practices of maintaining mouth hygiene without using terms that would make the patients feel bad for their lack of it. The community agents explained how being diligent with their medical appointments would help the patients' health and would be beneficial to them in the long run. It was the agent's job to ensure that the patients followed through with the instructions of the doctor but this did not always happen because of these cultural differences, which can be seen as a barrier to communication and proper treatment. In this case, it was the patients' differences in culture and language that affected accessibility to proper health treatment. Although the patient would understand what the doctor said in certain occasions, it would be difficult to incorporate new habits into their culture and lifestyle. In cases in which the patients did not understand the doctor's instructions because of language barriers, it was impossible for them to make any changes to their lifestyle. Therefore, this misunderstandings hindered the patients from proper access to medical care.

Language barriers were present during doctor consults at times, but especially during home visits carried out by the community agents. Doctors, a lot of times, spoke other languages such as English and sometimes Spanish. Also the patients were prepared to bring someone with them to translate in a doctor's appointment. Although this practice was very common, it was not always the case especially with Spanish-speaking patients since the language barrier was not as strong.

One specific consult in which there was a language and cultural barrier was between a Brazilian doctor, Dr. Lucas, and the mother of a Bolivian patient. The mother kept telling the doctor that her daughter had "*calentura en los pies*" which in English means, "fever on her feet". The doctor asked what she meant, and she continuously said that her daughter would put her feet

against the wall because they were hot. The mother described that she used alcohol to release the pain and lower the “fever. The doctor explained to her that alcohol could be irritating the skin and that is why her daughter seemed to be uncomfortable. The lady did not want to leave without a remedy. She did not understand what the doctor said in some moments, that is why he tried to speak Spanish with her and explain more slowly. In the end, although he believed there was nothing wrong with the little girl, he prescribed a lotion just so the mother would stop rubbing her feet with alcohol. After talking to her, Dr. Lucas explained to me that the only way to convince the mother to leave was by prescribing an ointment. The language and cultural barrier, in this case, made it harder for the patient to trust the doctor, and for him to treat the child properly. The mother believed in a traditional remedy, alcohol in this case, while the doctor found that harmful to the little child. The patient, who in this case was the child, had limited accessibility to proper treatment and care because of the misunderstanding between the doctor and the mother. If an interpreter would have been present communication would have been clearer and the mother would better understand why the child was complaining and that alcohol was not the solution to the problem. Community agents also faced similar problems when faced with language and cultural barriers.

The community agents had to visit the patients at their homes at least once a month just to check that everything was fine. In the case of elderly patients with limited Portuguese proficiency, a lot of times they would be home alone and unable to speak the language so although the agent tried to communicate with them, it resulted to be very difficult or impossible to talk to them. The agents ended up spending a lot of time with the patient and in the end, they would be unable to retrieve the information they needed from the patient or give the patient the appropriate information. This happened a lot with elderly Korean patients, while it was less

common with Spanish-speaking patients. In one instance, one of the community agents, Flavia, was not able to communicate with a Chinese patient no matter how hard she tried. The only way for her to communicate with this patient was when her husband was present and could translate.

Communication between the staff and Spanish-speaking patients was in general easier because of the similarities that exist between Spanish and Portuguese. The medical professionals and patients would speak a mix of both languages or the medical professionals would speak in Portuguese and the patients would respond in Spanish. The similarity of both languages really aided in communication. There were cases where there were misunderstandings but in comparison to Korean patients, Spanish-speaking patients faced less communication barriers when seeking medical care. In the case of the doctors at the UBS, the majority of them acknowledged that they spoke Spanish, while the community agents did not. Based on the observations of sitting in consults with three doctors at the UBS, they all used different methods to communicate with Spanish-speaking patients. One of them attempted to speak Spanish or at least a mix of Spanish and Portuguese to ease the communication with the patient. Another doctor was a native Spanish speaker therefore he spoke in Spanish with all of his patients. The last doctor spoke in Portuguese with the patients because he believed that if both sides spoke slowly in the two different languages, communication was possible. However, although I was not able to observe this, he stated that if the patient could not speak or understand any Portuguese at all, then he would speak to the patient in Spanish. The community agents said that they did the same thing as the later doctor and spoke slowly in Portuguese while the patients answered in Spanish. Although this was very helpful and an option for this specific group of patients, it was only possible because of the similarities that exist between both languages. If Portuguese and

another language such as Korean were involved, this technique would not be effective and communication between the staff and patients would not be possible.

I spoke to several Bolivian, Paraguayan and Korean patients and one Chinese patient about my research. I asked very basic questions regarding how they felt about the language and cultural differences that existed between them and the staff. The Bolivian and Paraguayan patients were very skeptical at first and did not want to talk much about it. As soon that the community agents introduced me as a foreign researcher working at the UBS, they retracted and said that they liked the UBS. In these cases, I did not continue the conversation any further because I did not want to make the patient uncomfortable and because of ethical reasons. However, when the community agent asked them about these differences, they said that the problem was not the UBS but the other medical institutions they would be sent to for blood exams and more specific procedures. The lines were long and the patients were not always able to solve their issues or obtain what they needed. The patients described the medical professionals at these institutions as unhappy with their jobs, and not showing any interest about the patients' health. At the UBS, the doctors would try to explain the medical conditions in a way that the patients could understand them, while at these other clinics and hospitals, the doctors and nurses would just take the blood exams and not show any interest. However, the doctor of these patients at the UBS was a native Spanish speaker which could be one of the reasons why these patients were satisfied with the services at the UBS.

Three of the Bolivian patients with whom I had a conversation, stated that they did not face any significant or serious language barriers when seeking care, especially at the UBS. One Paraguayan patient said that at times he would not understand what the doctor said or the doctor would not understand him. In order to solve this, he would talk to the Bolivian community agent,

Santiago, so he could clarify any doubts or concerns that either him or the doctor might have. The agent then would talk to both and ensure that both sides knew what was happening with the health of the patient. The patients blamed the outside medical institutions for limited access to health services. The lack of interest on the side of medical professionals and the long wait times sometimes drew the patients away from even attempting to receive medical services. Earlier, I mentioned that the doctors and nurses also commented on the long wait lines as one of the main problems of SUS and the reason for inequality of access.

I also had an informal conversation with a Chinese patient with the aid of a translator. The translator, who was another researcher of our team that spoke Chinese, asked the questions and the husband of the patient translated the answers to Portuguese. The young lady had been in Brazil for roughly seven years, but did not speak any Portuguese. Her husband had attended a university in Brazil therefore he spoke perfect Portuguese. She said that she did not face any language barriers when accessing health services because she had not needed medical attention since she had arrived in Brazil other than when she had given birth to her two children. During the first childbirth, her husband had been present and he had been translating, while during the second birth she had been alone in the room with the doctors and nurses. There was not really a barrier because they could communicate through mimicry and body language and she already knew the process. In other cases, if she ever needed medical attention, her husband translated for her. However, the woman did not speak a lot and it was the husband doing most of the talking, so some of these opinions could have been his and not hers, but there was no way for me to evaluate this. Also, in her case, she had someone who could be there to translate, but other patients did not always have this opportunity.

Section 6: Proposed Solutions to Minimize Accessibility Problems

As part of my research, I identified some of the ways in which medical professionals reduced linguistic and cultural barriers as well as other accessibility problems that existed in the field of public health in the city of São Paulo, specifically in the neighborhood of Bom Retiro. Some of these solutions were identified through observations and others in the interviews with the community agents and doctors. Some of the main forms of communication between patients who did not speak Portuguese as a first language and the staff were the use of a family member as a translator, the use of Google translator, through phone calls with the children of the patient or through someone else who spoke Portuguese on the phone during a consult. In other occasions, the doctors used body language and mimicry to try to communicate with patients. On very rare occasions, the doctor or agents had asked someone in the UBS or nearby that spoke the language to translate for the patient. This person could be another patient, a family member of another patient or any other person who happened to be in the UBS. However, this was not a preferred method because of ethical and confidentiality concerns. All of these methods mostly worked and decreased accessibility barriers for patients who did not speak Portuguese as a first language in particular for Korean and Chinese immigrants. The impact was more evident for these patients since they spoke languages that were not similar to Portuguese. Although the UBS did not count with professional translators they found a way to communicate with patients through other means. However, all of these methods were unofficial solutions to accessibility and communication problems. This could be a problem since they were solutions used by specific individuals. In order to better address the treatment of people who do not speak Portuguese as a first language, it is necessary to establish and implement official procedures when providing services to immigrants or people who do not speak Portuguese. As a result of

these unofficial practices, these patients trusted the UBS staff and kept coming in for their consultations and to use the medical services offered by the UBS.

Bringing a family member as a translator was very common during a doctor's consultation. Usually, in the immigrant families, one of the family members spoke Portuguese. The children usually spoke Portuguese, but in the cases of elderly couples who were not able to bring their adult children, one of the spouses spoke Portuguese better than the other. In the case of an elderly Korean couple, the wife spoke Portuguese relatively well, while the husband could barely understand anything in Portuguese. Yet, the husband had suffered a stroke a few years ago so he was the one who most needed medical attention and treatment. Therefore, the medical professionals would always try to find his wife when they did home visits so she could translate for her husband who did not speak Portuguese.

A lot of times, in other cases similar to this one, Dr. Alessandro would schedule consults with the husband and wife back to back so he could have more time and also so the person who spoke the most Portuguese could translate for the one who did not. This was effective in all of the cases that I observed. On top of translating, the spouse brought in extra information about the patient that might not have been obtained if a professional translator had been the one translating. This was a very effective and useful solution to communication barriers, however I only saw it being used by Dr. Alessandro. In order to make this available to everyone at the UBS, there should be an officialized protocol regarding cases similar to this one. The UBS could hold workshops every other month, in which the medical professionals shared specific solutions that they had found to decrease communication and accessibility barriers. The solutions that proved to be most successful could be implemented as official policies when treating immigrants or others who do not speak Portuguese as a first language.

In the interviews that were carried out, all of the community agents said that they would prefer having a family member as a translator rather than a professional translator/interpreter because of the extra information regarding the patient that the family member provided during consults. Most of the doctors had the same opinion when it came to translators. However, they still thought that a professional translator would be very helpful especially since family members were not always able to come along in consults. The medical professionals believed that having a translator or an interpreter available whether a family member or a professional would really facilitate communication between the medical professionals and the patients who did not speak Portuguese.

Another solution that was proposed by the community agents was having basic language classes in languages such as Korean and Chinese, so the agents could have at least a little bit of background knowledge on the language. They also thought that having a professional working in the reception that is multilingual could avoid a lot of communication problems because they would be able to direct the patients accordingly and aid in orienting them. These solutions would all prove to be helpful, however it is important to think about the high cost of such solutions. The last solution proposed was having a guide for the medical professionals in other languages that they could use during consults or home visits. This would be a more affordable solution to communication barriers. This guide would include basic information and questions that were part of the consults in another language and in Portuguese. The patients and the medical team could use this and figure out how everything was going and if there were any problems. As part of my research, I worked with another member of the research team and one of the doctors to create such guides in Korean, Spanish and English. We sent these guides to the UBS in Brazil a few months ago. The guides contained specific information that was mostly discussed during doctor,

nurse and community agent visits. The most frequently asked questions and necessary information to communicate were identified during the time I spent in Brazil and were also suggested by Dr. Alessandro. The guides contained specific information such as questions regarding registration, pregnancy, hypertensive patients, children and diabetes. My hypothesis is that these guides will reduce communication barriers between the UBS staff and the Korean, Chinese and Spanish-speaking patients. These guides will encourage more of these patients to frequent the UBS. These patients will have increased access to health services. I also hypothesize that the medical professionals will be more likely to actually use these guides now after the time that our research team spent at the UBS researching specifically topics such as language barriers, immigration and accessibility. Our presence increased consciousness of the differences that exist between the patients and the staff and the need for more initiatives and official procedures to better treat immigrants and patients who do not speak Portuguese as a first language. I intend to carry out interviews with patients and medical professionals this summer when I return to Brazil, to evaluate the use and effectiveness of the communication guides.

One last solution that one of the community agents, Santiago, proposed during our interview was to get the people themselves to become more involved with SUS. He believed that if patients participated more in SUS activities and received education on the services provided by SUS, they would be able to access all of the services offered by SUS to the fullest. Another agent, Flavia, also believed that SUS has wonderful programs that she had not known about until she started working as a community agent. Having classes that educate patients on the functioning of SUS could lead to increased access to health services in Brazil.

Conclusion:

Throughout this thesis, I have addressed the topic of accessibility in Brazil. The creation of SUS was an important change in the history of healthcare in Brazil. This new Consitution provided the right to access health services to every person who resides in Brazil regardless of race, social class, gender, employment or citizenship status. Although the system has its problems and flaws, SUS has played an important role in allowing immigrants to access health services in Brazil. Some of the main issues with SUS are the long wait lines for specific services, physician shortage, unequal regional distribution of health services and the lack of translators/interpreters for patients who do not speak Portuguese as a first language. Throughout the history of Brazil, there have been barriers and problems with regards to accessibility to health services. In different periods of time, different groups of people faced limited accessibility to government services including access to healthcare as well as other basic necessities. The indigenous people faced limited accessibility to healthcare and other services in the beginning of the 1500s when the Portuguese colonized Brazil. In the following years, the indigenous continued to have limited access to these services, but with the passing of time, many organizations were created to protect the rights of the indigenous people. These organizations helped increase accessibility to different government services and led to improved rights for the indigenous people.

Throughout the slave trade, slaves also faced decreased access to proper alimentation, housing, treatment and health services. Many of them found ways to improve the lack of access to health services by relying on witch doctors, healers and wizards. They also believed in traditional remedies and wearing amulets to prevent disease. With the abolition of slavery, this group of people had improved access to different government services, including healthcare

ones. Another instance in history in which there was limited access to public services and other aspects of life was during the military dictatorship in Brazil. The general public had limited access to information as a result of the strict censorship. Others suffered human rights violations as a result of all the violence used by the military regime. In the case of healthcare services, many of the political prisoners did not have any access to medical services. There were many disappearances and deaths of political prisoners during that period in time.

There are many aspects that affect accessibility to health services in Brazil including but not limited to social status, economic conditions, regional location, racial background and demographical data. All of these aspects are closely related and often lead to disparities in access to government funded services such as medical care. Brazil's wealth is unequally distributed across its five regions: the North, the Northeast, the South, the Southeast, and the Center-West. The majority of the resources are located in the Southeast which is the most developed part of the country. The Northern and Northeastern areas have the least resources and are the least developed. This is a result of the frequent droughts that many times result in high levels of unemployment. Healthcare is also the most developed in the Southeast. Cities such as São Paulo and Rio de Janeiro have a lot more medical resources than other states such as Bahia and Pernambuco. The Northern and Northeastern areas have a lower number of doctors as well as less medical resources than the rest of the country. When comparing the periphery with the center of the cities, regionality also affects accessibility. The city centers have an increased number of medical professionals as well as more resources while UBSs located in the periphery usually face more challenges in hiring doctors and obtaining the necessary medical resources.

Immigrants are one of the main groups that have decreased access to healthcare services. This is a result of their limited knowledge of the Portuguese language and the cultural

differences between them and Brazilians. Language and cultural different pose significant communication barriers when accessing government services. I was able to explore the topic of accessibility to health services by people who do not speak Portuguese as a first language during the summer when I conducted research in the UBS Bom Retiro.

The UBS is located in the neighborhood of Bom Retiro, in the center of São Paulo. Bom Retiro was a prime location for this research because it is known to be a multicultural and multilingual neighborhood. While I was in Bom Retiro, I was able to identify the main positive and negative aspects of SUS through interviews and observations. SUS has positive programs that can improve accessibility to health services such as the existence of different health posts including AMAs, UBSs, and UPAs, the presence of teams such as NASF and programs like *Mais Médicos* and the *Programa da Saúde da Escola.* By having different types of health posts, patients have increased access to healthcare. However, there also exist flaws with SUS including but not limited to doctor scarcity, unequal distribution of doctors and medical resources, long wait times for specific services, and lack of medication. Specific problems related to non-Portuguese speakers are the absence of interpreters and translators and programs and policies targeted to treat patients who face language and cultural barriers. I propose different solutions to increase access to healthcare by patients who do not speak Portuguese as a first language, including Spanish-speaking immigrants and other immigrant groups in Bom Retiro.

The first proposed solution to these communication barriers would be hiring professional translators and interpreters to enable communication between patients and medical professionals. This would be crucial for immigrants that come from countries such as Korea and China, who speak languages that have no similarities with Portuguese. While in the case of Spanish-speaking patients some limited communication is possible due to the similarities between Spanish and

Portuguese, in the case of Koreans and Chinese this is almost impossible. Although sometimes there are unofficial interpreters such as relatives and members of the community who speak Portuguese, this is an unreliable source since their presence is not always guaranteed. Official policies should be put in place to enforce the hiring of interpreters or staff members who speak these languages in UBSs located in neighborhoods such as Bom Retiro. This has already proved to be very helpful with the Spanish-speaking community in Bom Retiro through the hiring of Bolivian community agents and other Spanish-speaking doctors.

Another solution that has already started to be implemented in the UBS Bom Retiro is the use of communication guides in different languages that provide translation in Portuguese. As part of our research project, our research team along with Dr. Alessandro created these communication guides in Korean, Spanish, and English. I have included an example of these guides in Appendix 5. My hypothesis is that the guides will attract more non-Portuguese speakers to the UBS and will facilitate at least initial and crucial communication between the medical professionals and the patients. I intend to return to Brazil this summer to expand on this research. During the time that I am there, I would like to evaluate the use of the guides and confirm whether patients who do not speak Portuguese as a first language have increased access to health services as a result of the use of the guides. If the guides prove to be effective, it would be necessary to implement official policies on the use of communication guides to facilitate communication between non-Portuguese speakers and the medical staff. Although throughout this thesis I have mentioned many initiatives and ways that the doctors and community agents in Bom Retiro have incorporated to improve accessibility to medical services, these are all unofficial procedures. By turning these procedures into official public health policies, there will be an assurance that they will be followed and not be lost if there is a change of personnel or if

these specific doctors and community agents leave the UBS. These programs could be used more broadly in other clinics and hospitals throughout Brazil that have a similar demographic profile as the neighborhood of Bom Retiro.

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Appendix I - Table of Individuals

NICKNAME	CATEGORY	AGE (RANGE)	SEX	ETHNICITY	ADDITIONAL INFORMATION
Alessandro	Doctor	28 years old	Male	Brazilian	Doctor of the Green Team
Lucas	Doctor	25-30 years old	Male	Brazilian	Doctor of the Yellow team
Gabriel	Doctor	27-28 years old	Male	Colombian	Doctor of the Red Team
Victor	Doctor	25-30 years old	Male	Brazilian	Doctor at AMA Boraceia
Emiliano	Doctor	50-55 years old	Male	Korean	Owns his clinic – acupuncture and traditional medicine
Maria	Doctor	30-35 years old	Female	Brazilian	I never met her personally, she was mentioned in one of the interviews I conducted She did not work at the UBS Bom Retiro anymore
Catalina	Community Agent	45-50 years old	Female	Brazilian	Community Agent of the Green Team
Raquel	Community Agent	30-35 years old	Female	Brazilian	Community Agent of the Green Team
Francisca	Community Agent	25-30 years old	Female	Brazilian	Community Agent of the Green Team
Santiago	Community Agent	55-60 years old	Male	Bolivian	Community Agent of the Red Team
Flavia	Community Agent	30-35 years old	Female	Brazilian	Community Agent of the Green Team
Adriana	Patient	2-3 years old	Female	Bolivian	Mother believes she has "fever on her feet"
Manuela	Mother of Patient	25-30 years old	Female	Bolivian	Does not speak Portuguese fluently
Fabiana	Patient	6 years old	Female	Bolivian	Has an alphabetization problem
Julia	Patient	65-70 years old	Female	Korean	Does not speak Portuguese
Ana	Patient	60-65 years old	Female	Korean	- Speaks Portuguese relatively well – fluent - Husband does not speak Portuguese
Bruno	Patient	4 years old	Male	Paraguayan	Speaks Portuguese
Hugo	Patient	80-85	Male	Korean	Patient at Pequeno Jesus – Does not speak Portuguese
Guilherme	Patient	75-80	Male	Korean	Patient at Pequeno Jesus – Can speak some Portuguese but he is not fluent
Pedro	Patient	30-35	Male	Paraguyan	Met him in the street with Santiago
Mario	Patient	35-40	Male	Paraguyan	Had tuberculosis

Appendix II (Tables and Charts):

Tables (Brazil Demographics Data):

Area:

total: 8,515,770 sq km

land: 8,358,140 sq km

water: 157,630 sq km

note: includes Arquipelago de Fernando de Noronha, Atol das Rocas, Ilha da Trindade, Ilhas Martin Vaz, and Penedos de Sao Pedro e Sao Paulo

country comparison to the world: 6

Education expenditures:

6% of GDP (2013)

country comparison to the world: 49

Literacy:

definition: age 15 and over can read and write

total population: 92.6%

male: 92.2%

female: 92.9% (2015 est.)

School life expectancy (primary to tertiary education):

total: 15 years

male: 15 years

female: 16 years (2014)

Unemployment, youth ages 15-24:

total: 16.1%

male: 13.8%

female: 21.2% (2014 est.)

country comparison to the world: 76

Population distribution:

the vast majority of people live along, or relatively near, the Atlantic coast in the east; the population core is in the southeast, anchored by the cities of Sao Paolo, Brasilia, and Rio de Janeiro

Urbanization:

urban population: 86.2% of total population (2017)

rate of urbanization: 0.99% annual rate of change (2015-20 est.)

Major urban areas - population:

Sao Paulo 21.066 million; Rio de Janeiro 12.902 million; Belo Horizonte 5.716 million; BRASILIA (capital) 4.155 million; Fortaleza 3.88 million; Recife 3.739 million (2015)

Population:

207,353,391 (July 2017 est.)

country comparison to the world: 5

Nationality:

noun: Brazilian(s)

adjective: Brazilian

Ethnic groups:

white 47.7%, mulatto (mixed white and black) 43.1%, black 7.6%, Asian 1.1%, indigenous 0.4% (2010 est.)

Languages:

Portuguese (official and most widely spoken language)

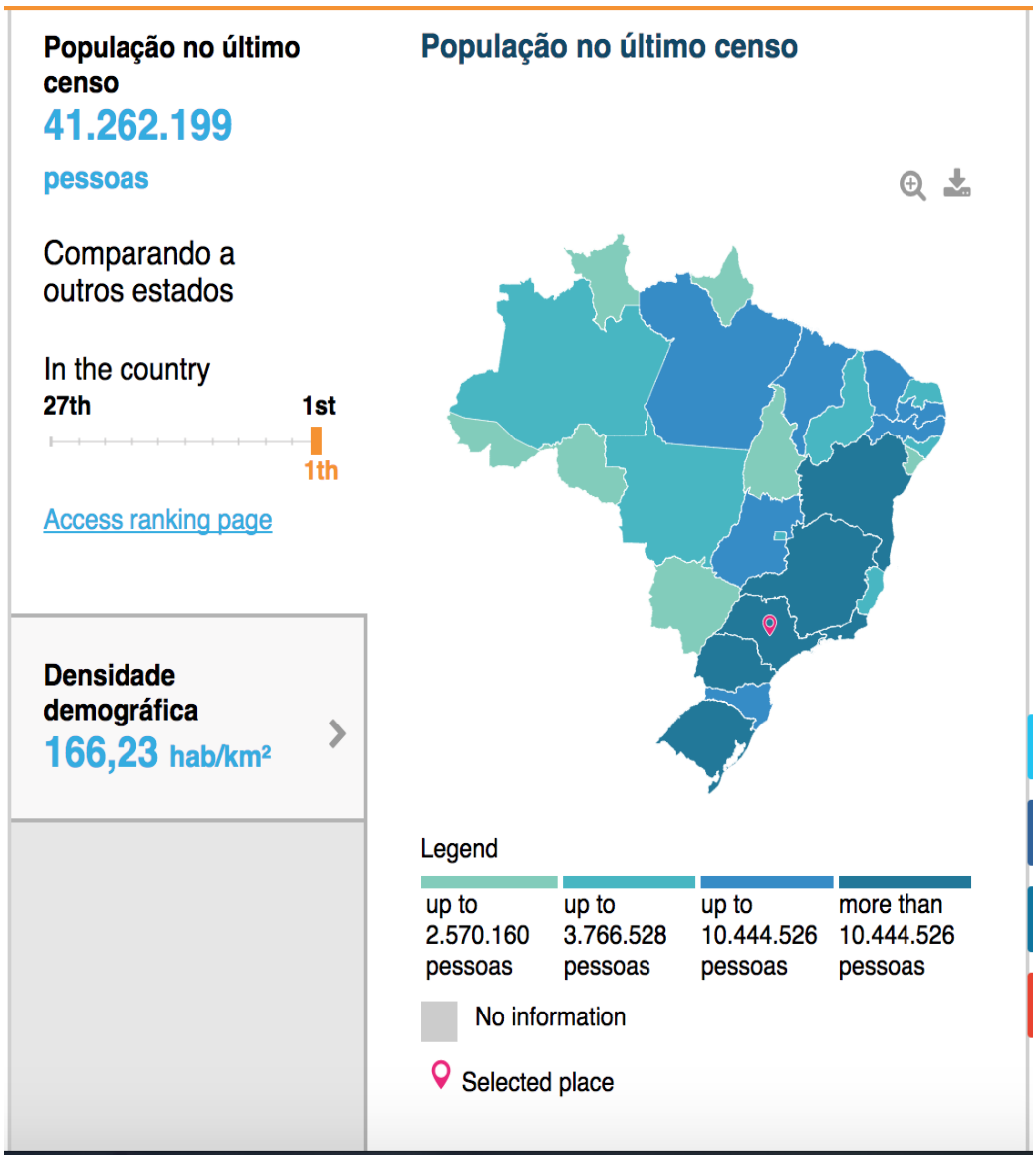
note: less common languages include Spanish (border areas and schools), German, Italian, Japanese, English, and a large number of minor Amerindian languages

Religions:

Roman Catholic 64.6%, other Catholic 0.4%, Protestant 22.2% (includes Adventist 6.5%, Assembly of God 2.0%, Christian Congregation of Brazil 1.2%, Universal Kingdom of God 1.0%, other Protestant 11.5%), other Christian 0.7%, Spiritist 2.2%, other 1.4%, none 8%, unspecified 0.4% (2010 est.)

Table 2: Demographics of Brazil [19]

[19] "The World Factbook: Brazil." *Central Intelligence Agency*, Central Intelligence Agency, 14 Nov. 2017, www.cia.gov/library/publications/the-world-factbook/geos/br.html.

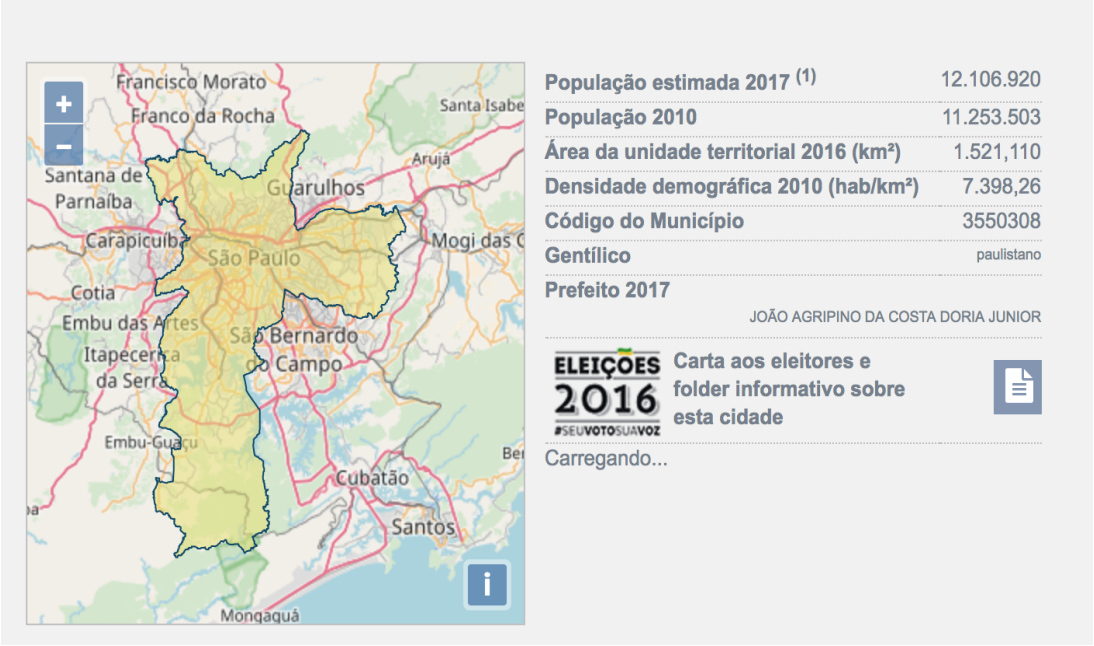


Map 1: Sao Paulo Population[20]

Sao Paulo Municipality demographics

[20] "São Paulo ." *São Paulo* , IBGE, 2017, cidades.ibge.gov.br/brasil/sp/panorama.

Sao Paulo state demographics



Map 2: Map of the city of Sao Paulo with population data [21]

BOM RETIRO

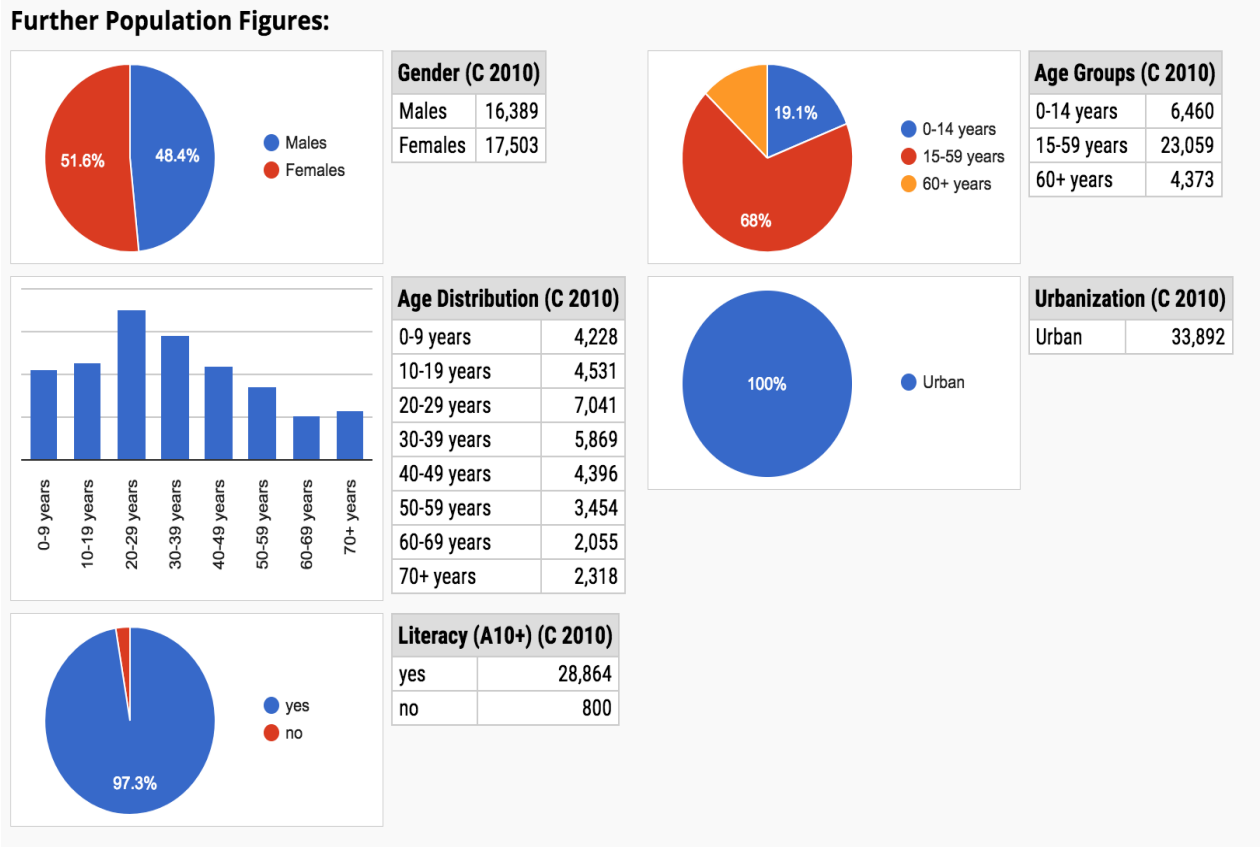
Municipal District in São Paulo

Population

The population development of Bom Retiro as well as related information and services (Wikipedia, Google,

Name	Status	Population Census 2000-08-01	Population Census 2010-08-01
Bom Retiro	Municipal District	26,598	33,892
Area: 4.18 km² – Density: 8,108/km² [2010] – Change: +2.45%/year [2000 → 2010]			
Bom Retiro District: Stadtbezirk in Sao Paulo			
São Paulo	Municipality	10,434,252	11,253,503

[21] "São Paulo ." *IBGE | Cidades | São Paulo | São Paulo*, IBGE, 2017, cidades.ibge.gov.br/xtras/perfil.php?lang=&codmun=355030.

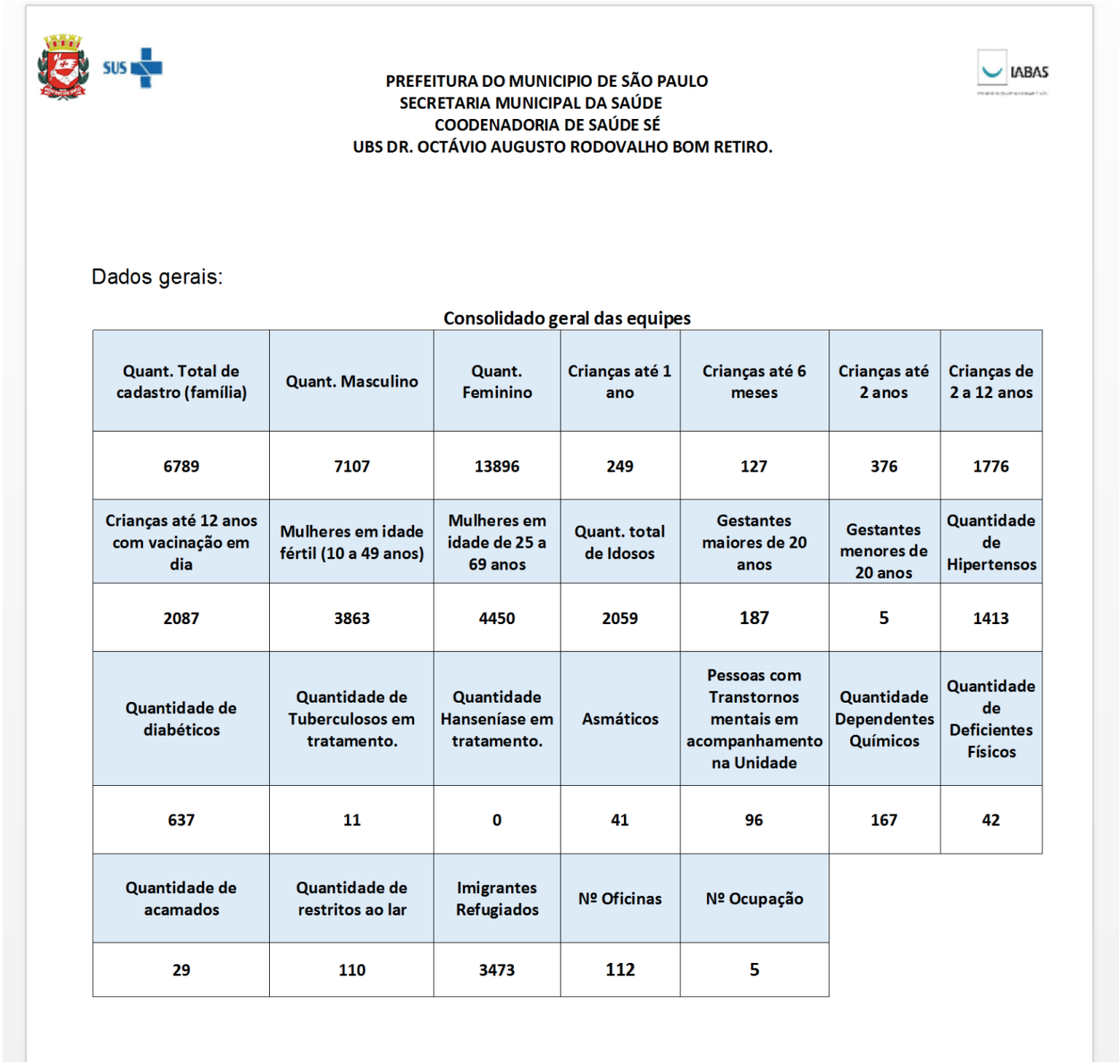


Figures 1&2: Bom Retiro Demographics [22]

[22] "Bom Retiro: Municipal District in São Paulo." *(Municipal District, São Paulo, Brazil) – Population Statistics, Charts, Map and Location*, www.citypopulation.de/php/brazil-sao_paulo.php?cityid=355030809.

Appendix 3 (Bom Retiro - Demographics of Patients):

These charts are obtained from the UBS Bom Retiro, Relatório de Gerência completed in 2017.



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Dados gerais:

Consolidado geral das equipes

Quant. Total de cadastro (família)	Quant. Masculino	Quant. Feminino	Crianças até 1 ano	Crianças até 6 meses	Crianças até 2 anos	Crianças de 2 a 12 anos
6789	7107	13896	249	127	376	1776
Crianças até 12 anos com vacinação em dia	Mulheres em idade fértil (10 a 49 anos)	Mulheres em idade de 25 a 69 anos	Quant. total de Idosos	Gestantes maiores de 20 anos	Gestantes menores de 20 anos	Quantidade de Hipertensos
2087	3863	4450	2059	187	5	1413
Quantidade de diabéticos	Quantidade de Tuberculosos em tratamento.	Quantidade Hanseníase em tratamento.	Asmáticos	Pessoas com Transtornos mentais em acompanhamento na Unidade	Quantidade Dependentes Químicos	Quantidade de Deficientes Físicos
637	11	0	41	96	167	42
Quantidade de acamados	Quantidade de restritos ao lar	Imigrantes Refugiados	Nº Oficinas	Nº Ocupação		
29	110	3473	112	5		

relatorio de gerenciamento correto Print

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Dados referentes referente ao território da Ubs, por área e micro áreas.

Ubs Bom Retiro - equipe 1081 verde	Ana Barreto	Daniela Colin	Marina	Yracilda	Sheila	Luciana	Total
5) quantidade total de cadastro (família)	206	249	223	216	202	230	1326
5.5.1. Quantidade Masculino	256	269	263	233	253	301	1575
5.5.2. Quantidade Feminino	285	289	331	277	313	278	1773
5.5.3. Crianças até 1 ano	8	7	2	4	4	6	31
5.5.4. Crianças até 6 meses em AME	2	3	3	3	1	4	16
5.5.5. Crianças até 2 anos	16	1	5	4	5	12	43
5.5.6. Crianças de 2 a 12 anos	6	115	35	52	56	89	353
5.5.7. Crianças até 12 anos com vacinação em dia	83	15	37	52	61	95	343
5.5.8. Mulheres em idade fértil (10 a 49 anos)	154	74	159	138	205	195	925
5.5.9. Mulheres em idade de 25 a 69 anos	195	165	207	129	189	154	1039
5.5.10. Quantidade total de Idosos	94	47	174	160	58	43	576
5.5.12. Gestantes maiores de 20 anos	6	2	4	2	7	6	27
5.5.12. Gestantes menores de 20 anos	0	0	1	1	1	0	3
5.5.13. Há cadastro específico para Hipertensos?							
5.5.13.1. Se sim, quantos estão cadastrados?	94	33	89	89	30	20	355
5.5.14.2. Há divisão entre tipos?	0	0	0	0	0	0	0
5.5.13. Há cadastro específico para diabéticos							
5.5.13.1. Se sim, quantos estão cadastrados?	37	10	35	31	15	8	136
5.5.14.2. Há divisão entre tipos?							
5.5.15. Quantidade total de Tuberculosos em tratamento.	0	0	0	0	0		0
5.5.16. Quantidade total de Hanseníase em tratamento.	0	0	0	0	0	0	0
5.5.17. Há cadastro de Asmáticos? Se sim quantos?	0	2	2	2	2	5	13
5.5.18. Há cadastro de Pessoas com Transtornos mentais em acompanhamento na Unidade?	16	6	6	18	5	4	55
5.5.18.1. Se sim, quantos por tipo de patologia?							
Esquizofrenia, depressão emocional, bipolar, ansiedade, Insônia							
5.5.19. Há cadastro de Dependentes Químicos? Se sim quantos?	1	0	0	0	12	0	13
5.5.20. Há cadastro de Deficientes Físicos? Se sim quantos	2	0	1	0	2	1	6
5.6. Há acamados? Se sim quantos	0	1	1	3	0	0	5
5.7. Há restritos ao lar? Se sim quantos?	7	1	9	4	5	0	26
5.2. Atendem Imigrantes e Refugiados? Se sim quais e quantidades							
Bolivianos	62	51	5	25	106	179	428
Paraguaio	25	2	4	2	28	21	82
Peruano	0	0	0	0	8	0	8
Coreano	26	4	146	98		2	276
Judeu	7		46	15			68
Grego	0		21				21
Português	2						2
Chinês				8			8
Italiano			1				1
Sírio			8				8
Equador			6		1		7
Guiné	1						1
	Total						910
Tem OCUPAÇÕES no território? Quis endereços:	Não						
Quais equipamentos sociais atendem. Qual nome.							

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Ubs Bom Retiro - equipe 1083 Azul	Dália	Solange Breches	Patrícia D	Sandra Faustino	Janete Uchoa	Jeanneth	Total
5) quantidade total de cadastro (família)	208	198	204	227	200	202	1239
5.5.1. Quantidade Masculino	274	246	205	300	208	247	1480
5.5.2. Quantidade Feminino	334	290	198	265	250	279	1616
5.5.3. Crianças até 1 ano	15	4	5	11	2	19	56
5.5.4. Crianças até 6 meses em AME	7	4	4	6	2	8	31
5.5.5. Crianças até 2 anos	29	5	10	7	6	27	84
5.5.6. Crianças de 2 a 12 anos	91	17	40	22	41	120	331
5.5.7. Crianças até 12 anos com vacinação em dia	120	17	50	29	47	98	361
5.5.8. Mulheres em idade fértil (10 a 49 anos)	171	60	126	50	103	187	697
5.5.9. Mulheres em idade de 25 a 69 anos	179	105	145	85	115	143	772
5.5.10. Quantidade total de Idosos	127	60	51	65	125	3	431
5.5.12. Gestantes maiores de 20 anos	2	4	4	2	0	9	21
5.5.12. Gestantes menores de 20 anos	0		0	0	0	2	2
5.5.13. Há cadastro específico para Hipertensos?							
5.5.13.1. Se sim, quantos estão cadastrados?	82	89	46	45	66	2	330
5.5.14.2. Há divisão entre tipos?							
5.5.13. Há cadastro específico para diabéticos							
5.5.13.1. Se sim, quantos estão cadastrados?	35	33	11	30	33	0	142
5.5.14.2. Há divisão entre tipos?	Sim				0	0	0
5.5.15. Quantidade total de Tuberculosos em tratamento.			1	4	0	1	6
5.5.16. Quantidade total de Hanseníase em tratamento.	0	0	0	0	0	0	0
5.5.17. Há cadastro de Asmáticos? Se sim quantos?	5	4	0	5	0	1	15
5.5.18. Há cadastro de Pessoas com Transtornos mentais em acompanhamento na Unidade?	2	4	5		2	2	15
5.5.18.1. Se sim, quantos por tipo de patologia?							
Esquizofrenia, depressão emocional, bipolar, ansiedade, Insônia							
5.5.19. Há cadastro de Dependentes Químicos? Se sim quantos?	1	0	3	140	0	1	145
5.5.20. Há cadastro de Deficientes Físicos? Se sim quantos	6	0	2	11	1	0	20
5.6. Há acamados? Se sim quantos	2	1	0	0	1	0	4
5.7. Há restritos ao lar? Se sim quantos?	19	4	2	7	5	0	37
5.2. Atendem Imigrantes e Refugiados? Se sim quais e quantidades							
Bolivianos	**96**	35	35	74	3	290	533
Paraguaio	26	12	20	17	6	69	150
Peruano	7		7	0	0		14
Coreano	5	30	10	15	23		83
Judeu	4	10	0		7		21
Italiano					1		1
Espanhol					1		1
Argentino					1		1
Chileno					1		1
	Total						805
Tem OCUPAÇÕES no território? Quis endereços:	Não						
Quais equipamentos sociais atendem. Qual nome.	Florescer, Complexo Prates						
N de oficinas	**Nº Ocupação (endereço)**						
31 oficinas	2 ocupações						
Rua Antonia Hajjer nº 32, nº37, 37A, nº 41 e nº42; Rua Irradiação nº 75 e 59; Rua Leonardo Pinto,95 apt 11; Rua Matarazzo, 241 apt 04, casa 02; Rua Carmine Forte nº41, nº85 e nº99; Rua Solon,414 4º sub solo e quarto 3, Rua Solon nº 427; R Júlio Conceição, Rua Areal, Rua Mamoré, Rua David Iamposk, Rua João Kopker, Rua Jorge Velho, Rua Newton Prado, Rua Talmed Thara; Rua Prates, Rua Joaquim Murtinho e Rua Antônio Coruja	Rua Júlio Conceição,295 e Rua Rodolfo Miranda						

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Rua Italianos,549		
Rua dos Bandeirantes,498,463,272b		

Ubs Bom Retiro - equipe 1082 vermelha	Lady	Aline	Rosangela	Sandra Maida	Jorge	Tamara	TOTAL
5) quantidade total de cadastro família)	210	276	264	200	228	223	1401
5.5.1. Quantidade Masculino	174	40	331	230	337	168	1280
5.5.2. Quantidade Feminino	225	124	376	265	401	283	1674
5.5.3. Crianças até 1 ano	2	5	16	3	11	9	46
5.5.4. Crianças até 6 meses em AME	3	1	8	2	7	3	24
5.5.5. Crianças até 2 anos	2	2	19	6	6	7	42
5.5.6. Crianças de 2 a 12 anos	44	20	57	31	39	31	222
5.5.7. Crianças até 12 anos com vacinação em dia	44	20	57	40	39	47	247
5.5.8. Mulheres em idade fértil (10 a 49 anos)	89	69	297	97	173	122	847
5.5.9. Mulheres em idade de 25 a 69 anos	180	101	106	136	216	146	885
5.5.10. Quantidade total de Idosos	60	10	39	137	76	107	429
5.5.12. Gestantes maiores de 20 anos	1	3	7	1	13	3	28
5.5.12. Gestantes menores de 20 anos	0	0	0	0	0		0
5.5.13. Há cadastro específico para Hipertensos?							
5.5.13.1. Se sim, quantos estão cadastrados?	50	28	71	82	13	50	294
5.5.14.2. Há divisão entre tipos?							0
5.5.13. Há cadastro específico para diabéticos							
5.5.13.1. Se sim, quantos estão cadastrados?	30	17	22	44	32	21	166
5.5.14.2. Há divisão entre tipos?							0
5.5.15. Quantidade total de Tuberculosos em tratamento.	0	0	0	1	1	1	3
5.5.16. Quantidade total de Hanseníase em tratamento.	0	0	0	0	0	0	0
5.5.17. Há cadastro de Asmáticos? Se sim quantos?		1	0	0	4		5
5.5.18. Há cadastro de Pessoas com Transtornos mentais em acompanhamento na Unidade?	2	0	1	1	0		4
5.5.18.1. Se sim, quantos por tipo de patologia?							
Esquizofrenia, depressão emocional, bipolar, ansiedade, Insônia							0
5.5.19. Há cadastro de Dependentes Químicos? Se sim quantos?	2	0	0	0	0	0	2
5.5.20. Há cadastro de Deficientes Físicos? Se sim quantos	1	0	0	0	2	0	3
5.6. Há acamados? Se sim quantos	1	1	0	7	1	2	12
5.7. Há restritos ao lar? Se sim quantos?	13	3	1	7	3	3	30
5.2. Atendem Imigrantes e Refugiados? Se sim quais e quantidades							
Bolivianos	6		98	3	129	48	284
Paraguaio	0		43	36	46	6	131
Peruano	0		3	0	26		29
Coreano	67		0	136	62		265
Judeu	9		0	44	11		64
Grego							0
Japonês	10			4			14
Chinês				6			6
Polonês					3	1	4
Espanhol			1				1
	Total						798
Tem OCUPAÇÕES no território? Quis endereços:	Não						
Quais equipamentos sociais atendem. Qual nome.	CASA DO POVO						
N de oficinas	Nº Ocupação (endereço)						
Não temos oficinas nessa área	Não temos ocupação nessa área						

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UBS DR. OCTÁVIO AUGUSTO RODOVALHO BOM RETIRO.

Ubs Bom Retiro - equipe 1084 Amarela	Adriana silva	Edna	Daniela Leite	Fernanda	Cesar	Camila Duarte	Total
5) quantidade total de cadastro (família)	225	200	200	230	236	188	1279
5.5.1. Quantidade Masculino	185	204	240	242	220	204	1295
5.5.2. Quantidade Feminino	203	237	296	251	276	289	1552
5.5.3. Crianças até 1 ano	6	11	9	11	7	11	55
5.5.4. Crianças até 6 meses em AME	4	3	2	3	1	7	20
5.5.5. Crianças até 2 anos	3	15	17	13	16	20	84
5.5.6. Crianças de 2 a 12 anos	27	78	85	89	23	30	332
5.5.7. Crianças até 12 anos com vacinação em dia	36	89	94	113	16	60	408
5.5.8. Mulheres em idade fértil (10 a 49 anos)	107	157	197	158	184	22	825
5.5.9. Mulheres em idade de 25 a 69 anos	179	126	159	177	120	82	843
5.5.10. Quantidade total de Idosos	44	45	56	43	12	45	245
5.5.12. Gestantes maiores de 20 anos	3	6	5	5	11	4	34
5.5.12. Gestantes menores de 20 anos	0	1	2	0		1	4
5.5.13. Há cadastro específico para Hipertensos?							
5.5.13.1. Se sim, quantos estão cadastrados?	21	46	55	26	39	14	201
5.5.14.2. Há divisão entre tipos?	0						0
5.5.13. Há cadastro específico para diabéticos							
5.5.13.1. Se sim, quantos estão cadastrados?	10	7	15	12	14	36	94
5.5.14.2. Há divisão entre tipos?							0
5.5.15. Quantidade total de Tuberculosos em tratamento.	1	0	0	0	0		1
5.5.16. Quantidade total de Hanseníase em tratamento.		0	0	0	0		0
5.5.17. Há cadastro de Asmáticos? Se sim quantos?		0	0	0	0		0
5.5.18. Há cadastro de Pessoas com Transtornos mentais em acompanhamento na Unidade?	0		2	1	0	1	4
5.5.18.1. Se sim, quantos por tipo de patologia?							
Esquizofrenia, depressão emocional, bipolar, ansiedade, Insônia							0
5.5.19. Há cadastro de Dependentes Químicos? Se sim quantos?	0	0	0	0	0		0
5.5.20. Há cadastro de Deficientes Físicos? Se sim quantos	0	0	2	2	0	0	4
5.6. Há acamados? Se sim quantos		0	1	0	3	1	5
5.7. Há restritos ao lar? Se sim quantos?		0	0	1	4	0	5
5.2. Atendem Imigrantes e Refugiados? Se sim quais e quantidades							
Bolivianos	38	10	130	2	64	14	258
Paraguaio	0	15	19	1	15	7	57
Japonês		0	1				1
Nicarágua		1					1
	Total						317
Tem OCUPAÇÕES no território? Quis endereços:	Não						
Quais equipamentos sociais atendem> qual nome.	Autonomia em foco				Rua Vitor Airosa, 259 (asilo)		
N de oficinas (colocar os endereços no verso)	Nº Ocupação (endereço)						
Av.Santos Dumont,748,752,682	Rua Deocleciana,103						
Av.Tiradentes	Rua Vitor Airosa,31						
Rua frei Galvão							
Rua Itapirapés							
Rua Alto Pimenta							
Av.Estado							
Rua Vitor Airosa,57 A e B							

PREFEITURA DO MUNICIPIO DE SÃO PAULO
SECRETARIA MUNICIPAL DA SAÚDE
COODENADORIA DE SAÚDE SÉ
UBS DR. OCTÁVIO AUGUSTO RODOVALHO BOM RETIRO.

Ubs Bom Retiro - equipe 1085 - Black	Camila apaza	Lizangela	Tatiane	Thiago	Vanusa	Péricles	Total
5) quantidade total de cadastro (família)	250	250	203	189	210	199	1301
5.5.1. Quantidade Masculino	341	263	167	251	267	20	1309
5.5.2. Quantidade Feminino	6	294	270	283	368	300	1521
5.5.3. Crianças até 1 ano	3	10	14	12	4	9	52
5.5.4. Crianças até 6 meses em AME	14	3	3	6	1	6	33
5.5.5. Crianças até 2 anos	74	13	14	25	6	18	150
5.5.6. Crianças de 2 a 12 anos	88	74	81	80	96	88	507
5.5.7. Crianças até 12 anos com vacinação em dia	204	87	79	104	102	105	681
5.5.8. Mulheres em idade fértil (10 a 49 anos)	170	210	192	194	194	181	1141
5.5.9. Mulheres em idade de 25 a 69 anos	59	179	16	155	188	168	765
5.5.10. Quantidade total de Idosos	8	43	18	43	96	63	271
5.5.12. Gestantes maiores de 20 anos	0	11	7	3	5	11	37
5.5.12. Gestantes menores de 20 anos	28	0	0	2	0	2	32
5.5.13. Há cadastro específico para Hipertensos?							
5.5.13.1. Se sim, quantos estão cadastrados?	28	22	23	35	40	35	183
5.5.14.2. Há divisão entre tipos?							
5.5.13. Há cadastro específico para diabéticos							
5.5.13.1. Se sim, quantos estão cadastrados?	10	8	14	15	14	17	78
5.5.14.2. Há divisão entre tipos?							0
5.5.15. Quantidade total de Tuberculosos em tratamento.		0		0	1	0	1
5.5.16. Quantidade total de Hanseníase em tratamento.	0	0	0	1		0	1
5.5.17. Há cadastro de Asmáticos? Se sim quantos?	2	2	1	3	0	0	8
5.5.18. Há cadastro de Pessoas com Transtornos mentais em acompanhamento na Unidade?	3	2	0	4	8	0	17
5.5.18.1. Se sim, quantos por tipo de patologia?							
Esquizofrenia, depressão emocional, bipolar, ansiedade, Insônia							
5.5.19. Há cadastro de Dependentes Químicos? Se sim quantos?	0	0	5	1	1		7
5.5.20. Há cadastro de Deficientes Físicos? Se sim quantos	1	0	1	1	3	3	9
5.6. Há acamados? Se sim quantos	0	0	1	0	0	2	3
5.7. Há restritos ao lar? Se sim quantos?	3	0	0	1	3	5	12
5.2. Atendem Imigrantes e Refugiados? Se sim quais e quantidades							
Bolivianos	30	58	96	46		37	267
Paraguaio	24	39	17	48		22	150
Peruano	40	18		52		0	110
Coreano	1		2			0	3
Judeu							0
Grego							0
Japonês							0
Chinês					11		11
Nicarágua					1		1
Espanhol					12		12
Bangladesh	14	2					16
	Total						570
Tem OCUPAÇÕES no território? Quis endereços:	Não						
Quais equipamentos sociais atendem. Qual nome.							
N de oficinas	Nº Ocupação (endereço)						
Rua Djalma Dutra,249,173							
Rua são Lazaro, 311,295,273,220							
Rua João Theododro,330							
Rua São Caetano ,712,722,517							
Rua Sá Barbosa							
Pedro Alvares Cabral							

Appendix 4 (Extended Methodology):

Expectations:

Before arriving in Brazil, I had a well-detailed plan on how I would obtain data for my research. I had planned to spend the majority of the time at the UBS Bom Retiro with the doctor of the Green Team, Dr. Alessandro. The main method that I would use to gather data would be observation. If time permitted, I would then conduct interviews with patients that I identified during consults that did not speak Portuguese as a first language. I would also conduct interviews with doctors and potentially nurses and community agents. My plan was to sit in on patient consults with the doctor and examine the body language and gestures that both the doctor and the patient used. Since I already knew that Bom Retiro was a culturally diverse neighborhood, which was also what inspired my project, I thought that plenty of patients who did not speak Portuguese as a first language would go to doctor consults on a daily basis. I had also spoken to the doctor in charge, explaining my research prior to my arrival in Brazil so I had a perfect plan of how my research would advance and what I would have to do to obtain my data. I was planning to spend roughly about five to six weeks in São Paulo. Four days a week, I would spend time with the staff of the clinic at Bom Retiro and usually the one day that was left, I would visit other types of clinics or UBSs so I could have a point of comparison. Then on the weekends or any free time that I would have after the consults I would visit archives to find primary and secondary sources for my thesis. Throughout the research period, possibly within the first few weeks, I would conduct interviews with the patients that I had identified during consults and with doctors and other medical professionals.

Reality:

When I arrived in Brazil, I met the team I would work with. During the first meeting with the doctor, I scheduled the times that I would shadow him during consults, home visits and any other activities organized by the clinic. I also found out how the UBS worked and that there were a lot of other activities that I had not known about that I could participate in to learn more about the public health system in Brazil. As I sat in doctor consults, I realized that basing my research solely on observations during consults would not gather enough data. There were days in which the doctor would have only one or two patients who did not speak Portuguese and others in which he did not have any patient that showed difficulty with speaking the language. In other occasions, it was very hard for me to analyze the body language and the level of Portuguese of the patient in only fifteen minutes, which is how long the consults lasted. At this point, I started working on my research plan again and I came up with multiple different research methods that I would use to obtain data. These methods included observation of patient consults at the UBS and an AMA with the doctor in charge, observation of patient consults with one of the doctors at the patient's home, home visits done with community agents at the patient's home, informal and unstructured interviews with patients, semi-formal and semi-structured interviews with medical professionals (doctors and community agents), and examination of primary and secondary sources.

I spent about four weeks sitting in doctor consults and observing the interaction between doctors and patients. I spent the majority of these three weeks with the doctor of one specific team. I spent some days observing consults with doctors of the other teams at the UBS Bom Retiro. I also shadowed two doctors at an AMA (Assistência Médica Ambulatorial), a type of emergency health clinic. The visits varied from regular check-ups, to pregnancy consults to children consults. The doctors usually have a set schedule per week on the type of patient they

see so I was able to observe a variety of consults. During the doctor consults at the UBS Bom Retiro, I paid close attention to the details of patient-doctor interaction including body language and language choice. I also tried to figure out how communication was carried out with Spanish-speaking patients. I would look out for whether the patient and the doctors were speaking Spanish, Portuguese or a mixture of both. At the AMA, I looked for differences compared to the UBS: how the consults differed from those at the UBS, were the doctors using a similar language, how long the consults lasted and how did the patient-doctor interaction differ in this type of clinic. I also paid close attention to the level of access to healthcare available to patients by comparing these different types of clinics.

During the time I was in Brazil, I also spent a part of the time going to the homes of patients with a doctor and a community agent. The doctor had about four to five hours available once a week to visit about three to four patients at their home. Usually, the patients who were eligible for this were bedridden patients or those who were not able to come to the UBS. During these visits, I paid close attention to the environment in which the consults happened, the relationship between patient and doctor, doctor and community agent and patient and community agent. I also paid close attention to how the patients reacted to my presence. I was usually introduced as a scholar coming from the US who was currently working at the UBS. All of the patients agreed to have me present in the consults, although some of them hesitated at first.

When I was not shadowing consults with the doctor or visiting another clinic, I decided to go on home visits with community agents. I went to home visits with several community agents from the UBS Bom Retiro and then on two additional occasions I went on a home visit with community agents at another clinic. During these home visits, we visited different types of housing systems including, well-furnished apartments, *cortiços* (tenements), an improvised

housing site on top of a parking lot, *predios ocupados* (occupied buildings) and a *comunidade/favela* (slum). I was interested in comparing the relationships between patients and community agents with the relationship that existed between doctors and patients. During the visits, I took notes on any communication barriers, the level of proximity between agents and patients, whether social class changed this level of proximity, and how agents eased accessibility to health services by patients.

During the visits with community agents, I was also able to carry out unstructured informal interviews with patients. The community agent introduced me as a student researcher who was working with the UBS and wanted to learn more about SUS. He/she would ask permission for me to be there first, and then if it was possible for me to ask them some questions. After they had agreed, I would ask them very general questions about their opinions in regards to the UBS, whether they had any communication problems, if there was something that they liked or they did not like about the UBS services. In some cases, they would answer very vaguely and in others more in detail. In certain occasions, when I did not obtain answers, I did not push the patients to answer because of ethical reasons. In other occasions, the community agent would rephrase or repeat my questions and would actually receive answers from the patient. I made sure to note this because my role as a researcher many times affected the responses I received or whether I received a response at all.

The last week of my time in Brazil was mostly reserved for time to conduct interviews with the doctors and community agents. I decided to interview the doctors and community agents that I had usually been interacting with throughout my time doing research at the UBS. I interviewed five doctors and five community agents. Out of the five doctors that I interviewed, three of them worked at the UBS Bom Retiro. One of the doctors worked at the AMA that I

visited, and the other was a Korean doctor who specializes in acupuncture and Korean traditional medicine. The community agents that I interviewed all worked at the UBS Bom Retiro. The doctor interviews were all conducted at the doctor's office, except for one which was done through Skype because of time limitations. The community agent consults took place either at the UBS or the Museu de Saúde Publica which is the building next to the UBS.

I used the same questions for both types of interviews. The interviews were structured but depending on how the interviewee would answer certain questions, sometimes I had to skip or add a few questions. The interview questions were separated in three different sections. The first section had general questions about the doctor/community agent such as name, amount of time working at the clinic and their opinions about their profession. It also contained a couple of questions about their perspectives of SUS. The second section contained questions about the perspectives of the interviewee in regards to their relationship with patients. The last section of the interview dealt with the opinions that doctors and community agents had regarding communication barriers in the field of healthcare. I asked all of the questions in Portuguese for both agents and doctors. In one specific interview, the interviewee spoke Spanish as his first language, so there were moments in which both the interviewee and I used Spanish or a mix of Spanish and Portuguese to communicate.

Interview Questions:

Basic Questions

1) What's your name?
2) Where are you from?
3) How does SUS functions?
4) What are some negative and positive aspects of SUS?
5) What is a part of your job that you enjoy the most?

Questions About the Relationship with Patients

6) What type of conflicts exist between you and the patient?
7) Please describe a typical visit (consult in the case of a doctor, and visit in the case of an agent).
8) Where are the majority of your patients from (other than Brazilian)?
9) What languages other than Portuguese do your patients speak?
10) Do you use any other languages when you speak with your patients?

Questions About Linguistic/Cultural Barriers that Exist in the Field of Public Health

11) São Paulo is very multicultural, especially Bom Retiro. Do you believe that there are linguistic and cultural differences that are reflected in the area of public health?
12) On a day to day basis, are there a lot of patient who speak little to no Portuguese?
13) How do you communicate with patients who have a hard time understanding what you are saying?
14) What is your opinion on the hiring of translators in the field of public health (would you prefer a professional translator or a family member)?
15) How can the linguistic differences between you and the patient affect the quality of care/treatment that the patients receive? Do you remember any specific case in which this happened?
16) Do you know any program or resource of SUS that helps in the treatment and communication of patients who do not speak Portuguese?
17) Can there exist communication problems with Brazilian or patients that are fluent in portuguese - or even, with patients that speak Portuguese very well?
18) What methods or procedures could be used to decrease the effect of language differences?
19) How can the cultural and linguistic differences affect your work and what could be done to solve this problem?
20) How long have you worked as a doctor/community agent?

The last method I used to obtain data was finding different primary and secondary sources regarding the issue of accessibility in Brazil, communication barriers, immigration and other demographic information. I went to about three different archives in São Paulo but after looking at the information available, a lot of it was available online or they did not contain any information useful for my research. Therefore, I decided to spend the time remaining gathering the rest of the data at the UBS and other clinics and then find the primary and secondary sources once I came back to the US. I found a large e number of sources once I got back which I analyze

in order to better understand accessibility to healthcare and how the history of Brazil, São Paulo and Bom Retiro specifically relate to the phenomenons that I observed in the present in Bom Retiro.

Limitations:

My research methodology had many limitations. Some of the methods had more limitations than others because of their nature and also since they involved interaction with patients. In terms of doctor consults, whether at the UBS or at home, I could not control the number of patients visited that did not speak Portuguese as a first language or that faced inequality of access to healthcare. Another limitation is that there might have been other residents of the neighborhood who do not speak Portuguese as a first language and do not have any access to healthcare that I might not know about since the only way that I met patients and residents of the neighborhood was through the medical team. This is quite a big limitation for my research since that is an important aspect to keep in mind when answering my research question.

Another limitation was time. Although five weeks in São Paulo allowed me to collect a significant amount of data, I was not able to schedule semi-formal interviews with patients just like I did with medical professionals as a result of time limitations. My relationship with patients was also more sensitive than with medical professionals, because of ethical reasons.

Appendix 5 (Communication Guides Example)

Introdução - Paciente novo

Médico: Oi, meu nome é _____.
Eu sou o médico da equipe _____.

Enfermeiro: Oi, meu nome é _____. Eu sou a enfermeira da equipe _____.

Técnico: Oi, meu nome é _____.
Eu sou a técnica de enfermagem da equipe _____.

소개 – 신규 환자

의사: 안녕하세요, 제 이름은 _____ 입니다.

간호사: 안녕하세요, 제 이름은 _____ 입니다.

간호 테크니션: 안녕하세요, 제 이름은 _____ 입니다.

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[23] Cosentino et. al, Emory University, 2018