"An Identity Crisis for Sickle Cell Disease in Brazil"

by

Melissa S. Creary
Doctor of Philosophy
Graduate Institute of the Liberal Arts

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An abstract of

A dissertation submitted to the Faculty of the
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Abstract

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The concept of race and its contribution to health disparities has garnered global attention and has planted itself firmly in medical, public health, and scientific discourse. The current debate over the epidemiology of health disparities reflects long-standing disagreement about the meaning of the concept of race in science. The interpretation of this concept cannot be separated from the epistemology of its creators. This is especially the case in the interpretation of race and admixture in sickle cell disease (SCD), particularly in Brazil. SCD is often ascribed to African ancestry, but it is a marker for ancestry in a geographic location where malaria is or was prevalent. Despite this, the cultural malleability of biology and the subsequent definition of racial disparity allows for SCD to be produced in different ways.

This dissertation is based on eighteen months of collective ethnographic fieldwork data gathered primarily in Brasília, Rio de Janeiro, and Salvador, Brazil between 2011 and 2014. It examines how patients, non-governmental organizations, and the Brazilian government, at state and federal levels, have contributed to the discourse of sickle cell disease (SCD) as a "black" disease, despite a prevailing cultural ideology of racial mixture. This multi-level identity crisis is in constant contestation of competing racial frameworks at the micro, meso, and macro level. I explore how the multiple constructions of SCD in Brazil demonstrate the cultural malleability of biology via political processes of sickle cell disease (SCD)-based social policy. I examine the experiences of those who draw upon both the sickle gene and African heritage to make competing claims upon the State as well as legitimize their belonging to a social group. Ultimately, I argue that SCD represents a deep entanglement of biology and culture as shown through Brazilian actors who attempt to gain access to fuller participation in society through what I call *biocultural citizenship*—a flexible mode of enacting belonging that varies depending on skin color, social class, recognition of African lineage and other identifiers. This analysis provides lessons relevant to both Brazil and the US on how future policy can be designed. Specifically, I examine how policy developed around specific population groups can be measured against policy framed in relation to a specific disease.

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#dontletthesicklestopyou

#blacklivesmatter

I am indebted to many who have crossed paths with me leading up to and during this doctoral journey. My personal, academic, and professional lives are lucky to intersect where the foundation of this project lies: sickle cell disease. And each individual in this vast network has pushed and propped me up during this process. Foremost among these are people living with sickle cell disease (SCD), whom I have served in a professional capacity in my role as health scientist at the Centers for Disease Control and Prevention (CDC), whom have befriended me and taken me in as family both in the United States and Brazil, and from whom I had the honor of learning stories of hope, suffering, and joy. My own diagnosis of SCD has fueled this and many other inquiries into the lives of people living with SCD and I am grateful for the doors, which have been opened in order for me to do so. I dedicate this work, in part, to Débora, Gilberto, and Sílvia. Though SCD claimed your lives before this project could reach fruition, your influence and stories live on in these pages. Thank you.

The institutional support I received, particularly over my combined twelve years of higher education from Emory University, is immeasurable. I met Dr. Howard Kushner during my undergraduate years at Emory and many years later it was he who convinced me to join the esteemed ranks of the oldest interdisciplinary program in the United States, the Graduate Institute of Liberal

Arts. It was here that I was able to interrogate my iterative project ideas intentionally without disciplinary boundaries. Even with the shuttering of the department, I will be forever grateful for that experience. Were it not for the rigor, steadfastness, and dedication of Dr. Jeffrey Lesser, my training as a Brazilianist would be incomplete and lacking the care and attention that he requires from his students. It is true that Brazil is not for beginners and with his keen understanding, guidance and contacts, I was able to negotiate the maelstrom of a new and complicated country. Dr. Lesser pushed me to go beyond the disciplinary boundaries of public health; in particular to be as embedded as possible within the Brazilian communities I'd be working with and learning from. With a full-time job, I was reluctant, but eventually convinced that this was the best approach to my scholarly work. Both my project and I grew exponentially from heeding his advice. I am eternally grateful for Dr. Mary Frederickson's compassion, commitment and dedication of time throughout the dissertation process. Meeting with me, at times, weekly to go over concepts, discuss narrators, practice academic presentations, and to remain encouraged, she often went above and beyond the call of a committee member in the attention and care she gave to me and the project. Her expertise in SCD and oral history were invaluable to me in the development of my data collection instruments and she pushed me to excavate deeper during analysis. I am thankful to the many years of expertise that Dr. Charmaine Royal shared with me on the subjects of SCD, genetics, ancestry and identity. Her commitment to exposing me to the scholarly networks of genomic ancestry has been generous and appreciated. I am also indebted to Dr. Camara Jones whose insight and steadfast mission to

recognize racism's effect on health has had a profound impact on my resolute stance as more than just a scientist, but as an activist as well. Finally, I am grateful for the enduring friendship and mentorship bestowed on me by Dr. Arri Eisen. His honors biology course was the first I took as a freshman, twenty years ago, and I am honored to have his insight on this project that completes my matriculation within this institution. I owe this dissertation committee an unquantifiable amount of gratitude.

I am also grateful for having received the financial support from a number of sources both internal and external to Emory University. The David L. Boren Fellowship allowed me to collect data in Brazil over a consecutive eleven months between 2013 and 2014. I thank them for recognizing the contributions this work makes to greater societal questions. Throughout my entire time at Emory, the Laney Graduate School funded me generously with summer research and training grants, as well as conference support to present my research. In particular, the Graduate School provided funds to allow me to take my first immersive Portuguese course as well as collect preliminary data as I began my commitment to the Brazilian SCD community. I also received funds from Emory's Science and Society Program who generously allowed me to extend my time in Brazil. I was also awarded the Emory Fox Center for Humanistic Inquiry Dissertation Completion Fellowship. With this grant, I was able to solely commit my time in the last year of the program to the completion of the dissertation. Providing me with space, computer, fellowship, and time—the Fox Center gave me the opportunity to fully engage with collected material to produce meaningful iterations of the project. The Fox Center also allowed me to engage with

colleagues I would not have otherwise without the aid of the institution. I am thankful to the staff, students and faculty at my academic home—especially with the loss of my department. Thank you to Amy Elkins and Ashleigh Dean who have become solidarity sisters as we race to the finish line. Special shouts to Drs. McKinley Melton and John Lysaker. Though not formally involved with my project, the support of faculty across Emory has been vital to the project's development and I am in gratitude to Dr. Thomas Rogers, Dr. Ana Catarina Teixeira, Dr. Karen Stolley, Dr. Kevin Corrigan, Dr. Phil MacLeod, and Dr. Kristin Mann. I am forever grateful for the administrative support from the ILA and cannot thank Ms. Ruby Buggs and Ms. Lolitha Terry enough for their patience and support, as well as my ILA cohort: Alan Pike, Jesse Pearlman Karlsberg, Mael Vizcarra, and Andy Ditzler. I'm so lucky to have had you as part of my Emory family.

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me when I fell ill, extending invitations to trips and vacations, feeding me, wiping my tears, and inspiring me. I am grateful for the friendship, proctorship, and intellectual guidance of Dr. Cristiano da Sousa Guedes at the University of Brasília. I arrived to Brasília as my first stop during my year of fieldwork and he was instrumental in helping me set up contacts, revising my project plan, sharing his intellectual network, and advising me on the necessary navigation of academic bureaucracy. Through him, I met Ivair Alves Dos Santos who provided required context for the movements with which I would be engaging with throughout my time in Brazil. At the University of Brasília, I also met Dr. Soraya Fleicher who invited me to participate in the Department of Anthropology's Seminar Series "Anthropology and Health Policies." I was also reconnected with Dr. Lenildo de Moura who I had met in Atlanta while he was a Humphries Fellow at the Rollins School of Public Health and who shared his contacts and couch with me while in Brasília. I am also indebted to Drs. Leny Trad and Clarice Santos Mota who were instrumental in providing me physical and intellectual space within the Institute of Collective Health at the Federal University of Bahia, as well as Maria Inês Barbosa an expert on race, racism, and health in Brazil and who was one of the individuals instrumental to the foundation of the Comprehensive National Health Policy for the Black Population. She spent many hours with me across several visits to Brazil. I met with several scholars and practitioners throughout the Ministry of Health, Fiocruz, the World Health Organization, Instituto de Pesquisa Econômica Aplicada (Institute of Applied Economic Research or Ipea), Newborn Screening Programs in Minas Gerais and Brasília, and Secretariat of Health in Salvador, Bahia. Though I met with and

spoke to many within the public health and sickle cell worlds throughout Brazil, I highlight only a portion within the dissertation. The voices of Gilberto, Zaira, Andrea, Flávio, Elizangela, Elvis, Nílcea, Luana, Bárbara, and Joice are archived here; their narratives elucidating a part of the complexity involved in having SCD and navigating the public health apparatus within Brazil. I am thankful for the sharing of these stories and their permission for me to disseminate them as their words.

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Finally, I can never repay the sacrifice, encouragement, pride, humor, and love instilled in me by my family all in the name of my professional and educational pursuits. It is not lost on me the importance of ancestry when it comes to this project. So too is the notion of ancestry integral to my personal story. I stand on the shoulders of many in the accomplishment of this and other goals. Thank you to Daphne Mitchell and Millicent Creary, my grandmothers—whose prayers have kept me covered for as long as I can remember. I thank God for strength, grace, and mercy. I thank God for my parents. Having a daughter with a chronic disease, my parents understandably worry about me. Despite this, when I told them I'd be resigning from the CDC to move to Brazil for a year, they supported and planned with me without pause. Linda and Anthony Creary have trusted this whirlwind and me—though difficult at times—and for that I am full of gratitude. They've taught me that there are no boundaries and I can do anything I put my mind to. This journey is just another testament to that. Thank you to my sister, Dena Creary Henfield, for standing in the gap for me. Always. Your and Enrico's love and encouragement has allowed me to be the scholar-activist I am today. You keep me grounded and have provided me with the love of my life and seed of my own sacrifice—Genesa. Genesa Victoria Henfield is well on her way to blazing a trail all of her own and I am honored to witness it and support it

with all I have. I dedicate this dissertation to my parents, my sister, and my niece whose love sustains me through every obstacle.

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PREFACE | The Assignation of Blackness

Introduction

Before I arrived in Rio de Janeiro during the heat of November 2013, Joice Aragão de Jesus told me that she would not be at home to greet me. I had met Joice two years prior through Jose Nelio Januario, a Brazilian scientist whom I had collaborated with while working at the Centers for Disease Control and Prevention, in a small cafe in Ipanema where she first told me about the perils and promises of the sickle cell population and related policies in Brazil. She had served as the National Coordinator for the Sickle Cell Disease (SCD) program at the Ministry of Health for the previous ten years and is credited with refocusing energy and resources towards SCD on a national level. In the conversations that followed during my time in Brazil, she was hopeful; frustrated by the perils of sickle cell advocacy work, but more focused on the promise. This was the case in our first conversation, and her optimism persisted in the many subsequent conversations that we had during five months of living and traveling together.

Once Joice arrived home, undoubtedly tired from her travels, she had several houseguests waiting for her. Walking down a long hallway to the living room, she passed a framed poster of Nelson Mandela, family portraits, and an *olho de boi* amulet (used to protect the home from negative energy). She welcomed us with hugs and offers of cold beer. Her adopted daughter, Lidiane, who was in dental school and sometimes spent the night as a respite from her

school lodgings, lovingly embraced her. An additional guest - Altair dos Santos Lira - the then president of the *Federação Nacional das Associações de Doença Falciforme* (FENAFAL), or National Federation of Sickle Cell Disease Associations was in town for a three-day conference on the social sciences and humanities in health. Settling into a pattern that must have been repeated hundreds of time, they sat at the meal table, and began to converse on the current political climate of SCD. Once settled, I thanked her again for offering to provide me a place to stay and she told me, "the African way is to take care of everyone's child." I would find out over the following months how much Joice integrates those words into her everyday life as mother, doctor, friend, and government administrator.

Despite the biological evidence that describes SCD as an evolutionary response to malaria, Joice is just one of many actors in Brazil who assign blackness to those diagnosed with this disease. The terms "African" and "blackness" were often conflated among my research participants. According to Sansone (2003): "In Brazil, "blackness" is not a racial category fixed in some biological difference but both a racial and ethnic identity that can be based on a variety of factors: the management of black physical appearance; the use of cultural traits associated with Afro-Brazilian tradition (particularly in religion, music, and cuisine); status; or the combination of these factors" (12). In other words, "blackness" can be achieved by any phenotype. The conscious application of the moniker "African" however, was used by my narrators to depict a kind of blackness that is not attainable by just anyone. African ancestry is used as a vehicle to legitimate blackness. In 2006, policy was introduced in Brazil to bring

attention to a package of diseases thought to disproportionately affect Afro-Brazilians. Leaders in the *Movimento Negro* (Black Movement) (a political and cultural group of black activists), government officials, and people living with said diseases, used categories of genetics and social determinants of health, to group the conditions. The committee that helped to develop the *Política Nacional de Saúde Integral da População Negra* or National Health Policy for the Black Population[1] (NHPBP) chose sickle cell disease as their "flag to demand health rights"[2] and despite the biological underpinnings of the disease, constructed SCD to emphacize direct ties to African ancestry and the black Brazilian body. This policy and subsequent initiatives have contributed to the ongoing debate about ancestry, race, identity politics, difference, and biological determinism in Brazil (Fry, 2005, Maio and Monteiro, 2005, Laguardia, 2006, Santos, 2009, Calvo-González, 2010). When NHPBP took effect, criticism erupted from geneticists, social scientists, and some people living with SCD about the racialization of disease, the manifestation of disease in non-black bodies, and the reification of race as biological. Despite these arguments, in the decades it took to develop the legislation to the present-day, individuals, organizations, and the State have made unrelenting claims of sickle cell disease being "*um problema nosso"* (our problem)[3].

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[1] The literal translation of *Política Nacional de Saúde Integral da População Negra* is roughly Comprehensive National Health Policy for the Black Population, but for simplicity I will refer to it as the "National Health Policy for the Black Population" or "NHPBP" or "the Policy."

[2] Interview April 8, 2014

[3] In an article published in 2003, the authors Debora Diniz and Cristiano Guedes, provide the respective Portuguese and English titles: *Anemia Falciforme: Um Problema Nosso: Uma abordagem bioética sobre a nova genética* and Sickle Cell Anaemia: A Brazilian Problem: A

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In this dissertation, I explore how different Brazilian actors across time have contributed to the construction of sickle cell disease as a "black" disease. By interrogating how historical processes lead to contemporary policy development, I demonstrate the tensions between cultural and biological ancestry, universality and marginality, identity and citizenship. This study highlights how personal investment in seemingly static notions of biology are situated within a culturally fluid framework of race that records the ways in which personhood and programs are often entangled. Through an analysis of oral histories, questionnaire and epidemiologic data, archival documents, and ethnographic data that I collected over eighteen months, primarily in Brasília, Rio de Janeiro, and Salvador, Brazil, I assess how contemporary biology and public policy respond to Brazilian cultural and historical ideas about race, health, identity, and legitimacy. With data collected via lived experiences from actors on multiple levels, I build onto a rich body of literature about sickle cell disease, race and health in Latin America, and citizenship studies. I argue that:

1. Different participants within this study, on the individual, organizational, and governmental level, establish a fluid framework of race within a seemingly static notion of biology to shape their relationship between race and health.
2. Brazilians in this study draw on their African heritage (vis-à-vis SCD) to further enhance or legitimize their blackness in claims for health rights. This deep entanglement of biology and culture as shown through Brazilian

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bioethical approach to the new genetics. These two titles link ownership of SCD from the Brazilian authors to Brazil.

actors who attempt to gain access to fuller citizenship is what I call *biocultural citizenship*—a flexible mode of enacting belonging that varies depending on skin color, social class, recognition of African lineage and other identifiers.

3. The bicultural competency of key state actors allows for the recognition of biocultural citizenship in the form of what I call bounded justice—
   a merging of redistributive and restorative justice limited by social reality.

Positionality and Limitations

When I initially imagined this project, the first iteration was a domestic-based study on sickle cell disease policies in the United States. As someone who had helped to develop the national public health program and assisted in the design of the first national data collection program for SCD at the Centers for Disease Control and Prevention (CDC), I believed I had the entrée and capabilities to design a project that would tell a contemporary tale of the dynamics between federal agencies, the rise and fall of federal attention, and the levels of racism, especially institutional that were inherent in the apparatuses. I thought I might add a comparative aspect to the project and had my sights set on Cuba, but I was pressed time and time again by colleagues within the sickle cell and academic communities to consider Brazil as my site of interest.

This suggestion, on some level, made sense. I was tangentially working with Brazilian public health practitioners who were interested in a new data collection system for sickle cell disease in the U.S. that I had helped design. I was also being brought on to work with the Brazilian-American governmental team

formed around a new initiative titled the Joint Action Plan To Eliminate Racial and Ethnic Discrimination (JAPER). In 2010, at a JAPER meeting held at the CDC to discuss ways in which Brazil and the U.S. could collaborate on programming and data collection for sickle cell disease (among many other items), I met Altair Lira, a prominent Brazilian activist for SCD. The suggestion to explore SCD in Brazil was also complicated by my working full-time at the CDC, and my enrollment in a full-time doctoral program. Travel and language training would be necessary for proper investment in the project, and I was not sure I could find the time for either.

I decided to travel to Brazil for the first time during the summer of 2011 to investigate the feasibility of a project and to take an intensive immersion Portuguese class. It was during this trip that I met Joice Aragão for the first time; sat with Maria Cândida Quiroz in her newly minted office dedicated to *Anemia Falciforme* (sickle cell anemia) in a Salvador municipality secretary of health building; and toured the newborn screening (NBS) laboratories in Belo Horizonte, Minas Gerais, the first state to collect NBS data on SCD for the country. Besides the entrée that the CDC afforded me to navigate Brazilian public health spaces, it was the history and culture of the country - in conjunction with the people within and at the periphery of the sickle cell community – that filled me with hope for an interesting and meaningful project and that would significantly add to our growing understanding of global SCD, both in terms of the cultural and historical context in Brazil, but also regarding the relationship between the state, social mobilization, and individuals with SCD.

In Brazil, my positionalities shifted depending upon the viewpoint of narrators, associates, government officials, people living with SCD, and the general network of people I came into contact with in the course of my field work.[4] As a black woman, U.S. citizen, former government employee embedded in the U.S. SCD public health infrastructure, and a person living with SCD I knew that my insider and outsider status could be both advantageous and disadvantageous (Gilliam & Gilliam 1999, Twine, 2000, Caldwell 2007).[5]

As a dark brown skinned woman who wore her hair naturally curly or *cabelo crespo* (curly hair), a style often named by Brazilians as *blequepau* (black power), I knew I coded as *negra* (black woman).[6] This coding presented itself as a cloak, sometimes protective, especially in Salvador where I was not immediately assumed to be a tourist and went, at times, un-harassed. For the most part

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[4] In using the term "positionalities", I am referring to a concept articulated by Linda Alcoff (1991) that refer to a set of identifiers (gender, race, class, age, employment status, nationality, etc.) as relational positions rather than essential qualities. Nowicka & Ryan (2015) contends, "Research that requires a communication of opinions, feelings and experiences from the participants to the researchers needs to understand and negotiate, at least temporarily, the boundaries that may shape and impede that communication. These boundaries may be physical, temporal, ethical, linguistic, socio-cultural or religious and thus will be influenced by the gender, age, ethnicity and social class of participants and researchers" (2). See Maher and Tetreault, 1993, Holland and Leander, 2004, and Ryan, Louise (2015) for more.

[5] I was diagnosed with sickle cell Hb C disease (HbSC) at age three. HbSC is a variant of the disease that is milder in symptom presentation. My diagnosis is often highlighted in the U.S. SCD and public health communities in tandem with my career as a health scientist at the Centers for Disease Control where I helped launch a national program for SCD. See Rees, David (2010) for more.

[6] I wore my hair naturally curly and unstraightened 95% of the time during my research period in Brazil. My natural hair texture consists of tight coils, is close to the scalp sticking outward and not falling or swinging. It is above shoulder when unstraightened. As discussed in Gilliam and Gilliam (1999) and Caldwell (2007), this type of style highlights African ancestry. Several people remarked to me in passing on the street (yelling "blequepau!") or while speaking with each other, often when I was getting my hair washed in a salon (blequepau, né?) about the state of my hair on any given day. During a particularly tearful interview in which a dark skinned black female narrator who wore straightened hair recounted the hardships of her life, she remarked how brave I was for wearing my hair in its natural form. The courage she thought I exhibited stemmed from living in a Brazilian narrative that devalues black aesthetics. This could be seen repeatedly in song lyrics (likening natural black women's hair to a bombril (scouring pad)), advertisements for hiring requesting boa aparência (good appearance), and the million-dollar chemical hair relaxing industry. Caldwell (2007) discusses this extensively.

however, when I was not in the direct context of my work, I was treated as a devalued citizen, often ignored, at times denied entrance to certain establishments, and at other times assumed to be a prostitute. That is, until I began to speak. I often joked with many of my Brazilian friends that I was a *brasileira* until I opened my mouth.

> We were white to the degree that we spoke English and refused to speak Portuguese properly, since it reinforced our status as foreigners. We were black to the degree that we seemed Brazilian. (Gilliam & Gilliam 1999: 72).

The instant validation of foreignness was something I relied on many times; and Brazilian perception, tone, and attitude changed immediately upon learning that I was from the U.S. American blackness in twenty-first century Brazil is considered better than Brazilian blackness, and I was both comforted and deeply troubled by the privilege that accompanied my U.S. citizenship.

I did not speak fluent Brazilian Portuguese during my fieldwork. When I arrived in Brazil for my first visit, I had finished one semester of an undergraduate level class in Portuguese. By the time I started my fieldwork in 2013, and certainly by the end of it, my proficiency was deemed by tutors, friends, and colleagues as intermediate. At no point during the research period did I sound like a native, despite how I may have appeared. This was confusing initially to many I met, though the graciousness of Brazilians to anyone learning their language would have me believe that my Portuguese was perfect. Speaking English, and certainly my U.S. citizenship elevated my status to "white" in Brazil (see discussion of Brazilian racial categories on page 52). My status there was not solely dependent on my phenotypic racial classification (of which there was no

ambiguity), but included educational status, presumed wealth by virtue of travel to Brazil, as well as occupation (Telles, 2004). I was often introduced as a biologist[7] and sometimes as an official for the U.S. government, although I had resigned from the CDC to complete the fieldwork required for this project. Nevertheless, my professional status, based in the sciences and associated with the government, elevated me higher. Because I had spoken (in my official CDC capacity) at a national SCD symposium two years prior to my fieldwork, I was recognized by many in the tight-knit sickle cell community throughout Brazil. Some of the narrators in this study were introduced to me while I was in this role and I was never approached as just a student. This sometimes made passive observations difficult. In an attempt to do these, I would often try to sit in the back of the room to have the greatest vantage point, but only very rarely would I be allowed to remain in the back. This was in part due to the cultural practice of those I wanted to observe and their need to make me feel special; and in part due to the level of status I was perceived to have, and thus could confer on those with whom I sat.

The performativity of being Brazilian is not just dependent on linguistic fluency, but on the body as well. Judith Butler (1990) proposes the idea of gender performativity: that gender is not an expression of who one is, but what one does. *Brasilidade* (Brazilianess) is the same. It is a way of walking, dressing,

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[7] In Brazil, higher education (*ensino superior*) begins with an undergraduate (*graduação*) degree. Often the degree you receive at this level is how you are identified by others. Even though I received a masters in public health, was working on a doctorate, and was professionally known as a scientist, I was introduced as a biologist most of the time. Exceptions to this rule are for professions like doctor, dentist, or teacher/professor. I was sometimes introduced as *doutoranda* to imply that I was in school to receive a PhD or *pesquisadora* (researcher). In laboratory settings or in clinical contexts, I was sometimes introduced as a *cientista* (scientist).

of being and interacting with others in the world. As discussed above, I coded for a black woman vis-à-vis my hair, and by the end of the research period, at times, in attire and mannerisms. When I spent my last 5 months of fieldwork in the state of Bahia, I was told that even being Brazilian was not enough, that I was and needed to be *Baiana* (woman from the state of Bahia). This was not always successful. I was once told on a leisure trip to Morro de São Paulo, Bahia by a Brazilian book street vendor (in English) that I looked too "intelligent" to be a Brazilian. "We are not there yet," he said.

Though I was viewed as an outsider on a daily basis, I also had to navigate the insider status that some of my identities afforded me. At times I was in one position or the other, in between, or at the intersection of both. For instance, though I was hesitant to disclose my own disease diagnosis to narrators, associates, and the like, this was often out of my hands. While being introduced, I was usually described as: *Ela é uma Americana, biologa, e ela tem anemia falciforme* (She is an American, biologist, and she has sickle cell disease). At first, I was disturbed by my lack of agency in this exchange, but I learned that this act of disclosure by my companions was a cultural code of closeness. While many either knew of my disease status from previous encounters I had with the SCD community, or learned it soon after meeting me, I was still questioned about the authenticity of my diagnosis. Was it the homozygous genotype (HbSS) or a less severe form of the disease? When I responded that I had the genotype HbSC (a genotype that is often, but not always milder than HbSS), I was often met with nods of acknowledgement and comments that suggested my capabilities of appearing healthy and able to conduct such a research project was linked with the

fact that I did not have to live with the more severe version of the disease. Despite this line of questioning, my blackness, further legitimized by my disease, allowed me a bond that was relatively unique for a researcher studying SCD. But as anthropologist Kia Caldwell (2007) notes, "while a shared sense of blackness may function as a source of racial solidarity for members of the African diaspora, other forms of identification, particularly national origin, often become primary" (xvi).

My research was designed to investigate the varying levels of governmental programs and people associated within the SCD public health apparatus. Due to my former position at the CDC and how I was introduced to the SCD community in Brazil, I was able to gain access to high-level public health managers. My identity as a person who had years of U.S. governmental experience, in addition to actually having the disease, provided me with privileged access to datasets, personnel, political meetings, and personal reflections about the state of scientific, organizational, and public health communities in Brazil. I did not take this privilege lightly and often wondered about potential repercussions that might arise upon writing something with which the narrators, some of them colleagues and friends, disagreed.

Because of my primary identification as a U.S. citizen, many of the narrators for this project who were scholars, scientists, or other high-ranking officials, often spoke to me as if I were a social class peer. It should be noted that most of my elite narrators who fit into the professions mentioned above were self-identified as *branco* (white). Labor-market discrimination, inadequate access to higher education, social networks, and patronage often kept black Brazilians

from being socially mobile and in general unable to become elite professionals (Telles, 2004). At times it seemed that my blackness was negated by my other identities. In one interview, in response to a question about the (dis)organization of SCD civil societies in a particular Brazilian state, the following was said:

> I know you have sickle cell, but you are very different from my patients. The intellectual level makes the whole difference…my patients have low intellectual level, the majority of them…

In this moment, this narrator felt the need to qualify first that she was aware of my SCD diagnosis and second that I embodied SCD differently than "her [Brazilian] patients." In this statement she wanted to differentiate me from them by assigning a high intellectual status to me. This assignation, also colored me "white" in opposition to her black patients. Ben-Zeev et. al. (2014) found that in a U.S. based study, black males tended to be remembered as "whiter" after being primed with the word "educated" during psychological tests. This is in accord with cultural beliefs that are transnational.[8] I was regarded this way (educated and "white") in many instances during the research period. Elite narrators were comfortable with me, as long as I discussed safe topics. I soon found that when I asked questions directly related to race, my blackness became more apparent and subsequent narrator responses were often abrupt and short. In these cases, silences proved as important as spoken words.

Though some narrators and others within my research network perceived my social status as equal to whiteness, it did not thwart the eagerness of some

[8] Telles (2004) and Schwartzman (2007) discuss the effects of education on racial classification. While there seems to be some ambiguity, Telles found that interviewers classified highly educated (self-identified) black women "whiter" than their self-report on the color continuum.

narrators to speak with me. My Brazilian participants, much like U.S. research participants living with sickle cell disease, were weary of their inclusion as research subjects, but not in broader conversations and actions to help alleviate their medical distress. Many narrators revealed to me that they were weary of researchers asking them for information but never seemingly returning to share findings or give something back to the SCD community in general (Shavers-Hornaday, 1997, Rouse, 2009, Benjamin, 2013). Several narrators spent hours with me relaying the experiences they had lived through from childhood with an unknown diagnosis, but a keen understanding in the knowledge that something was wrong. I often heard stories of betrayal, disappointment, and neglect. Despite these narratives, most of the narrators seemed excited and pleased that a foreign researcher had taken interest in their lived experiences.

If we were to situate the SCD community and all of its parts, using social network theory, Joice Aragão de Jesus would be the actor in the center of the network.[9] Her position of centrality is filled with access, connections, and prestige. In line with this theory, if she is removed from the network, it could fragment and fail abruptly (Kadushin, 2012, Carolan, 2014). Due to the close proximity I had with Joice—her access, connections, and prestige were advantageous to me. She called and arranged interviews on my behalf when I could not get a direct connection, she introduced me to top-tier managers, she

[9] Social network theory is the study of how people, organizations or groups interact with others inside their network. Central to the analysis are the connections among social units (also known as actors) and the outcomes associated with these connections. An actor's location inside the social network can be an indicator of the strength of the ties associated with him. A person near the center of the network often has more links between himself and the other actors, as opposed to someone on the outer fringes of a network. See Brian Carolan (2014) for more.

allowed me to accompany her to several closed door meetings, and she allowed me to live with her for the duration of my stay in Rio de Janeiro. By the end of the research period, she was *Tia* (Aunt) Joice. With her influence, some aspects of the research process were eased. However, my connection to Joice also meant that I was not able to obtain (maintain) a position of complete neutrality. During my first week in Brazil, I met with an Afro-Brazilian scholar embedded in the *Movimento Negro* and he warned me of the perils of providing too much information about myself to others within the *Movimento*, citing factions within the larger movement as well as in the black health movement. He suggested that I not reveal who I was living with or had plans to interview, and that I present myself as a harmless student researcher. When I was afforded this opportunity, I followed his advice.

Despite this stance of neutrality, it seemed that I was often being associated with either my former role within the US government or with my close ties to Joice. People I met within the sickle cell community would comment on remembering me from the talk I gave at a SCD conference, make reference to my role at CDC, or comment on my research, directly mentioning Joice or Altair or Cândida. Over the course of three years, I was becoming a familiar face to Brazilians in the sickle cell communities—at least in the public and organizational spheres. I was greeted warmly at meetings and felt embraced:

> *When I got off the plane in Salvador, I felt the same way I do when I attend a Sickle Cell Disease Association of America (SCDAA) meeting. I have pleasure at seeing familiar faces, knowing that this time I can communicate with them better. It makes me think that even though the time has been relatively short and discontinuous, I've done a good job in getting to know the SCD community here. CDC has helped tremendously, but my travels*

*throughout the country meeting the people living with SCD and the people who work with them pays off in recognition and "*Oi Melissa! Querida!*"*[10]

On my very first visit to Brazil, I was told by a scholar (after I carelessly revealed my disease status), that my research and subsequent writings would be biased in favor of a population that "drained the system." As discussed by Chiseri-Strater (1996), "All researchers are positioned…by age, gender, race, class, nationality, institutional affiliation, historical-personal circumstance, and intellectual predisposition" (115). Considered an expert by some of the narrators and those in my research network, I was asked to give advice to people living with SCD in clinical settings, made to address a group of public health managers, mentioned as an ally in organizational meetings, and even literally became the face (of several) of a city wide SCD campaign that took place in Salvador, Bahia landing my picture on billboards and the sides of buses.

I recognize that I am not only constructing the narrative I present in this project, but that I am part of it as well. My investment in SCD is academic and professional, but also deeply personal. Encountering the despair of SCD exhibited by many of the narrators in my study, at times I had to place distance between the research and myself. When I learned that a young and vibrant narrator, who was excited about starting a family and driving a cool car, had passed away from complications of SCD, I grieved. My positionality placed each of the collected narratives on equal ground. The voice of the scientist is just as important as the activist, perhaps that is because I see myself in both.

[10] Excerpt from Fieldnotes, November 19, 2013

Organization of the Dissertation

Chapter One provides a historical discussion based on the question: "why is sickle cell disease constructed as a "Black" disease?" This chapter is delineated by political, cultural, and biological backgrounds, followed by an explanation of my research sites, data, and methodology. Topics such as race, ethnicity, democratization, social exclusion, social control, and tensions between universality and marginality set in the Brazilian context are explored here.

In Chapter Two, "Contestations of Citizenship and the Cultural Malleability of Biology," I delve into the distinctions of citizenship from an aspirational, cultural, biological and finally bio-cultural perspective. This chapter historically contextualizes notions of race, nation, and sickle cell disease and puts my study into conversation with discourses of biopower and genomics in Latin America.

In Chapter Three, "Color, Class, and Claims: Narratives of Biocultural Citizenship," I highlight the narratives of patients and family members of those who have been diagnosed with sickle cell disease. Coupled with demographic data, I explain the fluidity of racial identity in study participants and how this fluidity is negotiated in the diagnosis, embodiment, and claims on behalf of sickle cell.

In Chapter Four, "Bicultural Competence and Policy Formation:
A Story of Elite Engagement," I examine a key interlocutor in the SCD policy development for Rio de Janeiro and Brazil—Joice Aragão de Jesus—and the strategies she employs to navigate both the governmental realm and world of the SCD Movement. Analyzing text from speeches, public interviews, and oral

histories, I discuss how political processes are used to the advantage of SCD by state actors.

In the concluding chapter, "Strategies in Belonging," I summarize how the respondents (government officials, community activists, and patients) construct, understand, and interpret their civil rights, identities, and potential contribution to policy development. Finally, I discuss how the concept of cultural trauma moves us toward a more racialized view of biopolitics.

CHAPTER ONE

INTRODUCTION | The Contemporary Trajectory of Historical Quandaries

Part I: Background

Hemoglobinopathies such as thalassemia and sickle cell disease are associated with substantial morbidity and mortality in affected individuals. Considered a public health problem across the globe, an estimated seven percent of the world population have these hemoglobin disorders. SCD is the most common hereditary hematologic disorder in Brazil and throughout the world (Cançado and Jesus, 2007). Sickle cell disease is usually ascribed to African ancestry, but it exists in Mediterranean and Indian populations as well. SCD is not a biological marker for race, but it can be considered a marker for ancestry from a geographic location where malaria is or was prevalent.[11] Given that the biology of sickle cell stems from the endemicity of malaria and the subsequent protective and genetic response, and as a result is not attached to any one ancestral or racial group, it serves as a disease that might represent the Brazilian lore of a geographically, culturally, and racially diverse and integrative nation (Stepan, 1976, Peard, 1997, Lima, 2007, Bala, 2009). Instead, the Brazilian state has assigned sickle cell disease exclusively to Afro-Brazilians, negating all others who do not identify as such. While assigning this disease to a single race, the

[11] The biological basis of race continues to be controversial, though it is widely accepted that race is a sociological construct (Risch et. al, 2002, Duster, 2005, Smedley and Smedley 2005, Hauskeller, 2014, Morning, 2014). In this project, I contend that race is indeed a social construct, but also that the biologization of race or "race-as-biology" (Gravlee, 2013) is a reality. See Chapter Two for more on this, as well as the Brazilian framing of race.

State and its policies simultaneously propagate the ideologies of both miscegenation and hypodescent.

When the National Health Policy for the Black Population (NHPBP) became a reality, it created the space for Brazilian scholars and journalists to respond to what was being deemed as racialized policies (Caldwell, forthcoming, Pagano, 2011). Since then a continuous stream of discourse has been produced from Brazilian social scientists, mostly from the fields of public health and anthropology. There has been a dearth in the English-based literature around the subject of race-based health policy in Brazil, especially out of context with the conversations on HIV/AIDS. Both Kia Caldwell (forthcoming) and Anna Pagano (2011), U.S. based anthropologists, cover this topic thoroughly, but with SCD serving as only part of a larger discussion for how the Brazilian state and related actors engage with race and health. This dissertation will highlight sickle cell disease as a lens that elucidates how the Brazilian state and its citizens regard biological determinism, ancestry, color, and disease.

Racialized Brazilian health policy is a relatively new phenomenon. As such, so is the production of literature on the subject. This is not the case for race scholarship about Brazil, which has been produced for generations. Further still, much can be found in contemporary literature around the race-based social policies that produced affirmative action directives for education. These policies laid the groundwork for health regulations from the state in an attempt to address inequalities, though it should be noted that the federal government did recognize SCD separately from the umbrella of black health in 1996, before the educational affirmative action policies of the early 2000s (Oliveira, 2003, Fry,

2005). When the Brazilian government implemented NHPBP, it added health to the cadre of programs that formalize citizens' racial and ethnic differences in order to address inequalities among them. The imprint of these educational policies has remained strong and today we can see its legacy in newly formed mandates that reserve twenty percent of the federal workforce for *pretos* (blacks) and *pardos* (browns). Unlike affirmative action for jobs or education, the health policies introduced for the *população negra* (black population) rely not on the reallocation of resources for a specific population, but on the recognition of *being* biologically and culturally different. SCD has been constructed by many of the actors I spoke with as a "black" disease and packaged with anti-racist language under the banner of black health in general. This claim to legitimacy as a citizen vis–à–vis health is different from just a claim to the right of health that the newly democratized constitution of 1988 promised.

There are three major questions that drive my research:

1. What are the ways in which different actors construct notions of race, ancestry, and identity in relation to sickle cell disease in Brazil?
2. Does diagnosis of sickle cell disease change the relationship a Brazilian individual has with his/her own identity?
3. What is the historical development of sickle cell policy and what does it tell us about Brazilian society and framings of racial difference?

The title of this project, "An Identity Crisis for Sickle Cell Disease in Brazil," speaks to a multi-level identity crisis that is in constant contestation of

competing racial frameworks at the micro, meso, and macro level. I manage these complexities with a flexible notion of biological citizenship that considers frameworks of biology, social determinants, and policy in ways that are uniquely responsive to the cultural and historical contexts of how race, identity, health, and legitimacy operate in Brazil.

Part II: Research Sites

Here in Brazil…

> … I say I'm *branco* (white) because of my skin color, but not to declare that I am of the *branco* race. Also here in Brazil there was a lot of mixing. There were Indians, then Black people came, then the Europeans, the Italians and the Chinese and Brazil became a cauldron of peoples, a mixture of color, of everything. On one hand it's bad as hell and on the other hand it's good as hell because you learn about everyone. For me race is indifferent. I only say I'm *branco* because of my skin color, just that.
>
> - Flávio, person living with SCD, self-identified as branco[12]

> … Here in Brazil we like to say, and think, that we don't discriminate against anyone. We're not racists. We're used to that idea, and truly, in many occasions that's true, we're more tolerant. The fact that racism was never legal makes a difference. But it's tough to talk about. Yesterday I saw a phrase saying "the poor are invisible." That's getting better. But the middle class,… people are irritated.
>
> -Dora, scholar on race and health, self-identified as branca

> …She is the daughter of a *negra* (black) woman with a *branco* man. She is always treated poorly by her *branco* family. She likes [my work] because primarily it has to do with race. She buys a lot of books… Mandela, books on racial relations. She is always pointing out discrimination in society, and argues on the issue. She dates *negro* (black) men. Here in Brazil, 'Innane[13] is *branca*, she is *morena* with straight hair, but she doesn't see herself that way. I think that is very important for her.
>
> -Joice, public administrator, self-identified as *negra*

[12] The use of racial terms when discussing Brazil can be complex. I will adopt the model discussed in Telles, 2004 utilizing both Portuguese and English terms for color/race. I keep most racial terms Portuguese as said to me when I share verbatim translations. See Telles, 2004, pg. 21 and Chapter Two for more.

Brazilian citizens trace their ancestry from populations all over the world; descendants who came to Brazil in different ways. The combination of Portuguese colonizers, enslaved African, and native Amerindians is held deep within the cultural imaginary, but migrations from places like Italy, Japan, Germany and the Middle East contribute to the formation of national identity (Parra, 2003, Lesser, 2013). Myths of national identity in Brazil are different from the myths of national identity in the United States. Most of the Brazilian citizens I spoke with during my fieldwork held to the lore of racial mixture as part of their identity. Introduced in the 1930s by Gilberto Freyre, Lusotropicalism was "the supposedly unique capacity of the Portuguese to thrive in foreign, tropical settings because of their innate openness to sexual and cultural mixture" (Alberto, 2011:230). Based on his book *The Masters and Slaves* (1933), which claimed that miscegenation had been a positive force in Brazil, this stance was taken up by the state and spread widely to emphasize cultural diversity and racial harmony. Freyre claimed that the mixture between African, indigenous and European populations would create a comparatively more superior mixed race (Peard, 1997). In addition to asserting a mixed-race national identity, Brazilians have traditionally constructed racial identity based on *côr* (color) as a malleable condition rather than an essential one.

This view on race in Brazil is in contrast to how some in the U.S. view it. Frank Tannenbaum (1947) looks to slavery to help interpret why views of race may be incorporated in distinct forms within these two nations. He explains that the slavery system of Brazil (and much of Latin America) allowed for a more favorable integration of former slaves into Brazilian society. The system itself, in

comparison to the U.S. system was deemed less rigid and harsh. The patterns that arose from the U.S. in response to slavery, included legislation to decrease an integrative process. The "one-drop rule" or hypodescent historically refers to a single drop of black blood conferring blackness to anyone who is descended from someone with African heritage. This was used to exclude blacks from housing, education, and voting (Nobles, 2000, Washington, 2011). The idea of hypodescent weaves itself into the conversation around Brazilians when sickle cell disease is involved. I argue that the claiming of African heritage, specifically through the vehicle of the sickle gene, is based on this notion despite the reigning viewpoints of *mixtura* (mixture). When we analyze the Brazilian flexible construction of race against the typically racialized construction of sickle cell disease, we are given the opportunity to investigate ideas, conflations and contradictions concerning ancestry, race mixture, privilege, and identity. The quotes I open this section with speak to the identity crisis that is occurring in my narrators living with sickle cell disease (especially those who do not self-identify as Afro-Brazilian), in the general population of Brazil, and in the actors associated with the state's public health apparatus.

I use the term identity crisis, not in the traditional sense of a psychological state of confusion about one's role in life, but in a way that expresses how the state, civil society, and patient population are at odds with each other concerning their actions around sickle cell disease. These themes emerged repeatedly within the narratives of the research participants. The national identities enmeshed with an individual and regional identities also present themselves and complicate the narratives of people living with and working on sickle cell within Brazil.

My fieldwork took place primarily in Brasília, Federal District; Rio de Janeiro, Rio de Janeiro; and Salvador, Bahia; three distinct cities that have their own histories and cultural imaginaries. I also spent a week in São Paulo and Belo Horizonte to collect the narratives of leaders in some of the first developed sickle cell disease community-based organizations and speak with leading scientists about the data collection for SCD in Brazil. Part of this project is to help elucidate how narrators navigate their own national, regional, and racial identities. This complication is especially present when I interview phenotypically and self-described *brancos* with SCD in Salvador, Bahia. No matter where the narrator is from, however, all convey a complexly human experience rich with joy, curiosity, pain, and hope.

Brasília, Federal District

Brasília is the capital of Brazil and the location of Federal branches of the government. The Ministry of Health and associated offices are situated here amongst a cluster of Federal departments and offices. The Ministry of Health is the agency of the federal executive branch responsible for the organization and preparation of plans and policies aimed at the promotion of health, prevention of disease, and the provision of health care for Brazilians. During my long-term research period between October 2013 and September 2014, I spent ten weeks in Brasília where I explored the mechanisms of policy development as well as gained access to documents at the Ministry of Health and the Pan-American Health Organization, and other associated entities involved within the *Sistema Único de Saúde* (SUS) or Unified Health System. I spoke with and interviewed

members of the federal *assessoramento técnico em hemoglobinopatias* (technical assistance in hemoglobinopathies) team and other members of the larger group of *coordenação-geral de sangue e hemoderivados* (general coordination of blood and blood products) where the team resides. Part of this project includes an elucidation of how municipal, state, and federal parts of the government work together and disjointedly around the attention and care of SCD. I observed and learned about these processes at each level, as well as how the federal government worked with civil societies throughout the country. The use of civil society in the development of policy in Brazil is well documented (Coelho, 2004, Labra et. al., 2005, Avritzer, 2009, Houtzager et. Al., 2003).

Rio de Janeiro, Rio de Janeiro

The historiography of medicine, public health, and science in Brazil is dominated by work produced mainly by urban centers like São Paulo and Rio de Janeiro. Physicians and other scholars from Rio in the nineteenth and early twentieth centuries attributed to the early production of knowledge around hygiene and disease. Contributing most notably to this discourse was the *Instituto Oswaldo Cruz*, created in 1900. This institute and its affiliate *Fundação Oswaldo Cruz* (Oswaldo Cruz Foundation, collectively known as *Fiocruz*) was founded to control the public health problems of Brazil and is still regarded today as the premier institution for health sciences in Brazil. There is epistemic authority that stems from this institution for public health and science. Much of the critique of the national policy for black population health and associated

sickle cell programming comes from this institute as well.[14] While Rio is important to this project because of access to Fiocruz and it's scholars, the main purpose in choosing the location was to observe and interview Dr. Joice Aragão de Jesus, the National Coordinator for the Ministry of Health's Sickle Cell Program. Using ethnographic methods, I observed her and her everyday interactions with government officials, community leaders, patients, friends, and family members. I lived with Dr. Aragão de Jesus for approximately five months in Rio de Janeiro and accompanied her to Brasília and Salvador as she conducted her official duties (meetings, conferences, workshops). She provided access to federal, regional, and municipal level health practitioners, people living with SCD, and leaders in the civil societies whom I also interviewed.

Salvador, Bahia

Salvador serves not only as the capital of Bahia, but as the metaphorical capital for black identity. Blacks in Salvador have used religion, music, and a claim to land rights to affirm their racial identity (Pagano, 2011, Calvo-González, 2010, Bartholdson, 2007, Sansone, 2003).

According to the epidemiological data that has been collected thus far, the highest rates of incidence for SCD in Brazil occur in Salvador.[15] The Reference Service for Neonatal Screening of Salvador in 2004 found three percent of the population in the capital had SCD. According to newer estimates, one in 800

[14] See Caldwell, Kia (forthcoming)

[15] Data for SCD in Brazil does not provide a comprehensive picture. As of my fieldwork in 2013, national data collection was being ramped up from within the Ministry of Public Health, but the infrastructure to collect the information is not in place outside of urban centers. Data collection methods on the federal, state, and municipal level will be discussed in Chapter Two.

people have the disease in Bahia; compared to one in 1500 in Minas Gerais, one in 2500 in São Paulo or one in 8500 in Rio Grande do Sul, the southernmost state in Brazil[16]. A movement all of its own came out of Salvador, spearheaded by Altair Lira and Maria Cândida Queiroz, a married couple with a child with sickle cell disease. Both have contributed heavily to and helped shape NHPBP for SCD in Bahia and Brazil.

I spent approximately five months in Salvador, Bahia and observed both Altair and Cândida, the municipal health officer who directs the SCD program. During this time, I shadowed Cândida while she implemented a new four module training in six districts across the city of Salvador titled *linha de cuidados em doença falciforme* (line of care in sickle cell disease). In addition to observing her and her staff during these trainings, while in Salvador I attended class at the Institute of Collective Health and meetings sponsored by the local SCD community organization, including support groups. I also interviewed other activists and medical professionals, and participated in the national SCD symposium, which takes place every two years in Brazil. I observed Altair and Cândida as they interacted not only with professionals, but with friends and family. I collected oral histories from people living with SCD who were in attendance at the national symposium in Salvador, as well as those suggested by my social network. I collected oral histories from a variety of people living with SCD, including those who do not identify as Afro-Brazilian, to help articulate the complexities of race, disease, and policy in Bahia, and in the country as a whole.

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[16] I received this information from a slide distributed to me by personnel in the secretary of health office for the city of Salvador, Bahia. The slide sourced "Programa de Atenção à Saúde da População Negra, 2012."

Part III: Research Data and Methods

My dissertation connects concepts from sociology, medical anthropology, political science, history of medicine, and public health. In order to capture the relationships between these discourses and effectively describe how state, organizations, and individuals in my project have changed over time I utilized both historical and qualitative methodologies. I employed three methods: analysis of archival materials, participant observation, and oral histories. These methods allow me to analyze how the respondents (government officials, community activists, and patients) construct, understand, and interpret their civil rights, identities, and potential contribution to policy development.

This project is based on eighteen months of ethnographic fieldwork data gathered primarily in Brasília, Rio de Janeiro, and Salvador, Brazil between 2011 and 2014. During preliminary research visits to Brazil, which usually consisted of four to six weeks during the summer months between 2011 and 2013, I interviewed key actors in the sickle cell movement from within the government and national and regional patient organizations in Rio de Janeiro and Bahia. I went to Brazil while serving as a health scientist at the Centers for Disease Control and visited under official auspices to the newborn screening programs of Minas Gerais, the municipal programs for SCD in Salvador, Bahia, and was an invited speaker at the national SCD symposium in Fortaleza, Ceará. These events were included in the analysis for this project. During the long-term data collection period of eleven continuous months (plus an additional visit two months later), in 2013-2014, I collected 50 formal oral histories from a cross-section of racial, class, professional, and educational categories (see Chapter 3,

page 99). I spent extended time with three key narrators (Joice Aragão de Jesus, Maria Cândida Quiroz, and Altair Lira), observing them in both work and home settings. The average formal oral history interview ranged between 60 to 90 minutes, though some were as short as thirty minutes or as long as six hours. Longer interviews were held over a series of days, or within the same day with breaks, usually around mealtimes. These formal interviews were supplemented by informal interviews and conversations with the fifty noted narrators, as well as with people with whom I had informal interactions, including receptionists, students, taxi drivers, and friends of friends. I attended trainings, workshops, conferences, and technical meetings as part of this project and drew on narratives from those experiences as well. I observed and spoke with people in both formal (Ministry of Health offices, congressional hearings, and hospital rooms) and informal (*terreiro*, cafes, soccer matches, and residences) settings.

Spaces of formality and informality were often blurred, and the ambiguous lines of professional and personal often were crossed[17]. Of the fifty formal interviews, five were conducted in English and four were conducted in a combination of Brazilian Portuguese and English. The remaining ones were conducted in Brazilian Portuguese. All interviews and select conversations, lectures, meeting discussions, workshops and trainings were digitally recorded, translated, and transcribed. Observations were noted in a field notebook or on my phone during and directly after events and conversations occurred. A

[17] See DeMatta, Roberto (1991), and Buarque de Holanda & Monteiro (2012). In particular the idea of *homen cordial* (cordial man), a theory developed by anthropologist Buarque, which describes the Brazilian love of informality in personal relations, and the heightened levels of public intimacy and openness, both physical and emotional, that come with it.

bilingual research assistant traveled with me to interviews while I resided in Rio de Janeiro.[18]

In addition to interviews and conversations, I observed narrators in various aspects of their personal and professional lives. Very often these two realms blended and overlapped. Due to the different ways I was perceived by the narrators (former U.S. government official, "niece" of Joice, sickle cell patient, American scientist), I was granted privileged access to the inner workings of the sickle cell program within the Ministry of Health and the associated public health activities that fell within it, as well as the higher-tier, often elite personnel who ran those activities.

Sample

This study has three main categories of narrators: persons who live with sickle cell disease of all races identified in this chapter and throughout the dissertation as PLWS[19], public health practitioners or managers (*gestores*), identified in this chapter as PHP, and civil society (non-governmental

[18] The interviews conducted in Portuguese, in the beginning of fieldwork during my stay in Rio de Janeiro, were often conducted by myself and a research assistant (RA). My RA was a young white ex-pat woman from the United States who had lived in Brazil for four years, studied Portuguese, and was fluent in the language. This dynamic was sometimes challenging as power and assumptions of expertise were often shifted to her. This was due, in part, to her mastery of the language, but also because of her whiteness. Though many have written about the hesitancy of black respondents in participating fully in research with white interviewers (Twine and Warren, 2000, Whaley, 2001, Dovidio et. al., 2002, Williams and Turkheimer 2008), the anti-black racism expressed by some Afro-Brazilians may insert the same level of mistrust for black interviewers as well. Hordge-Freeman (2012) describes the anti-black socialization which occurs in Black Brazilian families that occurs as a result of "a white supremacist and patriarchal society where Afro-Brazilians are constantly inundated with normalized racist images, messages, invisibility, structural inequality, and experience differential treatment at home based on phenotype" (117). As a result, subconscious and conscious anti-black beliefs may have been translated in the interview setting whereby inherent authority was believed to lie with my RA.

[19] Due to the fact that I interview each participant living with SCD during their well state and because they are a whole person whose illness is just one aspect of their human experience, I choose not to refer to my study participants with SCD as "patients," but persons living with SCD.

organization) leaders identified in this chapter as CSL. Due to the nature of the sickle cell community, several people fit in more than one of the categories. Each of the respondents was over eighteen years of age and resided in various states within Brazil. I also traveled outside my three primary sites and took weeklong trips to Belo Horizonte, Minas Gerais and São Paulo, São Paulo where I conducted additional interviews.

Epidemiological and other health-based studies often use a case-control study design, in which individuals with a particular disease or health outcome are "matched" with the same number of individuals who mimic as many identifiers as possible (age, sex, race, etc.) without the disease or health outcome. Though this study is about health, it is about the lives of actors who are somehow connected to health policy. The purpose of this study is not to necessarily compare the experiences of those with SCD to those without it. I was not examining risk factors, but instead analyzing the different ways in which each of my narrators interact with themselves, society, and the State through biological, cultural, and broader societal perspectives. To do this an embedded sense of place and a more fluid research framework was needed.

Persons living with SCD (PLWS)

Eligibility requirements for those in the PLWS participant pool included a diagnosis of some genotype of SCD (SS, SC, S-Beta Thal) and being over the age of eighteen. I formally interviewed 21 people living with SCD and five people who were a parent of a person living with SCD. I collected oral histories and demographic information from each narrator.

Public Health Practitioners (PHP)

Requirements to be included in this group included a current or past job within the public health infrastructure, *Sistema Único de Saúde* (SUS) or the Unified Health System. These narrators did not need to work directly with SCD, although most of them did. I included in this group those who might also treat PLWS and interface with them within the medical system, which was also part of SUS. I formally interviewed twenty-four people who may have fit in this category.

Civil Society Leaders

I also collected life histories from those who play a leadership role within the SCD movement. Requirements for this category included a current or past role in some form of leadership in a sickle cell based community organization. These organizations could represent persons living with SCD on a local, regional, or national basis. Almost all of the narrators in this category were either a current or former president of an organization. These included many of the same people who fit in the categories of PLWS or parents of PLWS. I interviewed eleven people in this category.

Recruitment

Primary sites of recruitment for persons who live with sickle cell included national, regional, and local conferences and meetings, office spaces of SCD organizations, and clinical sites such as blood banks and clinics. Points of contact with PWLS were either direct or mediated through my network of health officials, medical providers, or civil society leaders. It was through this network and the

larger network of Joice Aragão, that recruitment took place for public health practioners and civil society leaders. I created a research-based Facebook profile and recruited through this vehicle. Facebook Inc. has some 65 million users in Brazil, which makes it the company's second largest market after the U.S. by number of users. According to Maia (2001), the Internet has been highly valued for providing resources for groups to express and update their identities, their values and interests. Using snowball sampling, I expanded my network of potential narrators, as well as persons whom I could informally observe or converse.

Part IV: Methodology

I was interested in the development and implementation of sickle cell disease policy over time and seek to explain the historical tensions between the state's promulgation of racial democracy and a continuing emergent policy that highlights a racial binary. I examined this general historical question by consulting secondary sources, such as the sociological, anthropological, and historical works on black health in Brazil, specifically, the sickle cell movement.

Political Ethnography

Anthropology is not new to public health, however its contributions to health policy are less noted (Caudill, 1953, Baer et. al., 1990, Campbell, 2010). Because public health's primary concern is to improve the health of a population, it relies mostly on epidemiology to provide data from which conclusions that lead to policy can be extrapolated. According to Campbell (2010), anthropology's

minimized role in health policy development is likely attributed to the methodological and time-consuming practice of ethnography. When striving to understand disease etiology within a population, public health practitioners often turn to a social determinants of health framework. This model takes into account the many levels of influence on health and includes an individualistic viewpoint such as genetics, age, and gender and extends broadly to general socioeconomic, environmental, and cultural factors. Narrators interfaced within this framework in such a way that a standard questionnaire and focus group format was inadequate to capture the nuanced data necessary to explain the embodiment of SCD policy. I explored the implementation and implications of policy already developed. The utilization of ethnography (observations and interviews) can help elucidate how certain communities played a role in policy development and how they continue to interact with the legislation.

Policy dictates how human bodies are governed and influences every aspect of one's life—education, taxation, and health. Policy influences how citizens act and these citizens must "contend with, measure up to, subvert, manipulate, or simply internalize these ideal types as part of their own identity. The state's agenda can normalize the actions of the citizens (38)" (Wedel, 2005). Afro-Brazilians, who have been used to operating within a policy of neglect, have made decisions to subvert this norm and demand that the state create policy on how SCD is controlled. This project explored how each of the levels I encountered (individuals, organizations, state) were interconnected. By "studying through" (Shore and Wright, 1997), I hoped to "trace ways in which

power creates webs and relations between actors, institutions and discourses across time and space (40)" (Wedel et. al., 2005).

Despite my interactions with people living with SCD, many of them from low socio-economic backgrounds, I was aware that this is also a study of the elite. An anthropology of policy and this project in particular, focuses on policy professionals themselves—their worldviews and influences. Their roles and actions in official meetings are no less important than their interactions with family members and the grocery vendor. I observed a ministry of health official both in her role as national program coordinator, and in her "off-duty" life. According to Tilly (2006), "political ethnography commonly includes a continuum of procedures for collection of evidence, from intrusive to obtrusive" and includes "in-depth interviews, conversation, participant observation, passive observation of interaction, and covert observation of interaction" (410). I employed this ethnography for the micro, meso, and macro level of subjects.

According to McLaughlin (2003), "the adoption of a cultural analysis paradigm or perspective presupposes a belief in the explanatory power of culture and cultural activity. Mark Abrahms (1965) characterized the social scientific research process as involving three interlinked levels:

1. the definition and conceptualization of 'the problem'
2. the design of research strategies for 'attacking' that particular problem
3. the pursuit of these strategies in the most efficient ways (62)."

With this in mind, my general research design did not predetermine the choice of the best way to collect data. At times, I entered a setting where I assumed the narrator and I would be able to sit in a private and quiet area to conduct and

record an interview and instead the situation called for a casual conversation or a period of observation where I said very little. Many times I wanted to sit toward the back of a room to record, observe, and note-take and was instead asked to sit in the front row, asked to participate directly, and other times asked to give an impromptu statement about who I was and what my interest was with being present.

According to O'Conner (2011): "Qualitative research uses unreconstructed logic to get at what is really real—the quality, meaning, context, or image of reality in what people actually do, not what they say they do. Unreconstructed logic means that there are no step-by-step rules, that researchers ought not to use prefabricated methods or reconstructed rules, terms, and procedures that try to make their research look clean and neat." Heavy reliance on pre-determined questions instead of guidance from the research subject may have served as a deterrent to the types of information I was seeking (Hacking, 1982). Though I entered a planned interview prepared with a discussion guide and interview questions, I allowed the narrators to take our conversation in the direction they wanted. There were topics that I consistently wanted to cover (such as SCD policy, ideas about ancestry, and thoughts about color), but I did not adhere to a strict order or coverage of the questions I prepared. Often times, the response to one question would take the interview in an unintended direction which I allowed until I redirected the probing back to the discussion guide. As such, my research relied on a fluid methodology that left space for openness, especially during the initial stages of data collection until I felt familiar with themes that emerged frequently.

The semi-structured interview is broadly characterized by the "interactional exchange of dialogue; a relatively informal style; a thematic, topic-centered, biographical, or narrative approach; and the belief that knowledge is situated and contextual, and that therefore the role of the interview is to ensure that relevant contexts are brought into focus so that situated knowledge can be produced (62)" (Mason, 2002). The relatively open, flexible, and interactive approach to interview structure is generally intended to generate interviewees' accounts of their own perspectives, perceptions, experiences, understandings, interpretations, and interactions (Mason, 2002).

Oral/Life History

Interviewing modes such as open-ended interviews, life story interviews, and semi-structured interviews often draw upon the oral history tradition (Chaitlin, 2008, May, 2002). The techniques I used in eliciting oral histories share the following commonalities: questions were open-ended and person and experience centered, and the questions aim to elicit rich detail on the topic being studied and involve active listening. Opening questions can be extremely general and open-ended, leaving it to the interviewee to direct the interview. Oral history provides information that cannot be gleaned from any other sources, and it gives voice to ordinary and often marginalized peoples whose stories might never have been documented otherwise. Oral history methods provide a glimpse into how people of the past constructed their worlds what they believed, imagined, and valued (Chaitlin, 2008). In this way we can understand the importance of social

or collective memory, identity, myth and the self, together with the means by which life narratives are constructed (Gardner, 2006).

According to Giles-Vernick (2006), “it remains very difficult, particularly for historians, to resist interpreting oral historical narratives as depicting the past ‘as it really happened’ and thus to privilege such accounts as ‘truth’”, (92). Though methodologically critiqued, it was my role as researcher to situate the narratives of the subjects in the appropriate cultural and political context and to draw on other forms of historical evidence to help (White, 1995). Thompson (1978) explains, “The key point is to be aware of the potential sources of bias, and the means for countering them…One of the deepest lessons of oral history is the uniqueness, as well as representativeness, of every life story (129).”

The typical life history will cover the events of the respondent's life course up to the present. Hence, a biographical approach is indicated where the area of interest is either the effects of change across time, historical events as these events have impinged upon the individual, or his or her movement along their life course. According to Miller, “the techniques of biographical interviewing facilitate recall through a process of cross-referentiality as the respondent moves back and forth in their life history and makes linkages between different types of events and segments of their life (74)” (Miller, 2000).

There are several views on interviewing, but the main approaches include a structured interview based on a set of common questions and the other extreme which includes free flowing dialogue with no set pattern between the interviewer and interviewee (Thompson, 2000). My process lay somewhere in the middle of these two. While I had a semi-structured interview guide, I also allowed the

interview to deviate from these prepared questions in the direction that my narrator guided. Though I collected life history information from each narrator, I collected a more extensive history over several sessions with several key stakeholders. As suggested by Chaitlin (2008), I asked some participants to provide artifacts or documents, such as letters and diaries from different historical periods that added another dimension to their stories. This took place in the sharing of photos and access to personal computer files that archived the narrator's position in the timeline of sickle cell activities for Brazil.

Lastly, it is important to discuss terminology. As Leavy states (2011),

> Researchers have different terms for labeling research participants, and these terms are not interchangeable; they reflect epistemological assumptions. Quantitative researchers often use the terms *respondent* or *research subject* (9).

Due to the nature and relationship between the interviewer and interviewee, often viewed as collaborative, oral historians use the term "narrator." Like Leavy, I also use the term "participant," as is common in social science. Further, in accordance with the principles and best practices for oral history, I use identifiable names, except when anonymity is appropriate or has been requested. There are times, in ethical consideration, where I withhold names and contextual information even when the narrator granted permission. Some narrators requested the use of just their first name, two requested full anonymity.

Part V: Analysis

Narrative analysis is the study of any narrative texts, such as accounts found in the private, public, or political realm, oral or written narratives collected

for research purposes, or public policy documents. Informed by numerous theoretical orientations, most narrative studies pay attention to themes and focus both on what is being told (thematic) and how it is being told (structural) (May, 2002). I utilized both thematic and interactional analysis. According to Riessman (2005), the thematic approach is useful for theorizing across a number of cases – finding common thematic elements across research participants and the events they report. Following the methodology of oral history, I tried to interrupt as little as possible during most of the interviews (Thompson, 2000). For PLWS in particular, at times I found myself relying on the interactional approach, which emphasizes the dialogic process between teller and listener. As Riessman (2005) argues, "Interest shifts to storytelling as a process of co-construction, where teller and listener create meaning collaboratively. Stories of personal experience, organized around the life-world of the teller, may be inserted into question-and-answer exchanges" (188). As someone who shares similar illness experiences with PLWS narrators, due to my SCD diagnosis, this type of interaction did occur. The interviews often included exchanges of information and were not unidirectional, especially and often in the cases where I was viewed as a subject expert.

For analysis, both *a priori* and emergent or inductive coding were developed. *A priori* codes are developed before examining the current data at hand. They often are derived from previous literature, existing frameworks, analytical categories, and prior experience in the field. Inductive codes are grounded in the data and are developed by the researcher in the process of directly examining and thinking about said data (Dey, 1993). I used Glaser's

(1965) constant comparative method to compare new indicators to previously coded indicators as concepts are formed. As new codes emerge in subsequent interviews/oral histories, I reviewed previously coded interviews for indicators of newly developed codes. The constant comparative method also posits that, "while coding an indicator for a concept, one compares that indicator with previous indicators that have been coded in the same way" (LaRossa, 2005:841). Throughout the open coding process I constantly compared previous excerpts of codes to newer excerpts to validate the meaning of the code.

In addition to the data that I gather from interviews and observations, I also relied on a broad array of secondary material and sources including YouTube videos, pamphlets and other program products generated by SCD organizations, blood bank newsletters, prevalence data, and personal correspondence.

CHAPTER TWO

Contestations of Citizenship and the Cultural Malleability of Biology

Mutual Inclusion: Policy Making for Sickle Cell Disease in Brazil

When the National Health Policy for the Black Population (NHPBP) was drafted in 2006, the Brazilian State was continuing to enact the trend of a "new political paradigm" (Pagano, 2011:1) in which the State recognized the racial differences of its citizens in order to address certain inequalities. For health, translations within the Afro-Brazilian citizenry included additional attention on biological and cultural difference. Though this attention has the potential for reifying deterministic notions of race, it is important to interrogate the confluences between these constructs of difference and to illuminate the ways in which both exclusion and inclusion can take place (Duster, 2003, Kahn, 2005, Braun et. al., 2007, Clarke, 2009, Montoya, 2011, Roberts, 2011, Wade et. al., 2014). It is also useful to draw on anthropologist Annemarie Mol's (2002) idea of mutual inclusion here, which helps explain how biology or nature and culture are, in fact, in "coexistence side by side" (150). "This means that what is 'other' is also within" (Mol, 1999). Further, as Wade (2014) contends: "it is important to recognize that, in general, culture and biology—or culture and nature—are always intertwined in racial thinking, so it is misleading to think in terms of a simple temporal transition from one to the other" (18).

In this chapter, I will discuss how my work is in conversation with seminal texts about sickle cell disease, as well as various fields such as sociology of science, medical anthropology, and science and technology studies. Using an

intersection of analyses both here and in following chapters, I describe how participants within my study draw on both static notions of biology (i.e. hemoglobin S is a result of the substitution of a valyl residue for a glutamyl residue at the sixth position of the β chain) (Mosby's Medical Dictionary, 2009), in tandem with flexible notions of culture, to make claims to the State for access to resources, services, pharmaceuticals, and health promotion. Though it is important to recognize that concepts like biology and culture are reifying in their own way, this study shows how reification of these categories in Brazil is a strategy deployed by certain actors to gain access to rights around health (Bauhmann, 1996, Lee et. al., 2001, Duster, 2005, Murji & Solomos, 2005, Braun et. al., 2007, Epstein, 2008, Fullwiley, 2011, Mahtani, 2014). Like Montoya's (2011) elegant study on diabetes within the Mexican population, I insist that sickle cell disease, (particularly for, but not exclusive to, Brazil) "is social, biological, political, historical, material, cultural, and behavioral" (33). With this in mind, I define *biocultural citizenship* (see Figure 1) as a flexible mode of enacting belonging that varies depending on disease status, skin color, social class, recognition of African lineage, and other identifiers. It is dependent on the idea of biological and cultural difference that is coproduced by the State and Afro-Brazilian citizens.

Lock (1993), Dressler (1999 & 2005b), Gravlee (2009) and others help blur the boundaries that "race," "culture," and "biology" can lock us into. In a study that details how universal biological processes are culturally embodied differently for aging women in Japan and in North America, Lock emphasizes the need to consider the cultural aspects of the biologized. "A dialectic of this kind

between culture and biology implies that we must contextualize interpretations about the body not only as products of local histories, knowledge, and politics, but also as local biologies" (39). Within the context of sickle cell, this is further complicated by the fact that while considered a monogenic disease, SCD presents with polygenic phenotype (Driss et. al., 2009, Ballas, 2010, Fulwilley, 2010). The phenotype of skin color signifies race for some, especially so for some in Brazil and has been attached to culture in a previous study by Dressler (1999). In this study, Dressler measured the ability of a person to live up to cultural norms in a small Brazilian town. There was "significant interaction" between this measurement and skin color in relation to blood pressure for his sample. Though I do not measure any biomarkers as part of this study, I account for the "bio" in biocultural citizenship via the S allele in my study participants (as represented by sickle cell trait (AS), homozygous sickle cell disease (HbSS), sickle cell SC (HbSC), and sickle cell beta-thalassemia (HbSβ-Thal)). I account for my understanding of culture as collected via ethnographic observations and interviews in addition to a geo-historical understanding of Brazil that allows for the S allele to interact with a number of cultural variables (race/skin color, ancestry, geographic location, activism, gender, appearance, kinship, genetic imaginary).

Some public health scholars suggest not that we discount the biological aspects of race completely due the nuance it necessitates and confusion it brings when discussing the health disparities found in different populations, but that instead we seek to explain how "race becomes biology" (Gravlee, 2009:47, Baer et. al., 2013, Krieger, 2014). My intent is not to demonstrate "how experience

gets written on the body in terms of measurable physiological, psychological and even morphological outcomes" (Dressler, 2005b: 24). Instead, I assume that these processes are occurring and are emboldening study participants to claim these biocultural processes in either making claims or distributing resources, pharmaceuticals, and health promotion. This study undertakes what Sweet (2008) describes as "an understanding that the social and cultural environments that influence health are historically contingent and embedded in political economic fabrics that structure power and inequality" (189). These "fabrics" are demonstrated in my model (See Figure 1) as the outer layer and include specific societal variables: levels of racism (institutional, internal, and personally mediated) (Jones, 2000), discrimination, politics, social class, policy, healthcare access, occupation, education, income, lifestyle (Dressler et. al., 1998), social capital, and cultural capital. There are some in Brazil, who argue for the erasure of race and its use to develop anti-racist policies such as the NHPBP, and in doing so ignore how these fabrics are embedded in Afro-Brazilian citizens (Pena and Bortolini, 2004, Pena, 2005, Pena et. al., 2011, Fry, 2005, 2007, Kent and Wade, 2015). Reardon (2012) suggests the creation and use of genomic knowledge be paired with political and economic practices. The Black Movement has done just this in their citizenship claims, not just in the name of biological difference, but for cultural differences as well.

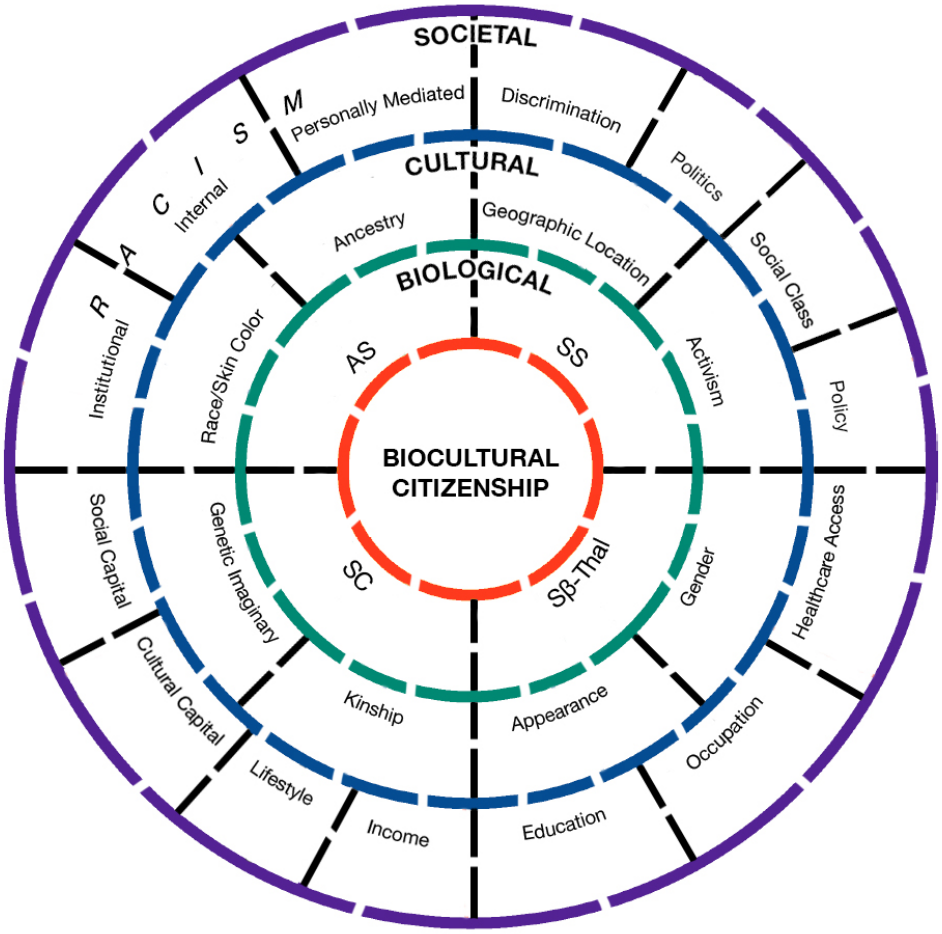

Figure 1: Biocultural Citizenship in Brazil

The rest of this chapter is divided into two parts. Part I will discuss a historical contextualization of sickle cell disease, race, and nation, and includes the social construction of sickle cell disease. Part II will lay out the various conceptions of citizenship that are important to this study and include general notions of Brazilian citizenship, biological citizenship, and cultural citizenship. I conclude this section with a brief explanation of biocultural citizenship. A more in-depth argument regarding this concept is included in Chapter Three.

Part 1: Sickle Cell Disease, Race, and Nation

Historical Constructions of Race and Nation in Brazil

While the concept of race is evolving, historically it has been "situated within power relations" and classification systems, (Wade, 2010:5). Power relations between Europe and Brazil were at the crux of how nation, race, and health were intertwined during the nineteenth century. The political and intellectual elite prioritized and linked nation building and "civilizing" society after Brazil's independence from Portugal in 1822. Schwarcz and Gledson (2006) and Liliane Liliane Moritz Schwarcz (2004) links the early images portraying the Brazilian empire's inclusion of its indigenous and black populations to efforts by the ruling class to recognize and celebrate a nation founded on *mestiçagem* (miscegenation) and so attenuate criticism that the new ruling class continued to be an extension of Portuguese colonialism. Though the Indian figure was highlighted more often than the black figure in these representations—in attempts to divert attention from slavery—black bodies were an ever present problematic for the State to contend with and maneuver around. Even as Europeans came to view slavery as a measure of political, economic, and cultural backwardness, Brazil's economy was still dependent on slave labor. Perhaps even more offensive to European sensibilities with the rise of race science (Stepan, 1982), its population had one of the highest rates of miscegenation in the Americas. The large population of mulattos and mestizos prevented elite Brazilian society from identifying as white (Skidmore, 1993, Peard, 1999, Telles, 2004, Moritz Schwarcz, 2006).

Leading up to and after the abolition of slavery in 1888, elites promoted Brazil (within its boundaries and to ruling groups abroad) as a place that harbored no racial prejudice, citing a lack of hatred between the master and the slave (Andrews, 1991, Skidmore, 1993, Alberto 2011). Despite these good relations, the goal of the political elite was to "whiten" the country (both biologically and culturally), primarily through immigration policies developed to assist in the replacement of laborers that slavery previously provided. This whitening was not a strategy to solely replace a workforce; it was also a method used to encourage modernity, modeled after Europe (Skidmore, 1993, Butler, 1998). Developed first during the Empire, decades before the popularization of Freyere's whitening thesis, this earlier version contended that with increased exposure to European migrants and migrants from other nations (and denial of black migrants), Brazil as a whole would become whiter and more modern. Elites hoped whitening would separate them from their mulatto past and usher them into a national identity more aligned with their European aspirational counterpart. Brazilian scientific and political elites used racial policies and measurement to invent identities, categorize individuals, and create a vision for a nation based on racial improvement (Stepan, 1991, Skidmore, 1993, Peard, 1999, Moritz Schwarcz, 2006, Santos, 2012).

The "constructive miscegenation" (Stepan, 1991:138) that elites promoted was not only to intended to produce offspring that ranked well on the racial hierarchy, but was also part of a larger scientific movement of racial science promoted by early eugenicists (Butler, 1998, Schwarcz, 1999). This was a highly influential factor in the development of Brazilian science and medicine. Though

Brazilian scholars were generally ignored beyond their national boundaries, they worked hard to contribute to the scientific discourse around race. The production of national medicine as reported in Brazilian scientific journals aided in the construction of a modern State even as the same discourses pathologized racial mixture (Stepan, 1981, Schwarcz, 1999). Brazilian scientists were caught precariously between the acceptance of foreign theories positing that race-mixing led to degeneracy and the need for the adaption of the same theories to justify their own national composition (Stepan, 1991, Borges 1993, Schwarcz, 1999, Santos, 2012). The middle ground was a Lamarckian eugenic stance, which sought the social and biological improvement of the human race by modifying external factors and conditions.[20] Elites promoted the prevention of disease through environmental control and the systematic collection of data on nutrition, flora, fauna, and epidemiology to prove that Brazil could be associated with Western powers of the world (Lima, 2007).

This softer approach to eugenics went against what traditional eugenicists saw as a natural solution to a racial problem (Stepan, 1991). Though the Lamarckian set of ideas from the early twentieth century were less overtly racist than the ideologies coming out of Britain, the United States, and Germany, Brazilian scientists still expressed their own brand of racism to ensure a better, more modern, whiter nation. While the eugenics of the early 1920s focused on the sanitizing and whitening of the Brazilian population, the late twenties and early thirties saw a rise in European and U.S. style eugenics. Renato Kehl,

[20] Jean-Baptiste Lamark was French naturalist who "proposed that a single 'national race' was biologically possible, and this provided the scientific scaffold for the creation of Brazilian immigration policies…" (13). See Nancy Stepan (1991) and Jeffrey Lesser (2013) for additional information regarding the application of eugenic principles in Brazil.

considered the father of Brazilian eugenics, began to aggressively declare the dangers of racial mixing and urged the state to take control of reproduction. He was contested by Mendelian critics who claimed that it was not the role of the state to interfere with "natural" hereditary and that instead it should focus on programs that promoted hygiene (Stepan, 1991, Dávila, 2003, Telles, 2004).

The 1930's ushered in a paradigm shift from the valorization of "whitening" to the celebrated acceptance of cultural heterogeneity. Gilberto Freyre was a key architect of this view. As an elite young man of a prominent family from Pernambuco, Freyre traveled and completed studies in the U.S., where he was influenced strongly by anthropologist mentors who emphasized the effects of culture—not race—on national identity. He popularized the idea of a *mestiço* (racially and culturally mixed) nation, constructing a vision of Brazil free of racism most notably in his 1936 *Casa-grande e senzala* (*The Masters and the Slaves*). Gone were the nineteenth century foci on indigenous symbolism. Instead Freyre's work focused only on the African and European. Freyre and other contemporary Brazilian intellectuals embraced the cultural union of these two populations, arguing that pacifistic race mixing had forged a new national identity. This view was soon sanctioned by the State under the rule of Getúlio Vargas (Alberto, 2011, Dávila 2010). Vargas incorporated Freyrean notions into his projects of federal unification, adopting symbols of African culture and reinventing them as Brazilian—all the while claiming *democracia racial* (racial democracy) (Skidmore, 1993, Butler, 1998, Alberto, 2011).

The integration of the idea of racial democracy with Brazil's national identity evolved from the 1940s, when it was introduced, to the 1970s. Racial

democracy had different meanings and uses for different groups of people. As described by Alberto (2011), the term was used by intellectual elites as a political metaphor to describe an amicable relationship between all of Brazil's racial and ethnic groups. This was, perhaps, a misnomer, at least in its earliest iteration, considering Brazil was under an authoritarian dictatorship. 'Black intellectuals' during the 1940s used the term to advance their position in society, calling on the state to create legislation that would make the claims a reality—a shift from an earlier nostalgic viewpoint that relied instead, on sentimental ties with white elites.[21] By the 1950's Brazil, likened to a racial "laboratory," drew the attention of the outside world for their seemingly harmonious way of life in terms of race relations(Maio, 2001, Alberto, 2011). Members within the United Nations Educational, Scientific, and Cultural Organization (UNESCO), influenced by Brazilian scholars and profoundly affected by lingering atrocities in the post-world war, set their sights on studying race in several Brazilian cities (Maio, 2001, Alberto, 2011). The results of these analyses varied. As Alberto (2011) explained:

> …even as the UNESCO studies challenge facile visions of Brazil as a racial paradise, they simultaneously contributed to discounting the role of race and racism as independent factors in creating and sustaining Brazil's social inequalities." (183)

Further, she contends that Freyrean approaches and other scholarship of the tiem, helped introduce a new vantage point for Afro-Brazilians to claim citizenship based on their active participation in the formation of the State.

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[21] Alberto (2012) describes this term to include "thinkers, writers and community leaders who proudly claimed their African racial or cultural heritage and who aspired to represent other Brazilians of color in national discussions about race and national identity."

Abdias do Nascimento, a prominent black intellectual, demanded a "right to rights" – not just the codified rights that were obligated to blacks with Brazilian societal membership as citizens, but the actual deployment of these rights (Alberto, 2011:171). It is this concept that contemporary actors in this study engage with in attempts to achieve full access to citizenship—most prominently in a "right to health rights" framework. Since the abolition of slavery, widespread views of racist science and eugenic reproductive practices have promulgated the exclusion of Brazilians of color from full citizenship. The biology of this population, in recent years, has been used to demonstrate new forms of inequality. While the data may be new, supporting different ways to claim entrée to citizenship, the long history of social exclusion remains.

Classification and Brazilian Conceptions of Race

The historical racial and national constructions of Brazil I discussed above were based on a racial classification system distinct from the United States and Europe. Unlike U.S. conceptions of race, which rely on the idea of the one-drop rule or hypodescent, Brazilians often use color (*côr*) terms rather than racial ones to describe themselves. It is important to recognize that different actors utilize different racial classification systems. Since 1991, the Brazilian census has employed the categories white (*branco*), brown (*pardo*), black (*preto*), Asian (*amarelo*), and indigenous (*indígena*). *Pardo* captures almost everyone in the continuum between *branco* and *preto*, though it is important to note that it goes beyond the admixture of white and black, but also includes other categories (i.e. admixture of black and indigenous). Created by the State, and shifting

significantly over the course of the nineteenth and twentieth centuries, the above are the formalized categories used to measure race in early twenty-first century Brazil.

In addition to the formal system, there are a multitude of informal terms and categories; Brazilians describe themselves with many different monikers. Schwarcz (2003) lists 136 different self-ascribed *côr* definitions from a survey administered by the *Instituto Brasileiro de Geografia e Estatística* (IGBE). *Côr* refers to both phenotype (skin color, hair type, nose shape, lip shape) and social position (Nobles, 2000, Parra, 2003, Telles, 2004, Travassos and Williams, 2004). This collection of data suggests that the notion of Brazilian racial fluidity is prominent even in state produced documents.

Hordge-Freeman (2013) highlights the applicability of the concept of a phenotypic continuum to describe the racial structure of Brazil, with blackness at one end of the spectrum and whiteness at the other. The term *côr* encapsulates the importance and hierarchy of phenotype for some Brazilians, many of whom eschew the term *raça* (race). Racial hierarchies often rank highest those phenotypes that most closely resemble whiteness. In some cases, some phenotypic characteristics, such as hair type, carry more importance than skin color for determining *côr* (i.e. a wavy pattern of hair on a brown and dark skinned woman, may place her closer to whiteness on the continuum), (Gilliam and Gilliam, 1999, Hordge-Freeman, 2013). Lastly, and most important to the story of the NHPBP, the *Movimento Negro* (Black Movement) created and promoted its own racial classification system. This system uses only two terms, *branco* and *negro*—collapsing the terms *preto* and *pardo* into the *negro*

category. The adoption of this bifurcated system as a tool of social organization may explain why the Movement called for health policies to follow suit.

Genetics, Race, Identity Politics, and Bounded Justice

In Wade's latest edited volume, Mestizo Genomics (2014), he and his coauthors offer a sweeping analysis that covers the genomic science that took place in laboratories in Brazil, Colombia, and Mexico. The authors in this volume join many others who have problematized nation, identity, race, disease, ancestry, culture, region, and appearance—some of this scholarship is mentioned above (Wade, 2002, 2010, Burchard et. al., 2003, Fullwiley, 2008, Koenig, Lee, and Richardson, 2008, Reardon, 2005, Maio and Santos, 2010, Gibbon et. al., 2011, Royal et.al., 2011, Abu El-Haj, 2007, Kent et. al., 2014). My work contributes to a growing body of literature that shows how these aforementioned concepts are imbricated in processes for citizenship. The identity politics at hand here may serve some sectors of the Brazilian population, at least for now. The SCD Movement relies on genotype and the notion of biological difference to set themselves apart to receive a set of health-based rights. Others in the Black Movement look to SCD as the "flag," metaphorically waved in victory. Some Afro-Brazilians are not in line with the strategic maneuverings of the Black Movement. Kent and Wade (2015) discuss how one individual in particular fears that positioning the Afro-Brazilian population as unique runs the risk of undermining the struggle for racial equality. They posit: "For some people, to what 'blacks' are entitled in Brazil is shaped by whether 'blacks' can be said to exist as a biological category – a question that others deem irrelevant to issues of

entitlement. In this sense, the category 'black' is co-produced as it circulates through genetic and political domains" (Kent and Wade, 2015:4).

The issue of "entitlement" and the question of who gets to deem its relevance contribute to the concept of *bounded justice*—an attempt to distribute health rights by making surface level changes that fail to generate substantive shifts in the conditions that created the initial problem. [22] Though Pagano (2011) applies the term "compensatory justice," to describe how the National Comprehensive Health Policy for the Black Population establishes "equity as a necessary pre-condition for the fulfillment of equality" (100), she does not tell the whole story. Compensatory justice is thought to be victim-based with no collective, community, or societal intentions. No strategies are offered to the victims or the victims' families to facilitate their recovery from their perpetuators' wrong doing (Brooks, 2013). Instead, in the case of the NHPBP there is a combination of redistributive and restorative justice practices in place. A more nuanced definition coined by Fraser (1998) is affirmative redistribution. Reforms of this type (welfare and affirmative action) tend to "seek to redress maldistribution by altering end-state patterns of allocation, without disturbing the underlying mechanisms that generate them" (45). Guimarães (2001) affirms this by noting that while the Brazilian State made great efforts during the 1990s (initiated with Cardoso administration with the promotion of racialized policies),

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[22] Onara O'Neill (2000) discusses "bounded and cosmopolitan justice" in which one must assume that the context of justice has boundaries and is based off the concept of John Rawls' "bounded society" (Rawls, 1971, 1989, 1993, 1999). According to O'Neill (2000), "Rawls conceives of peoples as territorially bounded and politically organized, and as able to appoint representatives21 through whom they are to reason with other peoples about justice beyond boundaries" (50).

it neglected to face the systematic racial inequalities demonstrated in income distribution and access to public services.

Affirmative redistribution tends to label its beneficiaries as distinct—and in the case of SCD—they want it to be so. However, to those outside the group they might be interpreted as lesser in addition to different, perpetuating a cycle of marginalization. Restorative justice focuses on the harmful transgressions of perpetuators and actively involves victims and offenders in the process of reparation (Ness and Strong, 2010, Brooks, 2013). In this case, the offender is the State, on trial not only for their contemporary societal transgressions but also for the historical ones that trace back to the legacy of slavery. Further, while a restorative justice based reconciliation process is not taking place in the intensive form of post-Apartheid South Africa, for example, the "victims" (SCD Movement) and "offenders" (administrators of the State via SUS) are working together as per the mandate of the Constitution. In theory, genetic analyses deployed for reconciliation projects can nurture the group's self-empowerment and "contribute to community cohesion, collective memory, or social transformation" (Brooks, 2013, Nelson, 2016:8). In reality, the deeply embedded, and at times, ineffective practices of the government, combined with the lack of experience of Afro-Brazilian citizens in handling political power, contributes to what I call bounded justice.

There are two sides working in conjunction to produce bounded justice. On one side is a powerful State that outside of a legislative mandate to address inequality is not interested in redistributing power. On the other are the descendants of a population who had their legal, economic, and general human

rights stripped from them and who have contemporarily been given political power in absence of other important pieces of power. The limited experience of Afro-Brazilians in wielding political power is a result of very active racism, and the legacy of the collective and cultural trauma of slavery. This anemic attempt at justice by the State, the splicing of redistributive and restorative justice, is limited by the social reality that the production of "legitimate" knowledge about the science and medicine of SCD is still dominated by individuals and institutions with no ties to the Black Movement. This manifests, as observed again by Kent and Wade (2015), in the "[impossibility] to mobilize scientific experts and their knowledge for the production of a counter-argument [within the Black Movement against the 'genetic argument'], or even to gain sufficient working knowledge of genetics to engage the scientific debate" (11).

Though the typological framing of the SCD policy has the potential to work against Afro-Brazilians in the very ways Duster (1990) warned, my study participants were not concerned. Though this policy (and the science behind it) has the potential to do damage long-term, in the short-term, people living with SCD were able to access better care and treatment for their disease—at least within the State's public health infrastructure. Even as it reifies a biological notion of race, linking genetics to race aligns with individual and population health interests in this case. This linkage allows for some to embed a campaign for better health outcomes into a politicized identity: "…In Brazil some worry…[and others still may hope]…that genetic accounts of race, rather than reifying the black category would dissolve it and thus undermine black political solidarity" (Kent and Wade, 2015:16). Those in the SCD Movement may not be

worrying about this, and rather are glad to receive the relatively small (yet realistically quite meaningful) benefits this health policy distributes. This is not incommensurable with their awareness that these benefits are microscopic in comparison to the larger scope of civil rights that ought to be afforded to them as Afro-Brazilians. As a political and scientific strategy, Afro-Brazilians have positioned their bodies as exceptional and in doing so have forced the state to respond to their claims.

Sickle Cell Disease

Sickle cell disease (SCD) has been a site of interrogation for many across disciplines, ranging from basic science (microbiology, immunology, biochemistry) to social science and humanities (sociology, anthropology, psychology, history, and ethics). On the cellular or molecular level, SCD remains controlled. Studies from this realm tell us that it is a genetic blood disorder of hemoglobin that damages and deforms red blood cells. The sickle-shaped red cells sometimes break down (hemolysis) and cause anemia. They also obstruct blood vessels, causing ischemic organ damage and episodes of unpredictable, recurrent, and sometimes severe pain in those who suffer from SCD. There are several common variants of SCD: SS, the most common and severe form of the disease (inheritance of one sickle cell gene from each parent); SC, a milder form of the disease (inheritance of one sickle cell gene and one gene for another abnormal type of hemoglobin called “C”); and S-beta-thalassemia (inheritance of one sickle cell gene and one gene for beta-thalassemia, another inherited hemoglobinopathy). Individuals who inherit the sickle cell gene from one parent

but who's other copy of the gene is normal are healthy carriers of the disorder and are said to have sickle cell trait (SCT) (Dauphin-McKenzie et.al., 2006). Sickle cell syndromes (hemoglobin variant groupings) occur in higher frequency in people from geographic areas where malaria is, or was, endemic. Those with sickle cell trait have protection against severe malaria infection (Platt, 2002).

Individuals with SCD are at risk for unexpected, intermittent, and at times, life threatening complications, including pain, infection, stroke, joint necrosis, and/or major organ damage, as well as psychosocial adjustment issues. SCD accounts for a notable proportion of visits to emergency departments and admissions to general pediatric and hematology units. One of the most common problems experienced with SCD is the pain associated with unpredictable vaso-occlusive crises or episodes. Vaso-occlusive crises are the clinical hallmarks of SCD. These events result in recurrent painful episodes and both acute and chronic pain is associated with SCD in adults and children (Stinson & Naser, 2003). SCD is often associated with suffering, distress, neglect, and stigma. These descriptors are often intertwined with the life experiences of some of the narrators in my study outside of their illness narrative (Rouse, 2009, Elander et. al., 2011, Royal et. al., 2011).

SCD is considered an important public health problem in Brazil and the United States due to the amount of estimated people it affects as well as its associated high mortality rate (Creary et. al., 2007, Brasil, Ministerio da Saude, 2001). The lack of medical services, regular follow-up, genetic counseling, and subsequent dependency on the health system has called for a comprehensive sickle cell program in Brazil (de Paiva et. al., 1993, Brasil, Ministerio da Saude,

2001, Ramalho and Magna, 2003, Kikuchi, 2007, Guimarães et. al., 2009, Fernandes et. al., 2010). It is estimated that the number of Brazilians with the sickle trait is 7,200,000, with the prevalence in the general population being between two and eight percent (Fernandes et. al., 2010).

Once we zoom out from the cellular level to the individual and population-based level, we become subject to cultural, social, and political patterns that problematize the once static framing of the disease. This social construction of illness includes the voices of patients, physicians, advocacy groups, government, media, insurance companies, scientists, and the pharmaceutical industry to name a few. It also includes an invisible context: transmissibility, moral judgment, and stigma. All of these ingredients make for a complex frame on which to hang what may seem like a simple diagnosis. Disease in this way goes far beyond pathology and genetics, and into the realm of medical sociology where people make Janus-like assignments: normal/abnormal, victim/villain, guilty/innocent, heroic/pitiable, good/bad (Herek, 1990). These assignments dictate how individuals, family members, and society perceive and respond to medical conditions and the individual who embodies the disease. The social construction of SCD or sickle cell trait and its ties to nationality, race or skin color, ancestry, geographic location, social class, and various forms of capital force us to move from the cellular environment to the societal environment in which bodies with SCD exist. These entanglements as demonstrated via narratives that have been written about in the context of the United States as a nation, as well as focused looks towards the U.S. South and California, Senegal, and now Brazil point to the complexity of the relationships that people living with SCD have with the State,

with civil societies, and with themselves (Duster, 1990, Tapper, 1999, Rouse, 2009, Wailoo, 2001, Hill, 2010, Fullwiley, 2011, Nelson, 2011, Benjamin, 2013).

The Construction of Sickle Cell Disease

Discovered in 1910 in the United States, the associated cells were named "sickle cells" in 1917. Three years later, the term "sickle cell anemia" was coined. Each of these hallmark events was linked directly to the black body where the disease was discovered and then relentlessly researched. Physicians involved in sickle cell research emphasized the racial specificity of the disease and claimed it as a marker of racial identity (Tapper, 1999). Linking disease with race was not new. Tuberculosis, which claims its own storied history of construction was noted in 1915 by a public health official as synonymous with the word 'Negro.' (Hunter, 1997, Wailoo, 2001).

In 1923, Sydenstricker and colleagues wrote that the sickle cell disease diagnosis is made "without difficulty—the race, the symptoms of anemia, with a history of rheumatic pains and abdominal crises, the scleral discoloration, the absence of splenomegaly, the presence or history of leg ulcer, all suggest the condition." Cooley, in 1928, wrote: "Sickle cell anemia is distinctly racial and possibly originally limited to a small section of the Negro race." In Brazil, scholars like Ernani Martins da Silva, who closely followed the literature being produced by their counterparts in the United States, made the same assignments: "The sicklization phenomenon of the red blood corpuscle is practically confined to individuals of negroid ethnicity and to their cross-breeds, the hereditary morphologic change in the red blood cell showing the largest incidence in man."

Sydenstricker, Cooley and many others went on to statistically assign the act of cells sickling to a group, a racial population (Wailoo, 1991, Tapper, 1999).

During the 1930s, population genetics began to grow, challenging prior theories regarding biological variation and eugenics. Early genetic studies of sickle cell anemia, for example, demonstrated that genetic mutations and variability could be beneficial in certain environments, rather than absolute liabilities as assumed by proponents of eugenics. Around the same time, blood studies using electrophoresis began to demonstrate great hemoglobin variability in world populations that did not correspond to existing racial categories (Mayer, 1982). In 1946, A.S. Wiener used serological data to show that "Australoids" and "Negroids" (Africans) had different blood allele frequencies, thus contradicting earlier anthropometric models, which had placed them within the same group.

As a consequence of attributing the act of sickling to only the black race, diagnosing sickle cell in an individual who was reported to be white immediately raised questions about the accuracy of the sickling test and the true racial identity of the diagnosed individual. This was witnessed in the diagnoses of sickle cell disease in the United States in particular where the "one-drop rule" by which individuals with even one ancestor of African origin were classified as black still characterizes racial thinking. Notions of invisibility get introduced to patients who do not phenotypically express the "black" characteristics. Tapper describes the misdiagnosis of sickle cell in the 1920s in the Southern European community instead of the related, and more acceptable thalassemia. The questioning of diagnosis based on race still persists today.

While in Salvador, Brazil, during the summer of 2012, I met a woman who upon finding out that I was researching SCD, excitedly exclaimed that she had *anemia falciforme* (sickle cell disease). She was a woman who would be considered "white" by United States' standards with dark blonde hair. I inquired about her ancestry, to which she told me she was of Italian heritage. Upon receiving this information, I wondered if perhaps she was confusing sickle cell disease with thalassemia. She was clearly pleased with having a potential African link vis–à–vis sickle cell disease. This fits the cultural profile of many Brazilians who stand firmly on a foundation of racial mixture—the opposite of the "one-drop rule"—as their racial ideology and believe that their ancestry is derived from the African continent. After further questioning about her childhood, symptoms, and an attempt to discuss her genealogy, she exclaimed, "*Oh! Eu sei! Eu tenho anemia do mediterrâneo*!" (I know! I have thalassemia!). As she made this proclamation she smiled wide and flipped her hair, making gestures that indicated the cultural desirability of being affiliated with a perceived elite Mediterranean lifestyle. This brief encounter encapsulates the conflation of sickle cell disease and thalassemia and the individual value judgments placed upon them.

In addition to asserting a mixed-race national identity and denying the existence of racism, Brazilians have traditionally constructed racial identity as a malleable condition rather than an essential one. The ethos of whitening constitutes a major ideological tool through which this is accomplished. "Whitening" refers both to a pseudoscientific theory and to a social practice in Brazil. During the late nineteenth and early twentieth centuries, prominent

scientists and intellectuals affirmed that the Brazilian population was growing progressively whiter due to miscegenation and the mass influx of European immigrants following the abolition of slavery (Skidmore, 1993). In the early 1900s, Brazilian elites attempted to, and were successful at, inventing identities, categorizing individuals, and creating a nation based on racial improvement and gradual whitening vis-à-vis reproduction. Brazil hoped this whitened population would separate them from their mulatto population and usher them into a national identity more aligned with their European counterparts. Though these Lamarckian sets of ideas were less overtly racist than the ideology that came out of Britain, the United States, and Germany, during this time, Brazilians still expressed their own brand of racism to ensure a better, more modern, whiter nation (Stepan, 1991). Although this belief was subsequently debunked, the ethos of whitening continues to influence racialization practices in Brazil, and it's legacy is still implicated in reproductive, economic, and political decisions.

In the US, the concept of "whitening" held both similarity and distinctiveness to Brazilian concepts. Many early twentieth century scholars saw the Negro as becoming extinct, not due to unfitness, but due to admixture of "white" blood. Anthropologists in particular, organized the discourse on the Negro around the concept of hybridity. Medical science used these concepts of whitening to help shape notions of "normality", "pathology", "race mixture", and "degeneracy" (Tapper, 1999). Sickle cell disease was in the middle of the whitening arguments in the United States, as scholars looked to differentiate the African from the "American Negro." American medical scientists working on SCD took the uneven distribution of sickling events between these two groups to

indicate the extent to which Africans in America had become a bio-genetically distinct population. The hybrid "American Negro" living with SCD was thought to be proof of the disadvantageous effects of race mixing. Throughout the 1940s, controversy surrounded the relationship between sickle cell trait and the disease. Further, many scientists wanted to investigate the pathology of sickle cell trait since the prevalence seemed to differ so drastically in the United States and Africa. These investigations helped build a portfolio arguing against the social practice of intermarriage, lending itself to the eugenics discourse of the time. The consequence of this social practice was thought to lead to hybridity *and* some form of disease state.

Tapper highlights that the eugenics discourse of the 1930s and 1940s emerged from the realm of social prejudice and the 1950s ushered in a relationship between eugenics and human genetics that constituted a continuum rather than two distinct fields. Tapper argues that that these two fields did not exclude each other, but instead often co-existed to produce "a new racialist anthropology that was informed and authorized by the language of molecular biology." At the forefront of this new science was Linus Pauling, whose research established sickle cell disease as the first molecular disease. According to Wailoo (2001), this new paradigm created the sickle cell patient as a commodity to clinical science. The push to publish new findings, get grants, and build research programs increased the value of the patient on one level and began to shift the conversation into one that was framed by economics. Geneticists, hematologists, cardiologists, and many more in hopes of developing insights and contributions

to their own fields now desired SCD patients. Federal support for such research increased exponentially.

In the 1940s in Brazil, miscegenation was the hallmark issue of sickle cell disease studies. Dominant discourses during this period promoted whitening as a solution for Brazil's "racial problem"; according to these theories racial mixture could actually help eliminate sickle cell disease (Cavalcanti, 2011). It was thought that sickle cell anemia was on the decline in Brazil because of miscegenation. The Brazilian view of whitening meant that racial mixture could actually help eliminate sickle cell disease (Cavalcanti, 2011). In a review of the medical thesis of Rio Grande do Sul physician Carlos Estevão Frimm, Maia de Mendonça (1948) stressed his argument that miscegenation could prevent transition from the latent to the active phase and thus influence the epidemiology of sickle cell anemia in Brazil. For Mendonça, in contrast to what was being argued in the United States, miscegenation could be a viable way of preventing sickle cell anemia. Frimm conducted one of the first prevalence studies in the country for SCD and collected information on blood types as well as the presence of sickled cells. U.S. medical knowledge on sickle cell was selectively applied to the Brazilian context. In his medical thesis, Frimm calculated the number of Brazilians with sickle cells in their blood based on statistics from Brazil's 1940 census (which gave the number of "individuals of color" residing in the country) and also on U.S. data, the latter indicating the proportion of sick to healthy sickle cell carriers. In Brazil, "interbreeding may have attenuated or altered the still unknown factors that transform a *drepanocitêmico* [carrier of the sickle cell trait] into a *drepanocitoanêmico* [carrier of sickle cell anemia]" (cited in Cavalcanti,

2011:388). This transformation was thought to lead to a decline in SCD, suggesting that miscegenation actually aided in the elimination of pathology. In his miscegenation analysis, Frimm also collected samples from indigenous groups as well to confirm that sickle cells were specific to blacks.

In January 1950, sickle cell anemia was a key subject in the collection of articles on hematology published in the journal *O Hospital* (the Hospital), where it was referred to as one of the most important diseases in hematological studies (Cavalcanti, 2011). Here parallel importance was beginning to be put on clinical science as the basis for further SCD investigation, likely due to the surge of interest in the disease in the United States.

By the early and mid-1960s, race relations and health care had become fractious issues for North Americans. Contributing to the debates over the Civil and Voter's Rights acts, healthcare highlighted the social inequality gaps between blacks and whites. Challenges to racial segregation, particularly in the south, put public pressure on those in power in the realms of business, education, and health. Against this backdrop, sickle cell began to rise as the new face of the "African-American patient" (Wailoo, 2001). Public discussions across sectors began to transform the visibility and discourse on black health as SCD became representative of a "Negro disease" (Tapper, 1999, Wailoo, 2001). Seeking to quell unrest, President Richard M. Nixon identified sickle cell anemia as a federal research priority alongside his war on cancer. The Sickle Cell Anemia Control Act of 1972 embodied the results of civil rights activism that continued to shape the disease.

The 1970s transformed the political presence and pertinence of sickle cell disease. Prior to 1970, sickle cell anemia was a neglected medical oddity, but not in the sense of clinical investigation. By this time, a significant amount of money was allocated to the research pipeline for sickle cell disease, creating programs and funding laboratories across the United States. Though clinics also began to spring up in urban cities, the seventies spotlighted the general absence of money directed toward the care of sickle cell patients themselves. The debates, accusations, and eventual federal funding were all preceded by a 1970 *Journal of the American Medical Association* (JAMA) article by a physician named Robert B. Scott that compared sickle cell disease to other genetic diseases like cystic fibrosis and muscular dystrophy. Lacking a distinct racial identity, the National Institutes of Health and private charities funded these diseases, privately and publically at much greater levels. The implication was that racial prejudice lay behind these funding disparities and that the social status of those living with the respective diseases shaped both public sympathy and levels of government funding (Nelson, 2011).

The JAMA commentary inspired the formation of the Black Panther Party People's Sickle Cell Anemia Research Foundation (PSCARF). By exposing a substantial research gap, the paper supplied the Party with evidence in support of the activists' assertion that a general lack of awareness was aided by the federal government's racially motivated fiscal neglect. SCD proved to be an effective vehicle for the Black Panther Party's political ideology. As a condition of blood, SCD evoked kinship and common autochthony. This bond entitled the Party to speak to and for the experiences of black suffering and to ground these claims in

the history of the African diaspora (Nelson, 2011). The health education dispensed by the Party strategically re-configured the essentialist discourse that anthropologists associated with the disease decades earlier. It explained SCD through a lens of "racial slavery, contemporary racism, and the vagaries of a profit-driven healthcare system that it alleged privileged revenue over healing" (Tapper, 1999). When President Nixon addressed Congress in his National Health Strategy address in 1971 and called for an increase in the budget for research and treatment of sickle cell disease, it blunted the Black Panther Party's accusation that the state neglected African American health concerns and simultaneously diminished the organization's ability to successfully frame the disease in a social health context.

While the United States faced the challenge of facing and responding to the demands of the black population via the civil rights and black power movements, Brazil would move through a comparatively less impactful *Movimento Negro* (Black Movement) of their own during the seventies. It would not be until the re-introduction of democracy in 1985 that grass roots organizations would begin to effectively find their collective voice to fight for rights for health, for Afro-Brazilian health, and more specifically, for those affected by sickle cell disease. One key area of engagement of the Black Movement in the 1980s was activism around health and access to care. To understand this aspect of the *Moviemento Negro*, first it is important to understand the development of the Brazilian health system in the second half of the twentieth century. Black health activists first pressured the state to address racial health disparities on a national level at the 1986 National Health

Conference. The final report from the 1986 Conference recommended increased public funding for the study of illnesses believed to affect certain "racial-ethnic groups" in a disproportionate manner (Oliveira, 2002). A flurry of activity took place after the development of the new constitution, which created a new federal public health agency inspired by democracy and requiring the heavy utilization of civil society (non-governmental or community based organizations) participation (Weyland, 1997). With the creation of the *Sistema Único de Saúde* (Unified Health System, or SUS), health became a universal citizen's right and the state became formally responsible for guaranteeing "universal and equal access" to health care (Weyland, 1997, Paim, 2011). This is discussed more in Chapter Four.

Situated Knowledges

Haraway's (1988) concept of situated knowledges proposes that any one vision of the world will always be inherently incomplete. As a feminist scholar, I draw on this notion, conceiving of my own work as *situated* and recognizing that my account of sickle cell disease builds on knowledge that has been produced both within and beyond academia and is in part determined by my positionality. In terms of academic scholarship, I draw upon a rich foundation of social scientific analyses that span the last twenty-five years. Here I discuss previous approaches to sickle cell disease that have been necessary to my own work.

The earliest scholarship on SCD focused on the disease as a window into the articulation of politics, science, and notions of racial hierarchy. Sociologist Troy Duster's 1990 seminal monograph *Backdoor to Eugenics* analyzed how

genetic screening programs could open the possibility for new forms of eugenic practices, mediated through medical authority. Duster highlighted the political processes embedded in the promotion of programs aimed at genetic disorders and funding on a federal level in the U.S. context. Almost a decade later, anthropologist Melbourne Tapper's *In the Blood* (1999) used SCD to elucidate key episodes in racial science throughout the twentieth century. Tapper coined 'anthropathology' to describe how U.S.-based physicians, medical investigators, and geneticists used the case of SCD to mark the American Negro as degenerate. He uncovers diverse histories to argue that scientific inquiry into SCD was driven by eugenic ideas of genetic purity and white racial superiority. Historian Keith Wailoo's erudite scholarship brought a new level of intentionality about place to the social study of Sickle Cell. He examined the contextualization of a specific city – Memphis – within broader politicized and geo-historical paradigms, and then looked at how the disease was used by politicians, medical researchers, and healthcare institutions to further their own goals. A springboard to scholarship on ethics, racialized politics, eugenics, genetics, and health disparities, *Dying in the City of the Blues* forces us to contend with the many levels of scientific coproduction for SCD in the United States.

The next generation of social scientists who turned to SCD did so with a focus on California's stem cell initiative, the U.S.-based Black Panther Party's health politics of the late 1960s and early 1970s, and the scientific underbelly of the construction of "Senegalese" SCD as a mild disease. Ruha Benjamin, Alondra Nelson, and Duana Fullwiley, two sociologists and an anthropologist who studied

under Troy Duster, drew on his interest in SCD and have continued to problematize how race, culture, justice, science, and policy are interwoven. Benjamin's 2013 *People's Science: Bodies and Rights on the Stem Cell Frontier* investigates racial/ethnic and class inequality within stem cell politics. She focuses on the reticence of families who caretake those living with SCD to be part of a biomedical framework in which they are otherwise ignored. Nelson, in her 2011 *Body And Soul: The Black Panther Party And The Fight Against Medical Discrimination*, argues that health concerns are part of a cadre of challenges taken up by the Black Panther Party in their struggle for human and civil rights She demonstrates the savvy of the organization in their fight for universal healthcare and an antiracist social order. Finally, Fullwiley's *The Enculturated Gene: Sickle Cell Health Politics and Biological Difference in West Africa*, published in 2011, is a rich ethnographic study that highlights how the Senegalese scientific, medical, and public health complex responds to patients based on genetic profile rather than patient suffering.

In conversation with one another, these important works examine broader questions about the conflation of biology and culture, the economy of disease and biomedicine, the nature of citizenship, the promise and peril of technoscience, state power, inclusion, exclusion, and resistance. My work draws on each of these monographs, while investigating empowerment, embodiment, and belonging in the multiracial setting of Brazil. Through the lens of SCD in Brazil, we are able to witness how historical social policies that legitimized cultural difference were translated and then coupled with public health policy that recognizes biological difference. And just as Brazil can give us answers about SCD, so too can SCD

shed light on Brazil: the historical development of SCD policy tells us much about Brazilian society and framings of racial difference.

The most compelling aspects of my research stem from the personal and political relationships developed in the field. The research participants shaped this project through their interactions with me, informed by their understandings of my position as a woman living with SCD. Furthermore, patients, policy makers, and scholars alike interpreted me through their perceptions of my racial identity, read as *negra* in Brazil, and my position as a foreign researcher from an elite U.S.-based institution, which often attenuated the depth of my blackness in their view. In conversation with study participants, I was able to capture the life histories of individuals living with SCD in Brazil. This included phenotypically black and phenotypically white people living with sickle cell disease. Their stories, along with others are highlighted in Chapter Three and demonstrate a fluid back and forth between racial ideologies based on mixture and hypodescent. Along with these conversations with people living with SCD, my long-term immersion with the director of the national sickle cell disease program, based in the Ministry of Health also provides a nuanced perspective of elite and institutionalized space. The back and forth between personal stories and policy making mirrored my own roles and identities: I was seen both as a person living with SCD and as a policy maker due to my previous experience at the CDC creating the U.S. policy for Sickle Cell Disease. As I explain more extensively in the Preface, I drew on both of these positions in order to engage with the activists and actors who have been responsible for shaping Brazilian understandings of SCD. Accessing these two realms allows us to pay attention to how personal,

individual experiences shape and are shaped by larger policy decisions, defning the very basic experience of citizenship and racial identity of those living with SCD in Brazil.

Part II: Negotiating Citizenship

Just as Sickle Cell Disease embodied the "social, political, and ideological tensions of the 1970s" (Wailoo, 2001: 183), so too was the case for SCD in Brazil in the 2000s. And just as African-Americans linked the disease with African inheritance and authentic alignment to African identity, so did many in Brazil, particularly those in the Black Movement. The use of SCD in a political space called for the state to recognize neglect and identify a racialized population as citizens. Health is mentioned thirty-five times in the 1988 Constitution, and is highlighted in it's own section under Title VIII—Social Order. The section starts, "Health is a right of all and a duty of the State and shall be guaranteed by means of social and economic policies…" (Brazilian Constitution, 1988). In this and following text, the State makes itself obligated to the citizen in the creation of a healthcare system, distribution of pharmaceutical drugs, and regulation of services all under the gaze of the citizen.[23] However, who is able to become citizen? How has that changed over time? What rights and privileges are afforded to the citizen? What follows is a discussion of citizenship—first a general citizenship offered by Brazil, based on inequalities and aspirational for many. I will briefly cover how citizenship changed over time and how the

[23] See the 1988 Brazilian Constitution with 1996 reforms at http://pdba.georgetown.edu/Constitutions/Brazil/english96.html#mozTocId339966 for more

development of citizenship and nation building was intertwined with race and health. I will also highlight how the transformation of the constitution in 1988 allowed the differentiated citizen with SCD to make claims to the State. Then, I will explore the concept of biological citizenship. Couched via the social determinants of health model, I will discuss how inequalities are linked to health and how race *becomes* biology. I will also examine how biology and culture are intertwined for SCD claims making in Brazil through broader concepts of biological and cultural citizenship.

At the base of my concept of biocultural citizenship is Marshall's (1950) definition of citizenship, which by itself consists of three parts: civil, political, and social. By his definition, "it is a loyalty of free men endowed with rights and protected by a common law" (92). It obligates the state to perform in particular ways to its constituency. Marshall draws social class into conversation with citizenship; two potentially opposing forces based respectively on inequality and equality. Marshall believes that the relationship between the two concepts is reconciled in the form of civil citizenship (one part of his citizenship equation), and posits that, "citizenship…provided the equality on which the structure of inequality could be built" (88). For the sake of this dissertation, I will be referring to the idea of complete citizenship as aspirational citizenship. According to Raco (2011), "an aspirational disposition is defined as a future-oriented outlook, focused on a desire for long-term improvement or betterment" (49). Situated in more than a politics of hope, some of my participants are actively engaged in claims-making to acquire full(er) citizenship, despite structures of inequalities. The State participates in what I call *bounded justice*—

an attempt to distribute health rights without disturbing the underlying mechanisms that generated initial inequalities.

These inequalities are the basis for Holston's (2008) reading of citizenship set within the Brazilian context. In *Insurgent Citizenship*, Holston highlights the "differentiated citizen" that is situated within a citizenship that privileges those in particular social categories. For those in this space, it means a lack of rights and power. It is this differentiated citizen, some with fuller access and some without that is the focus of this study. During fieldwork in Salvador, Bahia, I fell ill and had to go to the emergency room for tests. Though my illness was not related to my sickle cell diagnosis, I was told by those accompanying me that I should register myself as a sickle cell patient because they were prioritized higher within the system to be seen quicker than a general patient. In this instance, I received the privilege of being seen more quickly not by a social category, but a biological one. True, I am not a citizen, but I was treated as one in the public healthcare system due to the universal health care offered by Brazil. Though this example demonstrates a claim to citizenship as seemingly a mere convenience (the wait time for sickle cell patients has been associated with increased morbidity and mortality due to fast paced biological processes that can be fatal to patients during long wait times), many of my research participants have fought hard for numerous claims to the state based on their genetic profile.

Nikolas Rose and Carlos Novas (2005) as parsed by Wade et. al. (2014) use the term biological citizenship to refer "to the use of biological traits to define belonging and entitlement in a nation-state" (9). Adriana Petryna (2003) also provides a definition of biological citizenship, which positions it as a special

status or practice that arises from a "subsystem of the state's public health and welfare infrastructure where increasingly poor citizens…mobilize around their claims…of injury" (5). Further, though Duster (1990) may have warned about the potential peril in the use of biology to be used against citizens, Health, Rapp, and Taussig (2004) highlight increasing importance on how individual and collective identities converge to demand recognition and access using their biology.

Biological citizenship is a useful concept, but is unable by itself to explain the processes my actors must enlist in their aspirations for full citizenship. Sickle cell disease is deeply enmeshed with Africa and African heritage. Some of my research participants (often those with darker skin) living with SCD, use this linkage to African heritage to assert that certain rights are owed to them as a result of the sickle allele coming to Brazil via forced migration from Africa. The concept of cultural citizenship (Flores and Benmayor, 1997) is valuable when imagining the differentiated citizen whose norm is not of social privilege, but of social exclusion. Some Afro-Brazilian citizens draw on a less formalistic notion of citizenship that is less managed by the state and instead is influenced by cultural characteristics that "span racial, ethnic, linguistic, and geographical forms (467)" (Clarke, 2013).

Aspirational Citizenship

When I spoke with many study participants (though not all), they were resolute in the recognition of their "rights" as a Brazilian citizen, not just to health, but to policies around sickle cell disease. Like Holston's (2008) participants, my actors with SCD considered themselves as full Brazilian and

members of the nation-state. However, they simultaneously felt like disenfranchised citizens who were not able to access the same level of citizenship as others. Holston considers this version of double consciousness as two separate dimensions of citizenship. The first is "national incorporation" (40) or belonging based on a formal status of membership. It is based on birthplace and descent and dictates the admittance of some people as citizens, and others as not citizens. This type of dimension is conditioned at times, by race, religion, and residence, while the other is "substantive" or independent in the doling out of rights, obligations, and practices to those who would fit the first category. This duality of universality and simultaneous exclusion is still recognized, particularly in the creation and maintenance of the healthcare system, and it needs to be historically framed. What follows is a brief and consolidated history of citizenship in Brazil.

The first constitution, once Brazil declared its independence, was created in 1824. It stated that Brazilian citizens were considered those born in Brazil—recognizing birthplace. Concerning descent, there were more conditions: "…children of a Brazilian father, and the illegitimate children of a Brazilian mother, born in a foreign country, who come to establish residence in the Empire" were also considered citizens (Holston, 2008:63). No matter the racial or freedom profile, if you were born in Brazil, you were considered a citizen and part of the national profile. Although inclusive, Brazilian society was never egalitarian and even though all born within its boundaries were considered a citizen they were not legally equal or given uniform rights. Brazilian elites may have thought that blacks, pardos, and the indigenous were national citizens, but that did not stop them from restricting their access to rights. Thus, from the

beginning a differentiated citizen was defined within the context of Brazilian citizenship with unequal access to power and privilege (Holston, 2008).

My narrators sometimes conflated the words and meanings of privilege and rights. Holston examines this distinction. He posits that if people have rights because they hold a special status formally recognized and legalized by the state, bestowed only to the "right people," and completely discretionary, it sets a stage to convert rights into privileges. A right creates an obligation from the State but only to those who have enough power to be recognized by the State in the first place. Those who do not are left disadvantaged to all claims making and I argue must rely on other forms of citizenship to be recognized by the State.

Biological Citizenship and Sickle Cell Disease

The concepts of biopower and biopolitics help frame the link between nation-state policies and populations. The term biopower was introduced in 1976 "to designate forms of power exercised over persons specifically in so far as they are thought of as living beings" (Gordon,1991:5). Foucault imagined that in biopolitics, the practices embedded into the nation by the government could be used as tools of resistance. According to Lemmke (2011), "Biopolitics is not the expression of a sovereign will but aims at the administration and regulation of life processes on the level of populations" (4). The regulation of life itself is at the heart of biopolitics and for the purposes of this study via biomedicine. As parsed by Pagano (2011), Foucault (1978) asserts that whereas in the past sovereign power asserted itself by deciding its subjects' life or death, modern forms of state power (especially from the end of the eighteenth century on) are expressed

through a "positive influence on life, that endeavors to administer, optimize, and multiply it, subjecting it to precise controls and comprehensive regulations" (137). This power over life exists in two "poles": the "anatamo-politics of the human body" and the "bio-politics of the population" (139). The first is dedicated to increasing the (individual) body's productive potential, while the second is focused on regulating the population at large. The main purview of biopolitics is "public hygiene, with institutions to coordinate medical care, centralize power, and normalize knowledge" (244). Accordingly, biopolitics is often channeled through "campaigns to teach hygiene and to medicalize the population" (ibid).

Jasanoff (2011) introduces us to the term bioconstitutionalism in the following manner:

> "Observing that the contemporary state exercises power not by commanding the deaths of dissidents, but by regulating the bodies and lives of consenting subjects, Foucault spoke of an 'explosion of numerous and diverse techniques for achieving the subjugations of bodies, and the control of populations" (1998, 40). His followers too see the governance of lives as more than a two-way street—exposing subjects to state classification and control…but also creating scope for new forms of voluntary association facilitated by shared biological characteristics. Using terms such as biosociality (Rabinow, 1992) and biological citizenship (Petryna, 2003; Rose, 2006), social theorists of the genetic era have sought to capture, and to some degree celebrate, the opening up of agency from below" (6).

This agency is exhibited with the broadened concept of bioconstitutionalism in which "individuals work out their biopolitical relationships with the institutions that regulate them" (10), (Jasanoff, 2011). In the Brazilian context, my participants expanded their agency immediately upon the ratification of the 1988 constitution. The constitution, which stated that health was a universal right for every citizen, allowed the actors to hold the newly democratic State accountable from within. I argue that through these biopolitical processes, my Brazilian narrators have managed to reconfigure their relationship with the State. Furthermore, there is an additional layer of collective and ancestral trauma that impinges this relationship with the state. The diasporic spread of Africans to Brazil via the slave trade and the subsequent gene transmission has made way for race and biocitizenship to be discussed in novel ways. Perhaps even more interesting, is the response made by the government to these claims, which take the form of health reparations for those with sickle cell disease.

Despite these ambiguities in identity, biosocial groupings occur on multiple levels within the SCD communities. As I will show in this dissertation, claims to racial identity vis–à–vis sickle cell disease provide a window into larger arguments about legitimacy and recognition articulated by the *Movimento Negro* and Afro-Brazilians more generally. Here the theoretical tool of biological citizenship is helpful to make sense of how SCD sufferers make claims on the State. Biological citizenship, in this case, is about the reclaiming of citizen's rights within a changing political system; it is also about a dire precarity. Adriana Petryna's study (2003) documents how Ukrainian citizens demanded recognition and redistribution of resources, in the context of long-term health problems

following the Chernobyl reactor explosion, and the aftermath of the dissolution of socialism. Petryna's biological citizenship is a special status or practice that arises in a "subsystem of the state's public health and welfare infrastructure where increasingly poor citizens…mobilize around their claims…of injury (5)" (Petryna, 2002). Petryna explored how Ukrainian citizens dealt with emerging social problems by making claims to citizenship through their broken, ailing bodies and in the context of State failure to protect its citizens. This concept serves as the classic model for how some Brazilian citizens with a genetic point mutation can take action in requesting, né demanding, better care and service.

I, too, base my definition of biological citizenship on Petryna's work. The actors within the SCD paradigm attempt to reclaim their rights within a political system some consider still in flux. And though Petryna's subjects utilize their trauma and subsequent biological condition(s) to gain access to a political process, I ask how might the idea of collective and cultural trauma accessed through ancestry (much like the passing of a gene), further impact claims to the State. Further, how might the collective trauma of slavery incite the government to respond with health policies as part of reparations to the traumatized? This is discussed more in depth in Chapter Five.

Nikolas Rose and Carlos Novas (2002) offer us a slightly different interpretation of biological citizenship. They suggest that traditional ideas of citizenship that align with "cultural or religious unity, a bounded national economy" (1), or language are giving way to a new type of citizenship. This new model weaves a collective identity through biomedicine, biotechnology, and genomics as the thread to weave a collective identity. Careful to differentiate this

notion from ideas of eugenics, degeneracy, and racialized national politics, this new interpretation calls for a specialized scientific and medical knowledge of one's condition, particular knowledge of one's genetic makeup. Hacking (2006) deems genetic markers as "risk factors" (90) and suggests, "a set of people with a risk factor is a biological, not social group. But people at risk for the same disease will clump together for mutual support, joint advocacy, and … activism (91)." Rose and Nikolas contend that this particular form of citizenship involves specialized medical knowledge about one's disease, with this shared knowledge spurning subgroups to campaign for better treatment and general right to health.

Harper and Raman (2008) in "Less than Human? Diaspora, Disease and the Question of Citizenship" highlight Rose and Novas' (2004) contribution to the discourse on how biological citizenship impacts those who are part of diaspora communities. In an assertion for recognition, those who are most marginalized engage in "political economies of hope" (Rose and Novas, 2005: 454), (cited in Harper and Raman, 2008:10). The battle to claim this shared and unique identity and with it a new form of legitimacy manifests itself in this new notion of kinship (Heath, Rapp, and Taussig, 2003). This notion of collective identity stems from Paul Rabinow's concept of biosociality.

Rabinow (1992) envisions groups forming around biological identities marked by ill health or illness susceptibility. When civil societies form around a biological condition, they become inherently biosocial (Hacking, 2006). In particular, biosociality has mostly been used to describe groupings and activities based on a Western, rich, and white population and are dependent on biotechnologies, high-tech therapies, and genomic advancement. For example,

Emily Martin (2007) conducted ethnographic research of bipolar support groups and while this example of biosociality formed around health does not include a biotechnological component, it does focus on a mainly white subject population.

My research joins a growing body of work that examines biosociality in marginal communities, (e.g. Guell, 2011, Marsland 2012). Bringing biosociality to the question of Sickle Cell Disease in Brazil brings into sharp relief the contestation between a social group claiming biological citizenship on the basis of their serotypes and the scientific or medical elite who hold the epistemic authority. Sahra Gibbon and Novas (2008) state that: "the distinctiveness of biosociality lies in its attempts to name the kinds of socialites and identities that are forming around new sites of knowledge (genetics, molecular biology, genomics) and power (industrial, academic, medical)" (3). The Brazilian biological citizens in this study who have SCD have organized themselves into civil societies. In this process, they have become important stakeholders who interact on every level with the development and implementation of policy. Additionally I contend that the relative novelty of racial consciousness delivered with the diagnosis of SCD impacts how the new biological citizen interacts with new knowledge and opposing power. Narratives from *brancos* with SCD help illustrate these complexities. This intersectionality of identities may redefine current biosocial configurations. It will be important to note that the additional layer of otherness, while contributing to collective citizenship, still operates under a hegemonic culture that may not be willing to recognize and legitimate their citizenship in other ways.

Cultural Citizenship: Diasporic Membership in Hegemonic Spaces

Biological citizenship does not and cannot exist in a vacuum. In order to effectively explore this concept, we must also consider the concept of cultural citizenship as Kia Caldwell (2007) as pointed out in her work with black Brazilian women. Pointing to U.S. Latin communities, according to Flores and Benmayor (1997), cultural citizenship utilizes empowerment, agency, and affirmation as its major tenets. As Caldwell (2007) states: "the concept of cultural citizenship privileges the voices and experiences of marginalized communities by examining their vernacular definitions of citizenship and belonging" (3). Cultural citizenship offers a process to expand rights beyond the legal sphere into other public, cultural, and social realms. Renato Rosaldo (1994) defines cultural citizenship as "the right to be different (in terms of race, ethnicity, or native language) with respect to the norms of the dominant national community without compromising one's right to belong, in the sense of participating in the nation-state's democratic processes" (57). Cultural citizenship, then, is a way to counteract the exclusion imparted by the state, which is a natural process of citizenship. Even though the State created a universal public health care system under the premise that it provides care and treatment to all, many have reported discrepancies in how marginalized groups are treated within the system (Costa and Lionço, 2006, Kalckmann et. al., 2007, Guizardi et. al., 2014, Falu, 2015). Because policies and subsequent resources provided by the State have the capacity to define, enable, constrain and shape (both positively and negatively) the identities of its citizenry, it places notions of citizenship for these groups beyond the biological and into the cultural realm. Cultural citizenship is a means

of enabling identities, affiliations, and belonging (Mercer, 2002). A way towards cultural citizenship is a way beyond traditional liberal and historical conceptions. It "operates in an uneven field of structural inequalities" and its role in "a process of constructing, establishing, and asserting human, social and cultural rights" (Rosaldo, 1997:37, 12).

Aihwa Ong et. al. (1996) takes a different approach to cultural citizenship. Instead of the assumption that demands are made for cultural citizenship by the marginalized culture, she recognizes the concept of cultural citizenship as the cultural practices produced through negotiating with the dominant criteria for belonging. Cultural citizenship is therefore a "dual process of self-making and being-made within the webs of power linked to the nation-state and civil society" (Ong et. al., 1996:738). In this, she recognizes how members of the SCD Movement are being reconfigured in their biocultural claims as an attempt to be an equal citizen. The cultural practices and beliefs associated with being Afro-Brazilian have been historically negotiated with the State for recognition (i.e. samba, *capoeira*, and *Candomblé*) take modern form in the NHPBP and "establish the criteria of belonging within a national population and territory" (Ong, 1999:264). This negotiation is often through "ambivalent and contested" processes "with the state and its hegemonic forms" (Ong, 1999:264).

Here we are posited with two ways that citizenship can be enacted (biological and cultural) for resources and recognition. By interrogating how citizenship operates in these two realms, we are able to observe how legitimacy is engaged with differently. We can also problematize how identifiers like skin color interact with these notions in distinct ways. I discuss in the next chapter

how quite often the spectrum of skin color correlates with the real and perceived benefits of formal citizenry. Those actors living with SCD who are on the lighter end of the color spectrum tend to be afforded more rights and have less need to call on and demand their rights in biological terms. Some of the Afro-Brazilian narrators in this study live lives as second class citizens and in attempts for full integration into Brazilian society, they draw on biological citizenship to help level the playing field, but it is not enough. They need the additive effects of cultural citizenship in which they draw upon by their ties to the African continent. What cultural citizenship provides is not an exclusive relationship, the phenotypically white narrators with SCD may at times also make links they feel are necessary to Africa in a way to legitimize their own constructions of illness; while others may attempt to downplay all linkages to the continent as a way of deemphasizing any connection to blackness.

Culture was highlighted in a recent article entitled "Genetics against race: Science, politics and affirmative action in Brazil," in which its authors recognized "markers of a distinctive black culture" as a way to define blackness in Brazil when genetic arguments were used to deny the definition (Kent and Wade, 2015: 13). In this case blackness was also defined by African descent, which was also mostly framed in spiritual, religious and cultural terms, rather than in a biological one. Skin color and appearance played roles as well in the definition. Biocultural citizenship allows for some Brazilians to overlap both biology and culture in the ways in which they make claims to the State.

Biocultural Citizenship

The deep entanglement of biology and culture as shown through Brazilian actors who attempt to gain access to fuller citizenship is what I call biocultural citizenship. Shared biology in addition to cultural ties specifically to Africa has lead to successful claim making from the government. In the model I developed (see page 46) to help explain the concept of biocultural citizenship the core consists of shared biology—represented by sickle cell trait and different variants of sickle cell genotype (HbSS, HbSC, and HbSβ-Thal). Layered on top of that, and demonstrated in the middle core are cultural factors like skin color, geographic location, and ancestry. While each actor with a sickle allele is drawing upon different cultural factors at any given time, they are doing so while interacting within Brazilian society simultaneously vying for universal inclusion and distinctness. These societal factors overlap with social determinants of health. In 2005, the World Health Organization (W.H.O.) created a Commission on Social Determinants of Health to highlight a commitment to action in efforts to decrease said determinants globally. Coincidentally, the NHPBP was created the same year. Examples of socio-economic determinants include but are not limited to: age, gender, ethnicity, education, occupation, income, and housing. Other determinants include a number of psychosocial risk factors (depression, chronic stress, isolation) and community and societal characteristics such as crime and unemployment rate, domestic violence, and income inequality (Ansari, 2003). In this case, racism, class, whether someone grew up during the dictatorship or a democratic regime—all of these things are interwoven with each other, and are drawn upon in different ways for each person and affect the

relationship that study participants have with their disease and the associated policy. I represented the fluidity of these interactions with dashed lines to portray that this model is anything but static.

In the following chapter I draw on six narratives to demonstrate how research participants use the concept of biocultural citizenship to gain access to resources and services provided by the State.

CHAPTER THREE

Color, Class, and Claims: Narratives of Biocultural Citizenship

> …this is something I bring up at our [sickle cell] meetings…that the true "black health" related disease is sickle cell disease, not AIDS, as they've made it out to be. AIDS is infectious; our disease is hereditary. It's different. It's one thing for you to contract [a disease], it's another thing for you to get the disease from ancestors.
>
> -Barbara, SCD Organization President, self-identified as *preta*

According to Pagano (2011), "once the Ministry of Health started to mandate the collection of race-based data during the late 1990s, researchers were able to demonstrate that black Brazilians die in greater numbers than whites from HIV/AIDS, homicide, alcoholism and mental illness, stroke, diabetes, and tuberculosis" (2). Since then, the public health messaging around so-called "black health" has been focused on HIV/AIDS. This is due, in part, to the strong infrastructure that was in place to support and collect data from HIV/AIDS—in place before most other diseases under the purview of the public health system. Despite the institutionalized acknowledgement of prevalence within the Black Brazilian community, Barbara, President of a women's-based sickle cell disease (SCD) organization in Rio, disagrees. Not only does she disagree, but she believes the distinction must be made about infection versus inheritance. Further, she goes beyond the biological pattern of inheritance in which the S allele is inherited by either your mother or father, and places her inheritance in the hands of her ancestors. Not knowing how far back she assigns the lineage of

her ancestors, one might still assume that her intention is to evoke an ancestral imagery that brings us to the continent of Africa. This linkage to Africa usurps any prior messaging that deems AIDS the black health cause de rigueur. The "true" black health disease is the one authenticated by the African continent. Barbara's recognition of a biological definition of blackness and culture—which the chapter will elucidate as providing a cultural definition for blackness—provides us space with in which we can interrogate citizenship.

Individual and collective strategies for citizenship claims are often framed through biology (Wailoo, 2001, Petryna, 2003, Biehl, 2004, Bailey et. al., 2008, Harper and Raman, 2008, Biehl, 2009, Taussig, 2009, Fullwiley, 2011, Montoya, 2011, Nelson, 2011, Livingston, 2012, Pollock, 2012). Racialized biology via sickle cell disease (SCD) allows us to extend beyond the concept of biological citizenship (Petryna, 2003) to understand how advocacy for rights and resources are enacted. The notion of cultural citizenship (Flores and Benmayor, 1997) posits a citizen who is managed less by the state, and influenced more by normative practices that "span racial, ethnic, linguistic, and geographical forms" (Clarke, 2013). SCD represents a deep entanglement of biology and culture as shown through Brazilian actors who have gained access to fuller participation in Brazilian society through what I call *biocultural citizenship*—a flexible mode of enacting belonging that varies depending on skin color, social class, and other identifiers. The life experiences of my research participants provide us with specific viewpoints through which we can interrogate how privilege, ancestry, identity, and citizenship are intertwined.

This chapter examines how the personal is made political through "the temporal character of human experience"(Ricoeur 1984:52). I have chosen six narratives to demonstrate how a representative sample of my research participants use the concept of biocultural citizenship in gaining access to not just citizenship, but biosocial kinship as well. These narrators vary by class, gender, regional representation, and their place within a color spectrum of research participants. It should be noted that although we might be able to plot each narrator on a spectrum of skin color, I am not suggesting that skin color classifications provide a specific route, *carte blanche*, to citizenship. Just as an exclusive focus on culture argues for the risk of reification and belief uniformity, the focus on skin color has the potential to ignore variation (Dressler, 2012). Each of these actors has his or her own pathway to citizenship, but what I suggest here is that we take into consideration how some of these narratives are influenced by historic and systemic structures that often serve as a deterrent to accessing citizenship. They represent the tension beneath the contemporary Brazilian conceptualization of citizenship: how does one form a heterogeneous identity in the hegemonic universality of being a Brazilian citizen? Purvis and Hunt (1999) suggests that the reality of marginalized groups is contested with the rhetoric of equality—demanding space in which some seek recognition for their specificity. This space, for those living with sickle cell disease in Brazil, is both biological and cultural in origin.

Due to the historical and systematic experiences of racism and exclusion shared by many Afro-Brazilians, the claiming of sickle cell disease as a *doença de negro* or black person's disease, allowed the *Movimento Negro* (Black

Movement) to capitalize on the equalizing narrative found in the 1988 Constitution, which allowed the State to make itself obligated to every citizen in the creation of a healthcare system, distribution of pharmaceutical drugs, and regulation of healthcare services for all. As a result, the Black Movement has made demands on the State to correct for the asymmetry of resources and services (Kent et. al., 2014). Persons who are phenotypically lighter or white in skin color whom are also living with sickle cell disease may not feel the same pressures or have the same needs as those who are darker skinned in the claiming of rights. Access to certain "lifestyle" indicators as defined and modified from Dressler et. al.'s (1998) definition may help explain why Afro-Brazilians are more invested in utilizing their genotype and African ancestry to make claims. Lifestyle is defined "as the accumulation of consumer goods and the adoption of behaviors that help to define one's social identity" (Dressler et. al., 1996: 331). It is the formation of identities that influences how each narrator operates in relationship to their own disease and ultimately, to the relevant healthcare and governmental policies. The relationship formed between each individual and the State is influenced by the identity of each narrator. How does identifying as black, white, poor, female, *falcêmico*[24], mother, and/or activist alter this relationship?

Because participants were recruited through convenience and snowball sampling, they were invested in their biology as demonstrated through their

[24] *Falcêmico* is a term that many people with SCD in Brazil used as a self-identifier for someone that has sickled cells. This term is akin to "sickler," which is used in the United States and is applied to patients usually by people in the medical community and usually with negative connotations. In Brazil, *falcêmico* is used in more a positive and empowering sense by those who have the disease.

attendance at SCD-related conferences and meetings, their high levels of knowledge about their disease, and connection (even if tangentially) to the sickle cell movement. At times my narrators were exposed to the SCD movement by way of the healthcare system, though often of their own accord. Throughout the narratives of the study participants, there was a general pattern that connected hardship of livelihood with the need for increased recognition within Brazilian society. Found discursively throughout the narratives, references to items such as labor practices, educational attainment, social support, privatized healthcare, and international travel pointed to societal privileges that were, at times, lopsided in phenotypic representation.

According to Bairros et. al. (2011), "skin color can be considered a biological expression of race or the racialized expression of biology when exposed to racism…[and] "race/color" also relates to the use of phenotypical differences as symbols of social disparities, which can indicate class, group or political power status" (2365). This color spectrum represents the respective skin colors that were captured from portrait photos I took of each interviewee[25]. Since each picture was taken under different conditions and lighting, resolution, and saturation varied for each respondent, I captured the color by selecting an area on a respondent's face in Adobe Photoshop. Color varied pixel by pixel in the

[25] I am certainly not the first to capture skin color for scholarly or artistic pursuits. Most notable is the Von Luschan Color Scale developed to classify skin color and which has been used primarily by physical anthropologists from the 1950s into more recent times. An example of a more recent interpretation of this can be found in the art project Humanæ, created by Brazilian artist Angélica Dass– "a chromatic inventory, a project that reflects on the colors beyond the borders of our codes by referencing the PANTONE® color scheme" (humanae.tumblr.com). Recently, Krista M. Perreira and Edward E. Telles (2014) examined associations of observer-ascribed skin color with three correlates of health: skin color discrimination, class discrimination, and socio-economic status in Latin America.

area I captured on the face; I averaged the colors within that area using the average blur tool and used the average of those pixels to represent the facial complexion of each of my interviewees in the spectrum below. It should be noted that though the shades vary from very dark to very light and no two respondents had the same color (as quantified by the color code assigned by Photoshop), the questionnaire that asked each participant their race or skin color captured only six different answers. This limited variation is vastly different than the color classifications famously collected in 1976 in Brazil, which revealed 136 different colors that described the survey's respondents (Schwarcz, 2003). The size sample of this project is much smaller, but nearly 40 years later the answers provided by my actors may reveal the influence that the Black Movement has had on the country in how individuals define themselves racially.

A recent demography study investigated if the increase in identity politics by the Brazilian Black Movement since the 1990s was associated with a number of people changing their answers in the census from non-black to black (Miranda, 2015). Using census data, it found that nearly two million people reclassified from a racial census category of non-black to black during the 1990s and 3 million reclassified themselves in the first decade of the 2000s. According to Miranda, "the findings show strong evidence that the period of increased black political activism in Brazil after the 1990s coincided with a sharp increase in the number of people self-identifying as black." There are several reasons why this connection may have been seen, one of which includes an increase in race-based affirmative action policies. In my study it should be noted that in an open-ended questionnaire issued to twenty-seven people, a relatively limited range of

race/skin color classifications were recorded. The colors captured in the spectrum might easily solicit many more responses if shown to a larger public sample that included those not involved with some sort of race-based social movement.

Because each of the narrators resides somewhere on a social, cultural, and economic spectrum, I did not want to reduce the discussion about them on fixed categories. The respondents whose stories are told here had something to say about identity, race, class, citizenship, education, gender, and geography, yet rather than discuss these items topic by topic, they will be analyzed in terms of three primary themes: Structural Boundaries, Negotiation, and Authenticity. These themes are more fluid than the fixed topics mentioned above and are revealed in the respondent narratives that follow. Each of these six narratives is framed by a description of respondent demographic characteristics, followed by a brief introduction.

Structural boundaries represent how society bounds attempts for some of the respondents in their attempts to attain notions of citizenship. Part of the tension that arises within some of my narrators is based on the idea of existence versus aspiration. The framework of Social Determinants of Health will shape this section to help organize the discussion of how some narrators understand these determinants (education, systemic racism, employment, access to health care, social networks, etc.) in relation to their disease and to existing healthcare policy. The next section, Negotiation, explores how individuals and communities negotiate their belonging within the existing frameworks. Concepts of lifestyle, social stratification, and legitimacy will be brought in here to help explain how

the SCD Movement is utilized to negotiate space, how the alignment of SCD and Africa is used to create cultural space simultaneously legitimizing and isolating the movement, and how and why one takes up activism—is it based on collective or individual issues? Finally, Authenticity will address how one's selfhood is measured within claimed negotiated spaces. Who belongs? Is one authentic (enough) within the space that has been created? This section is based on concepts of identity formation and will discuss both individuals and place as it relates to authenticity for the story of SCD in Brazil. Ultimately, recognition by the State via biocultural citizenship weaves each of these sections together and helps explain the histories and lives expressed in the narratives included in each of these sections.

Figure 2: The Color Continuum

Characteristics of the Sample

What follows are the demographics of my full sample of people living with Sickle Cell Disease (N=23) and Sickle Cell Trait (SCT) (N=4) and the narratives of six people that are a subset of this group and who can each be found on the *Color Continuum* (See Figure 2 and Table 1). I interviewed fifty people throughout Brazil. I spoke with people living with SCD, SCT, members of the SCD and Black Movement, physicians, geneticists, Ministry of Health officials, laboratory personnel, professors, dentists, and senior public health administrators. Of the fifty, twenty-seven people had SCD or SCT. I offered a questionnaire specifically

to only those who had at least one sickle gene. As a result, the data below represent only those with some variant of SCD or SCT. Data collected included age, gender, race/color, religion, education, occupation, marital status, and data specific to the diagnosis of SCD (See Appendix A).

Eighteen respondents have the homozygous form of SCD (HbSS), three have HbSC, two have sickle cell beta thalassemia (HbβThal), and four have sickle cell trait (SCT) for a total of twenty-seven participants with a sickle allele. Twelve self-identified as *negro* (black or brown), six as *pardo* (brown), four as *preto* (black), and three as *branco* (white). Ages ranged from eighteen to fifty-five with the average being thirty-six years of age. The sex breakdown was twelve males and fifteen females. Eight participants hailed from the state of São Paulo, seven from Bahia, six from the state of Rio de Janeiro, four from Minas Gerais, and two from *Distrito Federal* (Federal District). A number of religions were reported with Catholicism the most common. Nine of twenty-seven attended or were attending college, six held a graduate degree, and twelve attended lower levels of school. Ten of twenty-seven were married and sixteen of twenty-seven had children at the time of the interview.

Table 1: Participant Demographic Information

Respondent Demographic Table	**N (%)**
Genotype	
HbSS	18 (67)
HbSC	3 (11)
HbSβThal	2 (7)
Sickle Cell Trait	4 (15)
Race/Color	
Negro	12 (44)
Pardo	6 (22)
Preto	4 (15)
Branco	3 (11)
Moreno	1 (4)
Mulata	1 (4)
Age	
18-30	8 (30)
31-40	6 (22)
41-50	9 (33)
Over 50	3 (11)
Missing	1 (4)
Gender	
Male	12 (44)
Female	15 (56)
State	
Bahia	7 (26)
Minas Gerais	4 (15)
Rio de Janeiro	6 (22)
São Paulo	8 (30)
Distrito Federal	2 (7)
Religion[26]	
Agnostic	1 (3)

[26] *Espiritismo* ("Spiritism") is a belief system primarily in Latin America and the Caribbean that good and evil spirits can affect health, luck and other aspects of human life. Seventh-day Adventist is a form strict Protestantism that preaches the imminent return of Jesus Christ to Earth and observes Saturday as the Sabbath. *Candomblé* is a religion based on African beliefs, which is particularly popular in Brazil, practiced by the *povo do santo* (people of the saint). *Umbanda* is a syncretic Brazilian religion that combines African traditions with Catholicism, Spiritism, and Indigenous Brazilian beliefs. *Rosa Cruz* is a fringe religious doctrine of German origin based on the belief in esoteric truths of the ancient past that provides insight into nature, the physical universe and the spiritual realm. One person within the sample chose two religions.

Evangelical	2 (6)
Esperitismo	3 (9)
Protestant	5 (14)
Catholic	9 (26)
Seventh-day Adventist	2 (3)
Candomble	3 (9)
Umbanda	3 (9)
Rosa Cruz	1 (3)
Pentecostal	2 (6)
Buddhism	1 (3)
Other	1 (3)
None	2 (6)
Education	
Fundamental	6 (22)
Intermediario	6 (22)
Undergraduate	9 (33)
Graduate	6 (22)
Marital Status	
Yes	10 (37)
No	17 (63)
Children	
Yes	16 (59)
No	11 (41)

The Narrators

The six highlighted narrators range in skin color from dark to light and self-describe their color as as *negro*, *pardo*, *mulato,* or *branco*. Each was chosen to highlight color, region, age, and gender variety within the sample, but do not serve as a composite representation for the sickle cell population. I have chosen these individuals because each one of them occupies a place along a social, cultural, and economic spectrum—of activism, color, education, class, and of region. The narratives are rich, complex, detailed, and nuanced. Each provides a part of the larger story for SCD, SCT, identity formation, policy development and

implementation. Looked at collectively and put into conversation with each other, these narratives speak to culture, biology, citizenship and agency in the constantly shifting world of health and race in Brazil.

Gilberto, 45
Rio de Janeiro
Negro
HbSS

I interviewed Gilberto when I returned to Rio de Janeiro for the 2nd Global Congress on Sickle Cell Disease in November 2014. It was a meeting that brought scientists, scholars and practitioners together from the United Kingdom, France, several countries in Africa, the United States and Brazil. I had tried to meet with him several times prior to this when I resided in Rio almost a year earlier, but our connections were thwarted by illness, communication, and transportation. We sat in the back of the small library in HemoRio, a state funded hematology center that provided a number of services including blood banking, dentistry, and inpatient care for those who had a hematological illness. His clothes, too big for his slight frame, often hung on him and he needed the assistance of a cane to walk. He was a man that looked unwell. One might look at him and assume he was meek, but he was just the opposite. I witnessed him at small local meetings, large national symposiums, and international conferences where he was fearless in making his voice heard. Gilberto grew up in *Vigário Geral*, a neighborhood in the North Zone of Rio de Janeiro, most notable for the massacre that took place in the large *favela* there in 1993. He beams with pride when recounting his childhood there, "I am a resident of a family of 7 children, a

humble, poor family with a lot of difficulty raising us… I am proud that I was born in that poor family and was a resident of Vigario Geral." Of the seven siblings, three had SCD. All three have died. Gilberto died in March 2013.

Flávio, 37
São Bernardo, São Paulo
Branco
HbSS

The opening ceremony for the 7th *Symposio Brasileiro de Doença Falciforme* (Brazilian Sickle Cell Disease Symposium) took place on November 20, 2013. Strategically falling on the same day of the *Dia Nacional da Consciência Negra* (National Day of Black Consciousness), the ceremony was full of pomp, circumstance, and symbols of blackness. After a series of films, a slim white man in a clown costume came to the large stage to officially start the program. As an audience member, I was struck with confusion. Dressed in red pants and suspenders with a whiter face painted on and a bright red nose, slow recognition came to me of who he was. Flávio responded to a recruitment flyer I posted on Facebook, and I was slated to interview him later in the week during the Symposium. His participation in the opening ceremony as a person living with Sickle Cell Disease made more sense to me and the initial shock I felt by the appearance of a white man performing an act discordant with the grandness of the event was abated. When we eventually sat down one evening at the conclusion of all conference activities for the day, Flávio was eager to talk. With the help of an interpreter, I had to interject at times to ensure that topics important to the study were discussed. By the end of the interview, it was clear

that Flávio, a *Paulistano* (a person hailing from the city of São Paulo) with expensive taste, had a very strong support system, was able to push past the limited boundaries of what he thought was expected of him, and represented a person living with SCD who believed his genotype was in conflict with his phenotype.

Elvis, 47
Brasília, DF
Pardo
HbSS, cured

By the time I spoke with Elvis in the living room of a colleague associated with CDC Brasil, he was living life free of sickle cell disease. He received a bone marrow transplant in 2005 when he was 38, due to the severity of his condition. Elvis explains his life in two phases: before the transplant and after. The transplant informs his identity as much as having SCD does. Raised in Brasília from age two, Elvis is compassionate, savvy and well connected. It was no wonder when I travel to *Asa Sul*[27] for his book signing party that the crowd, gathered there to celebrate him, was overflowing. He is the president, founder, and face of the *Associação Brasiliense de Pessoas com Doença Falciforme* (ABRADFAL), the Brasílian Association for People with SCD. He co-founded the organization in 2009, four years after his transplant. One might think that the

[27] Brasília, Brazil's capital city, was built between the years of 1957 and 1960 from a scheme proposed by architect Lucio Costa and is primarily divided into two: Asa Norte (North Wing) and Asa Sul (South Wing). The configuration of the residential blocks, commonly referred to as Superquadras ("super blocks"), is a 280m square occupied by long, six-storey slab apartment buildings. Costa's plan divided the city into 72 Superquadras each having 11 housing blocks with schools, stores, and recreational space to service them, capable of housing approximately 3500 people in 1584 apartments (Holston, 1989, El Dahdah, 2005).

seat of government, the hotbed of the SCD political movement, would be a prime location for the early adaption of civil society formation for the disease, but whenever I brought up Brasília to Joice Aragão de Jesus, the national coordinator of the SCD program at the Ministry of Health, she was dismissive—often with a wave of her hand and a change of topic. Perhaps due to the lack of organized patient groups or relative low incidence of cases in comparison to some other states (one out of 2500 people according to 2012 newborn screening statistics), historically Brasília has not had a seat at the proverbial geographic table for SCD (Ministry of Health, 2012). The collective actors of people living with SCD, medical providers, and SCD-related civil society leaders in Brasília have been trying hard to change this.

Elisangela, 30
Belo Horizonte, Minas Gerais
Negra
HbSC

Elisangela was born and raised in Nanuque, Minas Gerais, a small municipality that borders Bahia to the north and east and boasts a small nature-based tourism economy. She identifies as Baiana[28] despite the circumstantial placement of her family in the bordering state. She grew up near the *Rio Mucuri* (*Mucuri* River) and when I ask her to describe her childhood, both the river and pain play a dominant role. As a child she and others often played near and in the river, but the low temperature of the water caused physiologic changes in her that led to painful sickle cell crises. She grew up not knowing what was wrong, but

[28] A term used to refer to a woman who is from Bahia. In popular discourse, the term is associated with a dark-skinned black women who wears colonial garb and a head wrap or headscarf.

consistently in pain. The complications of her SCD and the distress it caused are the hallmark of her narrative. Diagnosed at seventeen, when I interview her at age thirty Elisangela was living in Belo Horizonte and though she was urged to go there for better healthcare, she is still distressed. There is sadness in her eyes when she sits to speak with me. She cries at several points during our interview, reminiscing about death and hardship. She is one of eight children. Six of the eight were born with sickle cell disease, two have died from its complications. At the time of interview, neither she nor her husband was working as he is ill, as well. Her course of SCD continues to be severe and though she has tried to go through the process to receive disability benefits, she has not been successful yet. SUS (*Sistema Único de Saúde* or Unified Health System), has been unable to completely provide the care she needs. When she could work, she has served in *serviços populares* (low wage domestic services): caretaker of elderly, housecleaner, launderess, seamstress. At times attributing her hardships to her blackness, she finds refuge in her faith and dreams of a better life.

Andrea, 42
São Paulo, São Paulo
Branca
HbSβ-Thal

Andrea does not spend a lot of time speaking of her childhood, at least not in the context of her disease. She does not reminisce about early hospitalizations, but instead remembers her yearning to go to school despite her health complications. She comes across as very nonchalant and unbothered about her diagnosis, and laughs easily while she shares her history with me. She brings

along a friend for the interview and when I ask Andrea if her friend will stay with us for the length of our time together, she responds that she has no problem recounting her stories in front of her. By this point in my fieldwork, I have learned that the concept of confidentiality must be thought of as a flexible principle. We sat outside of a bookstore café in the quaint neighborhood of Vila Madalena, both of us prepared with extra outerwear should it get cold and the temperature threaten our health. Though born in the city of São Paulo, after her parents' divorce, she, her brother, and her mother moved to a city in the center of the state of São Paulo called Jaú. Little is said of her time there other than to recollect that many members of her family also lived there, undoubtedly a motivating force for the relocation. Once she turned 18, her mother suggested that they move back to São Paulo because the health and educational infrastructures were better. Andrea attended university at 18 and studied biology, though her professional career has always been in administration and finance. Though she recognizes her limitations as a person living with SCD, throughout the interview her narrative belies that there is not much difference between her and someone living without the disease.

Zaira, Age not given
Rio de Janeiro
Mulata
HbAS

Two days before the beginning of *carnaval*, I was scheduled to conduct an interview with Ravica, the vice president of *Associação dos Falcêmicos e*

Talassêmicos do Rio de Janeiro (AFARJ) or Association of People with Sickle Cell Disease and Thalassemia for Rio de Janeiro. When I arrived at their office nestled in a corner on the 8th floor in HemoRio, I was told she was in a meeting. Annoyed, I probed further and learned that she was in fact in Day Two of a two-day meeting that I had intended to attend for Day One, but fell ill. I asked if I could sit in the back and observe and was granted permission. Coming in late, I went straight to the back but was soon urged to join the table. Seated at the table was the newly inaugurated President of the national SCD organization (FENAFAL) Maria Zenó Soares da Silva (Zenó for short) and representatives from all of the organizations based in Rio: AFARJ, *Associação de Mulheres com Doença Falciforme do Estado do Rio de Janeiro* (AMDF-RJ), *Associação Niteroiense de Doença Falciforme* (ANDF-RJ), and two smaller organizations that represent both men and women respectively local to the city of Rio de Janeiro. I interrupted a roundtable in which 15 people eventually participated—including Gilberto, his wife Silvia, and Zaira Costa, the current President of AFARJ. The leaders of each organization were relaying the needs and challenges to the new President who had made a trip to Rio to meet with Joice and other Rio-based practitioners of SCD. When it was Zaira's turn to speak she was animated and emotional—characteristics I was acquainted with by now when people spoke about SCD, especially in groups. It was the well-crafted performance of someone who was used to making appeals. Expounding on the successes of AFARJ, including the mention of me giving a talk earlier in the month, she fought for AFARJ's place at the national table and for her place as a

leader. She is the only one at the table who does not have the disease and I felt strongly her need to justify her presence.

What follows are a series of narratives and ethnographic accounts that help highlight each of the themes: Structural Boundaries, Negotiation, and Authenticity.

Structural Boundaries

The health and wellness of individuals and communities is dependent on a number of variables. These include but are not limited to gender, social network, age, place of residence, education, racism, poverty, family origin, occupation, income, sexual orientation, and religious affiliation (Ansari, 2003, Lopes, 2005, Jones, 2009, 2014, Badziak, 2010, Pellegrini Filho, 2011, Chor, 2013). Considered to be social determinants of health, these elements are separated from biological or genetic determinants of health, which include categories like age, sex, family history of disease, inherited disease, or HIV status (HealthyPeople 2020, 2014). Social inequities (unfair and avoidable) affect many of these determinants, but some such as family origin and age cannot be controlled (Chor, 2013). In a paper in which she states her concern for not enough Brazilian studies on race (particularly racial inequality) and health, Brazilian social scientist Dora Chor says, "Race, socioeconomic status, and gender influence Brazilians' health through different relations and with diverse magnitudes, depending on the target question." In 2005, Fernanda Lopes expressed the necessity to analyze the life experiences of blacks and non-blacks to measure racial and social inequalities in Brazil (Lopes, 2005). Some of these

structural inequalities are evident in the narratives of my research participants. What follows is a recounting of life history from several actors that reflect on how they have experienced these inequalities while simultaneously living with a genetic and chronic disease. For people living with SCD, social determinants and inequities have not contributed to a degradation of health per se as in the instance of environmental racism that leads to lead poisoning. Instead, because SCD is an inherited disorder, social determinants and general inequities contribute to an overall livelihood of hardship. What follows are narratives, the first of which from Gilberto, that shows how these alter live within the boundaries that their social determinants have set for them.

Gilberto 

Gilberto's maternal grandmother was a domestic for the *Atlético Mineiro* soccer team, a professional team located in Belo Horizonte, Minas Gerais. Though he never met her, he recounts how she let his mother wash the team's socks and how the group "symbolically sold" her a house in gratitude for her service to them. His mother was also a domestic and when I asked Gilberto to recount some of the jobs he has held, he mentions being a street market vendor, beach ice cream vendor, and finally an "office boy." It was at this last company that he continued on to work as a cashier, and where, after taking an accounting course, he became the company accountant. Women and non-whites in Brazil tend to populate the informal labor market. Domestic duties are prioritized for

women in this market (Telles, 1992, Lovell, 2000). Recent reporting from U.S.-based National Public Radio states that for São Paulo alone: "…at least 600,000 people are formally registered as domestic staff — nannies, cooks, cleaners. And of those, 96 percent are women. More than half of these women are from the darker-skinned, poorer sectors of society." These statistics come from a 2015 study conducted by the *Fundação Sistema Estadual de Análise de Dados* (State System Foundation of Data Analysis). According to Arcand (2004), "Browns and blacks are largely penalized in terms of human capital (educational attainment, labor market experience and health) with respect to whites" (1057). For those living with SCD, all three of these items are intertwined. Studies in the US, UK, and Brazil have reported that SCD has been a major impediment to finding and keeping work (Pereira, 2013, Barbarin, 1999, Franklin and Atkin, 1986). Many of my respondents spoke about how their illness was a direct cause for frequent absences and consequent termination from their place of employment.

Although Gilberto speaks of his origins as being humble, he is quick to contrast that with narratives of home ownership and education:

> Today I live in the Retraça des Protege and I live in the North zone of Rio de Janeiro, in Piedade in an apartment that is ours, an apartment that is in our name, which a lot of people can't accomplish. Thank God we had that victory, of having our own apartment.

Gilberto recognizes the value of homeownership and mentions its importance to him and his family several times throughout the interview. Townsend (1979) has defined material depravity as being located in the ability or inability of individuals to achieve a standard of living that is considered to be customary,

approved, or encouraged within a community. Despite the status that a house may bestow onto someone, their dark-skin may negate that value both in greater society and at home. As with most of my respondents, Gilberto can recount acts of racism from early in his childhood. He is open in sharing that his earliest accounts of racism came from within his household and from his father.

> [My father]… was someone that was tough/severe and unfortunately racist. He didn't like *negros*, despite being *negro* and having *negro* children. But he always told my sisters they had to 'lighten' the family, and date only white people. And if a black person said they wanted to date his daughter, he didn't like it and he would say this, I remember this phrase even today, he would say, 'a panela de cozinhar macaco em casa furou' (don't bring any monkeys home). He would send [black] guys away because he didn't want anything [from them]. He was very racist.

U.S. sociologist Elizabeth Hordge-Freeman's (2015) study on racial socialization within Afro-Brazilian families found pervasive devaluation of black/African influences, which was conveyed through implicit and explicit messages as well as concrete practices that promoted the stigmatization of negatively valued racialized physical features.

Camara Jones, a US-based expert on racism and health, describes levels of racism in three parts: personally-mediated, internalized, and institutional (Jones, 2000). Gilberto's father exemplifies the concept of internalized racism, subjecting his children to narratives of demoralization and devaluation of the black race, but Gilberto also made clear his experiences with the other types of racism as well. In what can be seen as a combination of both personally-mediated and institutionalized racism, he recounts a memory:

> We proposed a project when we were in AFARJ for an awareness campaign for SCD. We won a budget from the city of Rio de Janeiro for

> R200.000 (approximately $64,000). It was approved by the city council and everything. It just needed the mayor's approval. The mayor was César Maia. What did he do? He simply took it, saw that he could trick us, and said we would only get R10.000. The money had simply disappeared…we couldn't find the money. We knew it was in the budget account, but they couldn't figure out how to get to it, until he gave us R10.000 to us. He gave R10.000 for a disease awareness campaign, to prevent a disease. But then, in the same week, he paid R1.000.000 for a volleyball team that was called Rexona, to change its name to "Rio de Janeiro". That's absurd. In this case, it was an important issue for the health of the black population and the *prefeitinho* (little mayor) at that time, César Maia, that's what he did to us. Why? Because there wasn't anyone in his family with the disease, there wasn't anyone he knew that had the disease. If there were, I doubt he would have done that. We *negros* here unfortunately we suffer a lot.

The implications of personal connections to a health matter reveal itself in the story of AIDS in Brazil. President Cardoso may be most notable in public health circles for his passing of Law 9.319, which stated, "individuals living with HIV/AIDS will receive, free of charge, from SUS, all medication necessary for treatment," but the law was sponsored by former President Jose Sarney (Nunn, 2009). Rumored to have a personal and familial connection to AIDS, Sarney's political power pushed the bill quickly through Congress (Nunn, 2009). Not without future complications, this law stabilized the supply of antiretroviral drugs to Brazilian states and put Brazil in the global spotlight. A former sociologist whose career began with research on racial themes, Cardoso's administration began to examine social exclusion of the poor and Afro-Brazilians and to implement policies and programs to promote social inclusion for those groups (Bailey, 2004, Campos de Sousa, 2008, Reiter and Mitchell, 2010, Evans, 2011). While the gay liberation movement may have been a marginalized sub-

group, the HIV/AIDS policy development was proactive in ensuring that stigma was ameliorated from a legal standpoint allowing those associated with the AIDS movement to stand on more equal footing (Parker, 2003). Though most of the movement took a bottom-up approach to policy development, this top-down sponsorship brought the movement a new type of spotlight. Brazil, as an activist state (Biehl, 2004), worked to include those who were marginalized and socially excluded. In Gilberto's example we observe the opposite, though in chapter four, I will discuss the ways in which the enactment of activism takes place for SCD by the state.

While some of my narrators relied on their difference to catalyze beneficial activity from the government, some—like Andrea—perceived themselves to be no different than any other citizen and (at first glance) wanted nothing from the State.

Andrea 

> I think that I am a regular person. A normal person that worked, studied, got married, had kids, got separated, and has had problems. Sickle cell disease doesn't define me. I forget sometimes that I have it. My life doesn't revolve around it. I don't live it. I have friends who suffer from strong depression because of sickle cell disease and the limitations that sickle cell disease imposes, or because they don't think they're capable of getting a better paying job or whatever else. But I never wanted sickle cell to limit me financially or to stop me from getting an education or to having a personal life.

This viewpoint is very different than most of my narrators whose primary identity revolves around their disease. Andrea is privileged (by both her skin color and socioeconomic status) in her access to higher education, formal labor, and a livelihood that is seemingly minimally altered by the disease. Despite her language however, she has been on the Brazilian equivalent of disability services offered by the government for the last seven years and has not worked. There is privilege in this as well, as the possession of skills to navigate the *bureaucracy* of *Instituto Nacional do Seguro Social* (INSS) or National Institute for Social Security, as well as the accumulation of a network of people to potentially aid her in the endeavor may have aided Andrea in the attainment of this benefit. The INSS is responsible for collecting contributions that maintain retirement payments, pensions due to death, illness, disability aids, and other benefits. Elisangela (discussed below), though from another state, expressed frustration in her failed attempts to attain the equivalent. Andrea's counterparts that exist on the darker end of the color spectrum have a much deeper relationship with SCD likely due to the additional complications that having a chronic disease brings, exacerbated by the structural inequalities embodied in their blackness. Of these six highlighted narrators, Andrea is the only one not utilizing psychological services. As parsed in Ohara (2012):

> McClishet et al. (2005) assessed quality of life of 308 individuals with sickle cell disease using the SF-36 and found that the mental health component, including issues related to anxiety, depression, abnormal behavior or emotional imbalance and psychological welfare, was the only one that did not show worse scores than the general population. The authors explained this event as a result of increased social support,

> absence of other stressors or behavior change in face of their mental health, adapting to conditions that the chronic disease provide.

It is evident in her narrative, that Andrea has the indicators needed to assist her in being resilient throughout the life course of her disease.

Andrea has sickle cell beta thalassemia disease. This is a variant of SCD in which there is one abnormal beta chain, β^S, and a defective beta-globin gene. This means that an individual has one abnormal hemoglobin gene and one abnormal beta thalassemia gene. In people with this variant, the presence of sickle-shaped red blood cells is combined with the reduction or absence of mature red blood cells. As a result, many people with this variant look clinically identical to those with HbSS—the homozygous and often most clinically severe form of SCD. Despite the word "thalassemia" being included in her diagnosis, Andrea claims kinship with those with SCD: "I joke with people with sickle cell disease that they are my crescent moon siblings because our blood is different. So we are all half siblings in some way; we all come from a common ancestor [laughter]."

I asked my respondents what they think about blood and they respond uniformly that it is life. Besides bearing the gift of life in the transport of oxygen, the very thing that is altered in SCD, it also brings to mind ideas of purity and degeneration and though Andrea never attempts to explain her disease through the idea of mixed blood, many others do. Instead she points to kinship based on the molecular changes of the blood, rather than race, as the linkage to all who have SCD while simultaneously assigning the ancestry of all who have the disease to a sole ancestor. Perhaps drawing on her biological training, she brings to mind

the theory many scientists hold, including Darwin, that all humans are derived from a common ancestor (Theobald, 2010). Whatever her thought process, her narrative demonstrates how convoluted these tropes of blood and ancestry are, as well as how a biosocial grouping forms ties of kinship. These ties, for Andrea, go beyond feelings and beliefs, but also spill into actions.

In the retelling of a story in which she displays her frustrations about the "lack of good will from the government," she gives an example of an experience she had in Santos, São Paulo, a large coastal city approximately 90 minutes away from the booming metropolis of the capital.

> I lived for some time in the Litoral of São Paulo but I would get treatment in Santos, which was the only place in the area that had a treatment center for sickle cell disease, thalassemia and other hemoglobinopathies in general. And I saw it. Nobody told me—I saw it with my own eyes. A young boy that was around four years old came to the clinic with extremely low hemoglobin and the physician said, 'we need to do a blood transfusion on him, but we don't have a blood match for him at this blood bank.' … it's a smaller city [where] there are less resources. And so they didn't have compatible blood and she was going to have to search for a match in the blood banks of the nearby cities. She asked for the mother and the little boy to come back the next day for the transfusion, but the mother said she didn't have money to come back. And the doctor said, 'ok'. And I got so angry that I said, 'there is no transportation funds from the city government to bring them?' And she said that they only had a right to come once a month. And I thankfully was in a better financial condition than the mom and I opened my wallet and gave her the money and told her to come back tomorrow for her son's transfusion. I gave her money to go because I kept thinking that they wouldn't be able to return and that the boy was going to die. I don't know what happened, I don't know if they came back or not.

This speaks not just to the generosity of Andrea in this moment, but also the resources available to her. Andrea repeatedly demonstrated to me throughout

the interview how SCD had no bearing on her livelihood and in this example, we can see how her lack of financial limitations allowed her to give monetarily to her "crescent moon sibling." It also speaks to the limited "rights" offered by SUS, at least on the municipal level in Santos. The resources of the government in this scenario are out of alignment with the rights offered by the government. Andrea's anger is steeped in her thoughts of abandonment for the four-year-old child. In this instance the *hemocentro* served as a momentary "zone of social abandonment," though not in the way Biehl (2005) describes in which a formal institution is no longer present and able to provide adequate service to its constituents. In its place, is indeed a functioning institution, but one unable to provide treatment and care past its bureaucratic limitations. For some, these limitations could offer life or death situations. For others, the buffer of financial resources provides relief in the form of access to institutions, treatment, and care. Andrea is well aware of this buffer for populations as a whole, though she does not seem inherently knowledgeable of her individual privilege, even if incremental.

> I always say that attention isn't given to sickle cell disease because it's a disease of poor black people (*preto pobre*). Because those who are rich and white (*rica branca*) don't talk about sickle cell disease. They're treated in super specialized private centers and they don't have severe sequelaes maybe, I don't know. I think that maybe the greater populations that demonstrate major symptoms and go to SUS are *negros* or *pardos*.

I will address the first half of Andrea's statement below. Several studies have collected socio-demographic and quality of life indicators for people living with SCD (Felix, 2010, Ohara, 2012, Schotte, 2012, Terreri, 2013, Amaral, 2015, Barsaglini, 2015, Marques, 2015). In a recent Brazil-based study it was noted

that 85% of a small study sample (n=20) based in Minas Gerais were classified as C1, C2, and D (Amaral, 2015). These assignations translate to lower middle, vulnerable, and poor as social class classifications in Brazil (Schotte, 2012). Felix (2010) found that of 47 people living with SCD—also based in Minas Gerais—approximately 50% earned a living wage equal to minimum wage and 19% were without income. Class and other social determinants of health cannot be erased from the comprehensive picture of the profile of someone living with SCD. Poor is often used as a code word for black in Brazil. Though I did speak to a few black or brown respondents who might categorize themselves in the middle to upper middle class, I was unable to locate and interview a white respondent with SCD that might be classified in the low social class category. And though I did not collect income data in the questionnaire I distributed, I was able to estimate respondent's general class through responses given about the history of housing conditions, level of education, and occupation. The socioeconomic, political and cultural determinants of health have great influence, especially for a person living with SCD. In an interview I conducted with Dora Chor, a social scientist at the Oswaldo Cruz Foundation (Fiocruz) who studies the epidemiology of chronic diseases, with a focus on social determinants, we spoke about the relatively recent affirmative action policies implemented by the Brazilian government. Excited about the empirical data that longitudinal studies could afford, she recounted:

> The color of the universities and grad school programs has changed here, in Brazil. So we'll be able to see empirically if social ascension—completing university, for instance—what will that do for that person when they get to the job market? Just for having completed university, will he have the same opportunities as a white person? He got in because of quotas, but he

> was poor…poor his whole life; his cultural capital is different, and that always makes a difference, for blacks and for whites.

This difference not only allays Andrea and the other white narrators I spoke to of "uncertain suffering[29]," but also positions them uniquely in relation to their disease such that it does not serve as part of their primary identity. In this diminished role, so too is an investment in the offerings that the government may distribute. The fight for policies and other political machinations hold little interest to them. Their cultural distancing from Africa and Afro-Brazilians, as well as their collective experiential distancing in how they interface with SCD, specifically how their strong social determinant indicators shield them on some level from the severity of the disease, helps explain how they enact with claims to citizenship. Biocultural citizenship displays itself as a sliding scale demonstrating how the buttressing of whiteness and distancing from blackness can affect these claims. The statement above recognizes nuance and difference within the large population of SCD—black, brown, or white—in Brazil. This kind of color differential was evident for many in their childhood and in the environmental structures they were exposed to. The next two narratives paint a starkly different picture of access to health, security, and poverty.

Elvis 

With a long history in Brasília, Elvis speaks of a kind of stability that was

[29] This phrase references the title of Carolyn Rouse's Uncertain suffering: racial health care disparities and sickle cell disease, in which she highlights the uncertainty of care and treatment for people living with SCD.

created when his parents moved from Goiania, Goias to Brasília shortly after they discovered his diagnosis at the age of two. The status of his father holding a state job afforded Elvis a high level and continuity of care.

> It was really great that we came here. When we came, I attended the base hospital. Then I was transferred to a newly inaugurated hospital, the HSU, which was the *Hospital dos Servidores da União*. Since my father was a state employee we would get care there. It was a four-star hospital…and I started being seen there then (1973), and I only stopped going there after 2004 when I did the transplant in 2005. But that hospital provided the conditions for me to stay alive until the transplant.

This hospital was inaugurated in 1972 during the military regime and at the time served federal civil servants exclusively. It became the *Hospital Universitário de Brasília* (University Hospital of Brasília) in 1990 (http://www.ebserh.gov.br/web/hub-unb/nossa-historia accessed 7/11/15). Elvis was provided care there from childhood through adulthood and names his doctors from his pediatric experience until the transplant. The amount of social, medical, and familial support is evident as is his gratitude. "I discovered that there was life without pain, without priapism, without ulcers, without yellow eyes, without pale skin, without fatigue. My life changed completely." As a result of his successful procedure, 26 more transplants were completed and he, inspired by his experience, became active with the SCD Movement, traveled to Paris, and wrote a book—*Quatro Décadas de Lua Minguante* (Forty Decades of the Crescent Moon).

Elvis' access to continuous and comprehensive healthcare helped transform his life. This is not always the case, however as the majority of adults living with SCD frequently get lost in the transition from pediatric to adult care

(Telfair, 1994, Wojciechowski, 2002, McPherson et. al., 2009, Jordan, 2013). Some, due to lack of resources and/or knowledge (which Andrea and others argue are a result of the disease's association with blackness and poverty) never receive appropriate care even in their childhood. Take for instance, the case of Elisangela.

Elisangela 

> I don't have very good memories. I had a very difficult adolescence because I was hospitalized numerous times and we didn't understand why because medical professionals would say it was rheumatism in the blood. They didn't know it was sickle cell anemia. So I couldn't go to school consistently. I would come to the hospitals with one crisis after the other. When they discovered it I was already 15 years old. My childhood was practically spent in hospitals, with nurses treating me and it was really difficult. Very complicated.

After a sickle cell crisis that left her unable to walk occurred, Elisangela's aunt in São Paulo after learning about a study in São Paulo, asked Elisangela to get her blood drawn in Nanuque and have it sent to São Paulo for testing. Though her pain now had a name, no physicians in her area were familiar with it. She was not able to receive care, treatment, or relief. It was not until her pregnancy two years later that she was urged to travel 377 miles away to Belo Horizonte for proper care.

> I got to the fifth month and the pregnancy wasn't developing, the child wasn't growing, it was the 5th month and the same size, sixth month and the same size, seventh month and the same size. Then a nurse friend of mine called me in the hallway and she asked if I had any relatives outside of Nanuque? And I said 'I only have the friend of my husband who lives in Belo Horizonte'. And she said, 'if I was you I would leave because here

> there aren't solutions for you here. There is no blood bank. There's nothing. We have to go out and announce in a car on the street to find donors. There aren't blood banks, so you'll need to wait. If I were you I would leave because you already had a case where your sister died at 21 years old. It was her first pregnancy, and you're going down the same road.' That's when I left. I was 17 years old.

Blood banks are central to the provision of care for people with sickle cell disease in Brazil. In addition to providing blood for transfusions that are required by so many, they very often also serve as sites for emergency clinical care, inpatient hospital care, distribution of therapeutic pharmaceuticals, and even dentistry services for people living with SCD. Bahia, despite the proximity was not an option. In 2001 when Elisangela was 17, a program for SCD was not yet implemented. Even if it did exist, HEMOBA (*A Fundação de Hematologia e Hemoterapia da Bahia* or The Foundation of Hematology and Hemotherapy for Bahia) would have been even further away as the only site that provides care exists in Salvador. The state did not recognize a formal program by signing its own ordinance until 2007, and HEMOBA today does not offer emergency or hospital services—though they do offer transfusion and outpatient services (Personal communication, 2014).

The nurse who advised Elisangela may have known that the public health practioners in Minas Gerais were pioneers in establishing newborn screening for the state, the first in the country to begin to test for hemoglobinopathies in 1998. Although it was not until 2004 that *Centro de Educação e Apoio para Hemoglobinopatias* (Center of Education and Support for Hemoglobinopathies) was formed (an auxiliary organization funded by the Ministry of Health) and

began educating many across the state on hemoglobinopathies, the *Faculdade de Medicina da Universidade Federal de Minas Gerais* (UFMG) was a growing power for SCD testing, treatment, and education in the country (http://www.cehmob.org.br/?page_id=22, accessed 7/12/15). Activists in Minas Gerais have not petitioned for a formal ordinance that would, on paper at least, set up guidelines for a SCD program. UFMG and *Hemominas* (Minas Gerais' blood bank) have had a long standing collaboration, catalyzed and maintained by the University. It is not a state project and there does not seem to be much interest in it becoming one. Each region (there are nine) in the state holds a *hemocentro* and as a result the reach is far and they are able to assist many across the state.

> …they told me to go to Belo Horizonte as soon as possible to get treatment here at *Hemominas*. It was there that I was monitored and discovered what the disease was, what caused it, where it did and didn't come from, why it happens, how to control it. And that was a really big shock because to know we have a disease that doesn't have a cure and you have to live with the pain isn't a joke.

The new president for the national SCD association (FENAFAL) hails from Minas Gerais and also leads the state association, DREMINAS- *Associação de Pessoas com Doença Falciforme e Talassemia de Belo Horizonte e Região Metropolitana* (Association of People with Sickle Cell Disease and Thalassemia of Belo Horizonte and the Metropolitan Region). Although only five feet tall, Zenó is a force to be reckoned with. I was not able to spend significant time with the members of the organization, and wondered how their activism may have differed from other associations who relied more on the state for their services.

Nevertheless, the strong leadership for SCD in Minas was prepared for Elisangela when she arrived with nothing but her family. Her course of SCD, many years later, continues to be severe and though she has tried to go through the process to receive disability benefits, she has not been successful yet. At times, she connects some of her hardship during her youth with her blackness.

> I, thank God, I was always well treated. In adolescence, there were always those girls in school who would say mean things to us, *cabelo duro* (hard or rough hair), and so forth. In adolescence it was much harder for me because I had a lot of friends but they were all light-skinned, with long hair. And I was always the little sick girl, with harder hair. Thank God they launched [*Escova*] *Progressiva*[30]!

Elisangela is not the only one of my actors that associates life hardship with their race or skin color. Many of my respondents recount incidences of personally-mediated, internal, and institutional racism. Dressler (1990) and others have discussed the impact of skin color on the instances of racial discrimination and societal inequities (Lovell, 1998, Krieger, 1999, Espino, 2002, Telles, 2004, Borrell, 2006, Goldsmith, 2006, Hunter, 2007, Telles, 2014).

In this section, I have shown how some of my narrators live within preexisting structural boundaries. These preexisting conditions should not be thought of as a medical condition that existed before one's insurance took effect, but instead as a societal condition that many of my respondents were born into or lived in during the interview. Better thought of as social determinants of health (occupation, education, access to adequate healthcare, and racism), these indicators are known to impact the health of individuals and populations. The

[30] A hair straightening system found in Brazil

next section will demonstrate how respondents negotiate their belonging within the societal conditions that already exist for them.

Negotiation

At the foundation of this project rests the notion of belonging. For those living with SCD, attempts to create space in a hegemonic reality of normalized and able-bodied whiteness, are enacted by the negotiation of belonging within the larger national collective. Many actors, especially those who identified as black (*preto* or *negro*) with SCD, use the cultural and ancestral connection to Africa as well as the presence of a sickle allele, as a way to make structural boundaries more flexible. These same actors often found their way to the SCD Movement via the encompassing *Movimento Negro* (Black Movement). It was through the Black Movement that actors, both with and without SCD, became vocal for their particular piece of the proverbial pie. Baclear (1989) as explained by Pagano (2011), describes the general characteristics of Black Movement organizations: "a strong emphasis on black identity; the adoption of a binary model of race (black and white); denunciation of the myth of racial democracy in Brazil; commitment to procuring better social, economic, and political conditions for the black population; commitment to acknowledging the importance of the negro in the construction of Brazilian society; and commitment to preserving and protecting black culture against undesirable commercialization and folklorization by hegemonic sectors of society." Each of these characteristics can be found in the processes of developing the NCPBP and, in particular, the policy created to address the needs of people living with SCD. These tenets were heard repeatedly

during the interviews I held with people living with SCD, in meetings and larger conferences, by health officials in charge of administering the programs, and by general leaders within the *Movimento Negro*.

Gilberto 

Gilberto tells me of his early exposure to the Black Movement as a young adult. This exposure helped spur his interest in becoming involved as a volunteer for AFARJ. Gilberto became president of AFARJ between 1994 and 1995 and served as such for about a decade. During this time, he was also simultaneously creating the national disease organization, FENAFAL, in which he served as president from 2001 until 2004. He recounts FENAFAL's beginnings:

> There was a meeting of another NGO called *Geo Cidadania* that already existed and was more or less putting pressure on us. They proposed at this meeting that they wanted to represent us. In fact, they wanted to represent all the hematological diseases…all of them…but the folks with Thalassemia advised me to say no, and to not agree because they had already given a response of no… There was a woman who I heard talking to folks and she was saying it was absurd that we were letting this happen. 'How were we going to let others that don't have anything to do with our movement or our pathology represent us?' So we said no…and from that moment, we started to meet and I was proclaimed as the one responsible for starting to organize the association.

I want to focus on the pressure Gilberto felt from another in the questioning of who is allowed to represent whom? Rabinow (1996) predicted the potential progress and problematics of "a 'new genetics' [that is] embedded throughout social fabric at the microlevel by a variety of biopolitical practices and discourses" (186). "New genetics" is distinct from an older discourse of eugenics. Though

scholars such as Duster (1990) have warned against new genetic technologies that may open the space for screening, treatment, and therapies to introduce a "back door" eugenics, the participants who clamor for their rights in the production of these technologies are less concerned. "New genetics" emphasizes empowerment, choice, and benefits (Bunton and Petersen, 2002). Heath, Rapp, and Taussig (2004) define "new social movements" (Laclau and Mouffe, 1985) as "a label developed in the 1980s to describe collective demands surrounding issues of the quality of life, the colonization of private life by market and state, and identity politics constituted around cultural resources and rights to specificity and difference"(158).

"New genetics" meets "new social movements" in the passage above in that genetic differences are embodied in distinct disease-based movements. Further, their specific pathologies allow for the patients within these groups to enact on what Heath, Rapp, and Taussig call "genetic citizenship" in different ways. Though both the thalassemia and sickle cell groups refer to specific geographic ancestry and as well as respective cultures in their descriptions, the cultural frameworks of the posh Mediterranean (anemia do Mediterrâneo) and an impoverished dark continent bring to mind different imaginaries. Despite these imaginaries, and whether or not they could help or hinder a movement, often-times umbrella organizations that speak for a number of disorders create conflict among those who have vested interest in their own pathology.

Those in my participant group who identified as *pardo* or *branco* and also claimed space within the SCD Movement recognized the Black Movement, while also acknowledging their absence from its membership. Elvis, who identifies as

pardo, is genuinely committed to the SCD movement, though he is careful to make the distinction between it and the Black Movement. Unlike Gilberto, the Black Movement was not his entry point to his SCD activism.

> I think that we see in Brazil now there has been some redemption of all the cruelty that was committed against black people. I am on the technical committee for black health and I have a lot of friends from the Black Movement. I am also on the technical committee of hemoglobinopathies. I think the quotas that were created, in my opinion, are in reality a way to mitigate all the negative things that were done to black people. And even more with black people that have sickle cell.

Like many of my narrators who do not identify as *preto* or *negro* with sickle cell disease, they recognize a need for acknowledgement and action for the black population by the State and believe the racialized policies recently implemented are justified. Though Brazil's Constitution of 1988 made its citizens able to hold the State culpable for their health, this particular idea of debt and neglect reflects the deep-seated historical memory of slavery, simultaneously far removed from the contemporary SCD Movement, but also ever present in the minds of those involved.

Ironically, the attachment to the Black Movement provides both promise and peril for its constituents. Dressler (1990) has provided a sociocultural model of skin color and blood pressure steeped in "conventional class theory." The literature engaged by Dressler (Veblen, 1918, Weber, 1946, Bourdieu, 1984, Laux, 1986) as well as Dressler's own take on the concept of lifestyle and theoretical constructs of cultural consonance is helpful to us when thinking about how the *Movimento Negro* positions itself in greater society. Dressler (1990), citing Laux (1986) states:

> "… people use their social behavior as a means of communicating information about images of themselves and thereby attempt to influence the way audiences perceive and treat them. In doing so, they often influence the way they see themselves. Thus, creating a desired impression permits them to receive self-defining feedback that may help them to assess whether they *really* possess a particular attribute or not" (236).

By linking themselves both biologically and culturally to the African continent in the production of materials and images –in both the larger movement as well as in the SCD movement—actors within these movements have indeed attempted to influence certain audiences. But whom exactly are they influencing? In the next section, I will provide an ethnographic account to demonstrate the tension between general public health audiences and specific SCD and Black Health Movement audiences in the struggle for influence.

From February 3-5, 2015, I attended the Second National Exposition of the Experiences in Participative and Strategic Management in SUS (*Sistema Único de Saúde* or Unified Health System), located in Brasília, Federal Distrito. Held in a large convention center that utilized both indoor and outdoor space, hundreds of SUS administrators from the federal, state, and municipal level, academics, civil society representatives, gathered under the objective "to promote the exchange of successful experiences in strategic and participatory management within the SUS over 25 years." Though most of the general sessions were held in the main auditorim of the center which held thousands, tucked away in a smaller auditorium was a parallel meeting to address the Bi-National Seminar for the Brazil-USA Joint Action for Promotion of Equity in Race

Cooperation Brazil (JAPER) initiative. According to the JAPER website hosted by the Department of State:

> The U.S.-Brazil Joint Action Plan To Eliminate Racial and Ethnic Discrimination and Promote Equality was signed in March 2008. It is the first bilateral agreement targeting racism. This initiative leverages the interagency policy expertise in both countries, in a unique partnership with civil society and private sector committees, to address racial health disparities, environmental justice, access to education, equal access to economic opportunities, and equal access to the justice system.

Before this meeting, I served in an official capacity as a subject matter expert representing the United States and the Centers for Disease Control and Prevention to assist with the health portion of the initiative. Meetings had convened for the initiative in Atlanta, Washington, DC, and Brasília. I attended meetings in both Atlanta and Brasilía to assist specifically with the off and on interest by the Brazilian government in sickle cell disease. I attended the February meeting as a general participant and observer. The objective for the February seminar was:

> to [further] develop a partnership between Brazil and the United States in promoting health equity for the black population through the recognition of racism as a social determinant of health, according to the National Policy of Integral Health for the Black Population (Ordinance GM 992/2009), as well as [learn from] the American expertise in monitoring technologies, evaluation and breakdown of race/color in health promotion to specific groups. This initiative is in partnership with the Ministry of Foreign Affairs (MRE) and the Secretariat for Policies to Promote Racial Equality (SEPPIR).

With a heavy emphasis on research, governmental participation, and insight from US-based and Brazilian civil societies, the three days focused on not only information distribution, but solidarity building as well. An official from the

Ministry of Health, specifically the Secretariat for the Promotion of Racial Equality (SEPPIR) in her opening remarks told us, “We are all in the same boat and we’re going to take it to a good port.” This statement draws on the direct imagery of slavery and the transportation of slaves via shipboat to unknown and hostile shores. It also connotes agency and power. In the commandeering of this metaphorical boat, participants of this meeting hope to steer the conversation about health to one that is specific to the black population.

Of note was the space in which the seminar was held and who inhabited that space. I saw many white bodies occupying the space of the general meeting, with black and brown bodies interspersed in much lower numbers. In the JAPER Seminar, quite the opposite occurred. Black and brown bodies dominated the space. I wondered why, if black and brown bodies were overrepresented in the utilization of SUS, why even a small part of time was not designated for the topic to be discussed in the general and larger auditorium. A participant at the meeting even stated to the audience, “SUS needs to work for over 50% of the population.” Days later, Jurema Werneck, a long-standing and stalwart figure within the black women’s movement and obvious crowd favorite who began her talk to thunderous applause said during her address, “SUS doesn’t know what Black Population health is yet.” The legitimacy of the black health movement could seemingly be called into question if such low hanging fruit as presenting your cause to the larger public health audience is ignored. The influence of the black health seminar on audience members invested in bringing attention to racism as a social determinant of health is an easy task; more difficult is spreading that awareness to general audience members. Those outside this

specialized group, consisting of mostly white managers, provide negative feedback about the black population's self-presentation. Dressler (1990) continues to parse Laux regarding the process of this discounting. Within this process is the stress created via the threat to one's identity once no confirmation of one's self-presentation is acquired; the failed attempts of trying to influence other's opinions; and "the loss of self-esteem that follows the failure to achieve a desired status." The alignment of SCD with Africa and essentially blackness—as pronounced in the title of the Ordinance, National Health Policy for the Black Population—allows for legitimate space to be sanctioned for those who claim it. The Black population has this space negotiated on their behalf, but the attachment to blackness is simultaneously isolating. As evidenced by just a 3-day meeting, the respect and recognition that Dressler addresses in his most recent study about how the cultural domain of lifestyle intersects with life-span developmental goals (personal communication, 2015), is still wanted and needed by those whom are seemingly overrepresented in the public health system and by those whom inhabit the mostly white areas of SUS.

Not all of my research participants have played an active role in the black or SCD movement—although most of them did. Some, like Elisangela, were ushered into the movement via the healthcare system, and were less concerned about how the population with SCD fared and more interested in their own personal and individual benefit. Unlike Gilberto, who was introduced to his eventual leadership roles through the healthcare system, Elisangela became aware but took a less active role. She considers herself an activist through her participation in activities sponsored by the local SCD organization (DREMINAS)

as well as other virtual (Facebook, WhatsApp) spaces where her voice can be heard. As highlighted in Aureliano's (2015) analysis of how genetic technologies and medical discourses have been received in Machado-Joseph disease communities in Rio de Janeiro, those who participate in patient associations, do so at various levels of engagement. For some (like Gilberto), the associations serve as a space to champion for rights, while for others it is a place to not feel alone and to meet peers. As demonstrated by some of my actors, activism is performed in discursive ways. Elisangela is not involved on a political level and does not know much about the policies on the federal level, nor about the politics on the state level. Like Flávio (introduced below), she takes keen interest in learning as much as she can about her disorder so that she can serve as a support to others. DREMINAS' strong presence within the healthcare system allows for people like Elisangela to become tangentially involved in the Movement. While she does not have a direct interest in the "*direitos*" provided by the government for SCD necessarily (and certainly not as a proponent of a larger group), she is concerned with her individual rights—to claim services for her disability, to get the treatment and surgeries she needs, and to live life free of suffering. "It's not the life I dreamed for myself. I wanted to have, at minimum, good health so I could fight for what I want, and accomplish the things I always dreamed about."

Authenticity

The notion of authenticity, particularly among Afro-descendants and indigenous people in Latin America has been increasingly documented (Hanchard, 1998, French, 2009, Silberling, 2003, Perry, 2013, Forte, 2013,

Farfán-Santos, 2015). For Brazil in particular, the rise of affirmative action education and health related policies has often brought into question who has the right to make claims to the benefits bestowed to certain citizens by the government based on race or color. In the case of land ownership, biological and cultural distinction is measured by African ancestry and direct linkage to African slaves brought to Brazil. In her empirical analysis on *quilombos* in Bahia, Farfán-Santos (2015) argues that *quilombo* descendent communities' authenticity "depends not only on their ability to perform and describe their ancestry and the history of their community, but more importantly in their ability to tell a specific history of their past as it has been written and incorporated into the Brazilian national imaginary" (112). She further contends, "the politics of cultural recognition depends on a "black culture" that can be specifically defined and visibly identified" (120). In this section of the chapter, I discuss authenticity not of black populations in the context of a larger Brazilian political system, but instead an authenticity that frames how those who have already negotiated space for themselves gate-keep entry into a group that has already established a foothold in how their political identity is managed. Further how might entry into the group—in this case members who have sickle cell disease—contest with an individual's own perception of belonging and vice versa? Finally, how does geographic location authenticate collective identity and their subsequent regional movement?

Arguments used by the Brazilian state to justify the inclusion of sickle cell disease within the NHPBP draw a direct link between race, culture, and genetics. This linkage, at least between race and genetics has long been made in the case of

sickle cell disease—historically believed to only manifest itself in Africans and those of African descent and later becoming understood as a molecular disease. As El-Haj (2007) posits, the "commitment to race as a molecular attribute" (287) can be observed in the actions of the State. This typological thought process harkens to the racial science of the nineteenth and early twentieth century. The policies from nation-states that stemmed from this time period were created to control "the boundaries of inclusion and citizenship (286)," often of those considered non-white (El-Haj, 2007). I argue that the Brazilian state currently use these classifications to *create* routes of access and citizenship, specific to its Afro-Brazilian citizens. The merging of phenotypic and genetic identifiers used to speak about sickle cell disease creates a contested space in which the illness imaginary resides. Like the medical practitioners of the early twentieth century, Brazilian citizens who are phenotypically white, link their disease status to an ancestor who was undoubtedly African. The historical pairing of SCD and blackness takes real effort to dismantle. It is not the role of this project to take this dismantling to task, but instead to offer an analysis of both the promise and peril of this linkage. In a country like Brazil where actors work doubly hard to cement the association of blackness with SCD, it is no wonder Flávio, a phenotypically white man with homozygous sickle cell disease (HbSS) may feel in contestation with himself.

Flávio 

> My race, my skin color is white. But I have a problem that ancestrally speaking, I am considered of Black origin. I see that the disease is viewed as a black disease. That excludes me when thinking about what group I pertain to, because I can't say that I'm white…The little that I know about my genealogy and where sickle cell anemia came from, the disease probably came from my great-great grandfather that according to my great grandparents and grandparents and my parents, was black.

This statement fits the cultural profile of many Brazilians who believe that due to the country's long and storied history with slavery and consequent practices of miscegenation, their ancestry includes African origins. What remains, is a complicated narrative that rests simultaneously on racial admixture and the principle of hypodescent—or the "one-drop rule". As suggested by Kent, Santos, and Wade (2014), Brazil evokes simultaneous genetic imaginaries[31] based on nation, race, region, and diaspora. As part of this evocation, we might understand how the presence of SCD is disruptive especially for whites in Brazil on the phenotypic continuum.

> I say I'm white because of my skin color, but not to declare that I am of the white race. Here in Brazil there was a lot of mixing. There were Indians, then Black people came, then the Europeans, the Italians and the Chinese and Brazil became a cauldron of peoples, a mixture of color, of everything. On one hand it's bad as hell and on the other hand it's good as hell because you learn about everyone. For me race is indifferent. I only say I'm white because of my skin color, just that.

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[31] The genetic imaginary is defined by Neil Gerlach (2004) as: "a set of social concepts for thinking and speaking about the civilization of the gene and its future direction." It is constructed, in the same way in which illness might be—with many actors (physicians, advocacy groups, government, media, insurance companies, those who carry the gene, scientists, and the pharmaceutical industry, to name a few (Creary, 2013). See Gerlach (2004) for more.

Flávio's whiteness delegitimizes his disease status and alters the identity that society has assigned. He simultaneously interfaces with most of his community as a hegemonic entity while also navigating the marginal spaces that a white person with SCD must traverse. The discomfort he feels while occupying this space is evident: "…I am troubled because in Brazil there was huge miscegenation and today there aren't just Black people with sickle cell disease. There are many other types of people. I am white." Elena Calvo-González (2015), an anthropologist from Bahia, Brazil, discusses the notion of racial purity, and whiteness in a recent article through the analysis of Brazilian medical literature about hemoglobinopathies—paying close attention to discourse written about linkages of blackness to Hemoglobins S and C and of whiteness to beta-Thalassemia. She found that the texts obliquely question tropes of purity versus admixture through other topics such as by "referring to the 'nature of Brazil's population', implicitly invoking ideas of miscegenation" (Calvo-González, 2015: 5). This same trend can be seen in the following narrative from Flávio in which he explains to me the differences between Black, Brazilian, and African:

FC: When I say *negro* (black), the image that comes to mind is someone that is *bem escuro* (very dark). I don't consider a *moreno*[32] to be a *negro*… I consider them *moreno* with a certain mixing. I don't consider them *negro*. *Negro* for me is the *negro* from Africa. For me, a *negro* is a very dark person and from the African tradition, which I don't think exists in Brazil. There is no such tradition. Because Brazil is a different country

[32] The origin of the term "moreno" has a complicated history. José Luis Petrucelli in *A Cor Denominada* (2007) theorizes that the usage derives from the Latin *maurus*, meaning inhabitant of Mauritania. Filtered through Portuguese, the term *mouro*, literally means 'swarthy' and is a reference to the Moors, who were perceived as having darker phenotypes than Indigenous Europeans. In popular use in Brazil, it's application is extremely ambiguous, and although commonly used as a term for people with an olive complexion, it can also mean White people with dark hair (as opposed to redheads or blondes), be a euphemism for *pardo*, or even be used to describe person who might be considered 'Black' (Telles, 2004). It could be made synonymous with *mulato* or *pardo*.

> from Africa. In Africa I can say people there are *negro*. *Ne-gro (said slowly for emphasis)*. Here there are people whose race *(corrects himself)*... color... color is *negro*

MC: It's different...

FC: ... EXACTLY, the COLOR is *negro*, RACE is not *negro*... (race) is associated with ancestry and I respect that. Ancestry exists, yes. I don't ignore the merit given to the person that came from slavery. They could say, "*Eu sou negro*" (I am Black), but they don't have the same tradition that the *negro* has; they have traditions from Brazil that is another culture and another way of living.

In this passage, Flávio says many things, but for the purposes of this chapter I will focus on just two items—each a point on the content and the construction of the above narrative. The word "*negro"* is mentioned 13 times in this small transcript segment. As mentioned above, there are an increased number of Brazilians who have re-classified themselves from non-black to black (Miranda, 2015). "Black" could be defined in many ways and though it may be easy to quickly assign "*negro"* as "Black," we cannot make that assumption. As defined by Telles (2004), the classification system that utilizes the term *negro* has been recognized to come out of the Black Movement and is used in the most binary sense of racial classification. The simultaneous usage of these classifications (based on the census system, popular system, and black-movement system (discussed in detail in Chapter Two) by Brazilians is also represented in the narratives of all my respondents, and Flávio's fluid movement between notions of *mestiçagem* and a more binary of one versus an "other" repeats the pattern. Of note, the census system classification term for Black –*preto*- is never used in conversation to describe a person. It is not socially acceptable to call people by

the term, though acceptable as a descriptor for all other things. The term *negro* has become accepted by the government, media, and academia, and by many in the lay community within the Brazilian society (Telles, 2004). Though it is possible that Flávio may have been influenced by the term created by the Black Movement activism he undoubtedly has been exposed to it through the SCD Movement, we cannot assume that he uses the term in the political sense for which these groups intended it. *Negro*, when used in the popular sense of the word, refers only to those at the darkest end of the phenotypic continuum and equates to the word *preto* (Telles, 2004). This reasoning aligns with Flávio's first sentence in this particular narrative: "When I say *negro*, the image that comes to mind is someone that is *bem escuro* (very dark)." For him, instead of linking Afro-Brazilians as a whole population (those considered *pardo* and *preto*) to the continent of Africa as many in the SCD movement do, his linkages stem from a particular skin color. Those who may be lighter on the color continuum (according to data collected by Telles (2004), this could refer to people who occupy the full range of the color continuum except very dark and very light (white)) and may self-classify as *moreno* are assumed to be racially mixed and are excluded from these claims. Flávio also recognizes that while there may be descendants of Africans who exist in Brazil, they can claim the Black race vis-à-vis ancestry, but cannot make claims to the culture. By this account, someone lighter complected can claim being a descendant from Africa, but cannot be related through ancestry or connected by culture to those who are dark-skinned.

This passage represents the complex ways that race, skin color, and ancestry are considered by some Brazilians. Flávio is not the only one of my

respondents who considers them separate but connected entities. Even he has to catch and correct how he defines the terms. By assigning the term *negro* to only those of the darkest hue, Flávio negates the influence that any policy or program document may have which uses that term on those who do not fit that phenotypic profile. In his own explanations, he finds himself absent regarding the justifications of how SCD found itself in Brazil. In his own rationalization of how he came to inherit two sickle alleles, he refers to family genealogy in which he attributes the disease to a great-great-grandfather who has been reported as Black. Even four generations back, Flávio does not connect his relative to the continent of Africa, perhaps believed to be far removed from slavery. In addition, in his reasoning he has linked himself with only one Black relative as a way to explain how SCD came to be embodied. Despite his knowledge that SCD can be found in all racial populations, the reliance on the presence of blackness by his reasoning, cannot explain how he inherited SCD. The requirement of two black relatives is omitted. Further, Flávio distances Brazil from Africa, where he deems authentic blackness to reside. This distancing from blackness is not only evident in the content of this narrative, but in the construction as well. We cannot find Flávio located in the narrative anywhere. This "spatial distancing of blackness" (Godreau, 2006) in which actors "root blackness in other regions and then distance themselves from those regions" (Sue, 2013), is not exclusive to Brazil and can be found across the diaspora. Flávio inserts himself inside a presentist's discourse in which the recognition of racial purity (associated with slavery) is a thing of the past, while mixture is viewed as a phenomenon of the

present—making note that "the cultural outcome of that hybridity is construed as a homogenous national project,"(Godreau, 2006: 182).

Flávio continues to exhibit signs of distancing, not only in language but also in deed. When I asked Flávio about his role in the SCD Movement, he called himself *egoísta* (selfish). Mentioning the need to understand himself and his disease process foremost, he avoided any language that would associate him with other community members with the disease. And while he discussed being able to support others while first improving his own quality of life, he seemed reluctant, perhaps as a result of his personal identity crisis, to firmly attach himself to any political practices. Flávio does seem content however in lending his entertainment services to the cause of SCD. Enrolling in a clown course, Flávio takes his craft very seriously. And while he may not have spoken of it in his interview, his presence on social media paints a picture of his continued involvement in the SCD community via clowning. He, like many others with SCD, is connected in tangible and virtual ways. I argue that clowning provides ways in which he enacts opportunities for inclusion, but by being attached to a social group outside of the SCD movement. Even though Flávio evaded talk about his involvement in any formal capacity within the SCD movement, he is embedded in a way that feels safe and appropriate to him: "[clowning] opened up a space for art and helped me rediscover myself. I was reborn in a different way." In the application of white paint on his already white skin, could Flávio also be enacting performative distancing? Freitas (1997) explains, "Individuals try on diverse and intersecting identities for size as they test, express, construct,

interpret, and gauge identities in the context of self/other appraisals/relations and cultural discourses" (324).

While Flávio, as a biological member of the SCD-related biosocial grouping, rejects his presence in the group based on race and culture, Zaira, a mother who has sickle cell trait, considers herself an appropriate member of the group and is seemingly rejected due to her biological inauthenticity. Harris (2013) contends with the politics of authenticity in the context of U.S.-based indigeneity and makes the distinction between personal identities and social identities as defined by Snow and Anderson (1987) and Coupland (2007), respectively. Personal identities are the self-designations that one asserts during the course of social interactions with others, while the concept of social identities links one's representation of 'self' with "the social structures and groups in which the 'self' is embedded and ultimately constituted" (Harris et.al., 2013: 3). Harris further posits:

> The politics of identity can involve the construction, reconstruction or disruption of notions about what it means to claim particular identities, or the creation or recreation of meanings attached to them-- especially if these efforts are attempts to shift power relations within or between groups.

In the narrative below, we will see how Zaira's personal sense of self and the perceived social representation of self are in opposition with each other—especially when who she is and who she represents based on her fluid identities come into question.

Zaira 

In the sweltering heat of February, a few days before *carnaval*, I attended a daylong meeting in which all of the state and city representatives of SCD community organizations were present. At this meeting I witnessed Zaira fight for her assumed rightful seat at the table and woke the next morning to an email in my inbox sent to the officers of AFARJ and myself at 1:00AM. The subject heading read "*Carta aberta de uma mãe de falcêmico*" or "Open letter from a mother of someone with SCD." Excerpts of her letter include:

> What does the mother do when she sees her son is in acute pain crisis, screaming in pain and no medicine is effective?
> What does the mother do when the child looks at her, after the crisis of pain, exhausted and with hopeless eyes? …
> What does the mother do when the child dies in her arms at age 19?
> SHE ALSO DIES !!!!
> Who says that the mother with trait does not feel like the son, because she does not have the disease. It is to deny life. …
> What does the MOTHER do whose pain recurs with another child? **SHE DIES AGAIN!!!**
> This MOM with her heart torn, puts together the small part of the heart that is left, because she has other children, and they also need this Mother and she **SURVIVES!**
> **This Mother is me!**
> **Shut up those mouths that open to say that a mother does not feel the same pain as their child.** (author's emphasis)

While I was surprised to be a recipient of this message, I recognized that my interest, access, and status as an American researcher no doubt held strong

appeal. Her letter speaks to several things: her need for legitimization as leader of a disease organization (specifically one focused on SCD), her role as a mother to serve as a vehicle for legitimacy, and the ways in which her trait status place Zaira into *interstitial biosocial spaces*. Sickle cell trait is characterized by the inheritance of one normal hemoglobin allele and one sickle hemoglobin allele (HbAS) and is usually thought of as being clinically benign (Tsaras, 2009). Individuals with SCT rarely experience complications, though complications have been associated with trait status (Mitchell, 2007, Tsaras, 2009, Key and Derebail, 2010). Unlike the subjects of Duana Fullwiley's work in Senegal (2006) who have SCT, Zaira never claims pathology. The only pathology she recognizes is her children's, but her trait status places her in between notions of normal and pathological, whether she relies on medical care or not. Certainly her power struggles indicate that her inheritance of only *one* allele is problematic for others as she leads the organization.

In speaking with Zaira, though she is vocal about her leadership, particularly the successes of that leadership, it is clear that she does not consider nor want to be considered as a person with SCD. Her language is distancing, full of "they" and "them," and steeped in ideologies of noblesse oblige. Her primary identity is not one of a person living with SCD, but as the mother of two who carried the homozygous form of the disease. Their deaths fuel her fire and assist in her legitimacy. Not only did they have the most severe form of the disease, but their deaths were attributed to that severity. The letter she writes is about the pain of having a child with SCD, but focuses on her particular pain as a mother. Zaira never mentions her son by name. When I asked her early on about where

she came from she spoke about her childhood in Laguna, Santa Catarina, the abandonment of her father, and the respect her grandmother evoked.

ZC: I had lots of boyfriends. When I got married, it was basically because my grandmother forced me to get married to see if I'd give less trouble for the family. But I liked him – I got married to a guy I liked, I wouldn't have gotten married otherwise. At that point, funny, I was already involved in politics… Then I went to college, I met my husband there, we got married, and I had my four children. They have all graduated. I lost two and I have two.

MC: Lost two to SCD?

ZC: Well, yes, I didn't know my son had it, even though he always showed the characteristic symptoms. Now I know what they are, but I didn't know. When he died he was already in his second year of engineering at UFRJ. He was really smart. When he died, he had a really really bad pain crisis and he turned all yellow, he died in my arms. That day we did the tests at the Hospital of Santa Cruz and they said 'No, this is not rheumatic fever, this boy has SCD.

Zaira did not get involved with the SCD Movement immediately after her son's death. It was not until 2008 that she brought her skills to AFARJ.

I forgot about SCD. I didn't want to hear about it. I became a leader for protecting the rights of disabled people. So I had a lot of positions, working during a number of governmental administrations. I worked with the governor and always for rights of disabled people… Then I met Marcos, who was the ex-president of AFARJ. The governor had placed me as the representative for the palace at the Council for Disabled People…and one day at a meeting Marcos had a crisis and that brought everything back for me. Everything I'd tried to forget, drown out, came flooding back. So I said to him that he'd made me remember my son. He said, 'You have to come to our meetings.' I said, 'No, I don't want to. I have already suffered so much.' But he insisted so much that I came. So I started to participate. I'm such an intense person that when I get involved with something, I do it with all my energy. And I dived headfirst into this struggle.

One might imagine that as a mother, especially one of a deceased child, she might feel as though she is more affected than if she had SCD herself (Almeida, 2006, Burnes, 2008). We might also imagine that her anger is a product of her own and unwilling ignorance produced by a system not yet adept in knowledge about SCD. Hill (2010), who interviewed mothers of children with SCD for her study, posits that the meanings these women "construct and assign to the SCD experience develop from their own values, resources, and life experiences" (x) – even if the knowledge of a SCD diagnosis is delivered retroactively. Burnes (2008) conducted a study in Canada to assess the experience of mothers raising a child with SCD and found great frustration about the lack of knowledge and skills from providers surrounding the treatment and care of SCD. Yet this angst is not enough for some of the members of AFARJ and there are those who demand "authentic" representation. This authenticity, for many, is delivered via the homozygous form of the disease.

While in Rio, I gave an aforementioned lecture about the state of SCD in the United States at the request of Zaira for the constituents of AFARJ as part of their monthly meeting. Once I was done and opened the room for questions, my own authenticity was immediately questioned. "What variant of SCD do you have?" asked one audience member. After I replied that I had the HbSC variant, the audience collectively nodded their heads or chattered aloud. My less severe variant (later, they asked of my social class) was explanation to them of how I was able to travel, to be a researcher, and to overall live a life that seemed uninhibited by debilitating sequelae. Harris, Carlson, and Poata-Smith (2013) discuss authenticity through the lens of indigenous identity. "…expectations of

indigenous cultural purity … exist alongside the imposition of varying degrees of blood quantum as criteria for citizenship, political recognition and access to resources and services" (1). So too is the case for SCD in which a group of people rely on a particular genotype for their authenticity claims. This biosocial grouping is clear for those who express an authentic disease state, but what about the case of Zaira who is politically embedded within the group to fight (and win) rights for people living with SCD in Rio, yet is not fully accepted due to her trait status? I call this area that she exists in an *interstitial biosocial space*. In the case of activism around the BRCA gene in UK, Gibbon (2007) shows how the female BRCA carrier is elevated to iconic status. While Zaira's carrier status offers her no potential threat to a future pathology, the "gendered modes of identity making " are evident (Gibbon, 2007:21). While Zaira's constituents felt the need for authentic representation via two sickle alleles, she *has* claimed her authenticity through her maternal role. There's no doubt about her motherhood and it is that role that she emphasizes in her letter. Further, the practice of "memorialisation" (Gibbon, 2007:21) is also described as a way that breast cancer civil societies identify themselves via the remembrance of women who have had or have died with the condition. Zaira takes on an individualistic version of memorialisation through her work with AFARJ on behalf of her children. She occupies space on two planes: one in which she is connected biologically (even if by only one allele) to SCD and one in which her normal hemoglobin outweighs any perceived "value" as distributed by those who have two alleles. To Zaira however, her allele contributed to the disease status of her children and as a result should firmly situate her amongst everyone else. Her genetic contribution

to the death of her children authenticates her placement in the biosocial group of those with HbSS, even if the group does not authenticate her itself.

Also of note is that around the table that afternoon, Zaira was not only the sole person in the room with sickle cell trait, she also had the lightest skin color in the room. Could her lack of authentic representation be attributed to not only genotype, but phenotype as well? Could the absence of blackness be a contributing factor to the discomfort some people feel in her leadership? Zaira self-describes as *mulata* and mentions that her grandmothers are *negra*, her mother is *branca*, and her father is from the northeast. Though she never mentions his race, I assume based on all the other familial descriptors, that her father is *negro* (non-white). Due to the close association that blackness has with SCD in Brazil, arguments about the authenticity of her phenotype are likely embedded in the arguments that question her genetic status. In fact, her societal display of whiteness is what she attributes to the lack of diagnosis for her children. No one suspected that either she or her white husband could carry the trait. This notion of invisibility is potentially transplanted through Zaira as leader and in many eyes threatens the credibility of the SCD organization. Could her phenotypic lack of blackness also provide what Dressler defines as a cultural mode of lifestyle that is non-relatable to most of her constituents? Lifestyle in this sense is defined "as the accumulation of consumer goods and the adoption of behaviors that help to define one's social identity" (Dressler, 1996: 331). Throughout my interview with Zaira, she discusses points of privilege that set her apart, at least class wise, from others I interviewed associated with AFARJ. Zaira has attended college, her children have all attended university, her husband is a

lawyer, and on entering the SCD movement she remarks, "I abandoned all my other jobs; I had the freedom to do that because I didn't really need the money." Lifestyles help indicate fluid social identities. Several identities emerge through Zaira's interview, interactions, and observations: mother, president, trait carrier, target of conflict, woman of affluence, and activist.

Place

In Brazil, the linkages sickle cell and authenticity take form not just in personal or social identities of self, but in regional place as well. Places are constructed in more than one way. Physically, of course, places are built in a manner that takes up space in a city, state, country, etc., but according to Gieryn (2000) are "also interpreted, narrated, perceived, felt, understood, and imagined" (465). These interpretations, feelings, and perceptions are not just embodied by those who take up inhabitance or are connected directly to that place, but the imaginaries belong to a much larger group. Bahia, a northeastern state and place of metaphorical blackness, is where genetic disease, and regional imaginaries collide.

I attended the *VII Simpósio Brasileiro de Doença Falciforme* (7th Brazilian Symposium on Sickle Cell Disease) in Salvador, Bahia in late November 2013. This symposium takes place every 2 years and has been held in Rio de Janeiro, Fortaleza, Recife, and Minas Gerais. It is the only national conference on sickle cell disease and each time it convenes draws thousands of students, scientists, SCD organization leaders, public health administrators, noted Brazilian and international clinicians, and people living with sickle cell disease. The very first

iteration of this meeting occurred in 2001 was a smaller version and was organized by a hematologist, Dr. Isa Lyra, and a leading scientist associated with FioCruz, Dr. Marilda Goncalves. The meeting focused on scientific aspects of the disease, and while SCD organizations were represented, the impression I got from the interview I held with Dr. Lyra, was that the meeting was not necessarily for consumers or people living with SCD. By 2013, the Ministry of Health became increasingly involved and the meeting (backed by Federal and State funding) had transformed into a 3-day conference that involved the heavy presence of those with SCD. The state newspaper, *Correio,* titled an article on its health blog a few days before the symposium, "Salvador is the capital of sickle cell disease from November 20 to 23." Even beyond these dates, Salvador is thought of by many as the appropriate representative location of the disease. The national incidence rate, by the time of the meeting, was 1 out of 3500 babies born with SCD. In Salvador, one out of 650 babies is born with SCD. Antônio Purificação, the state coordinator for the Comprehensive Care Program for People with Sickle Cell Disease, said in an interview for the Tribune of Bahia that due to the large numbers of *pretos* and *pardos* (black and brown) in Bahia based on 2010 Census data (76.3%), "the event here takes on greater importance for Bahia."

The Symposium was initiated on November twentieth, the *Dia da Consciência Negra* (Day of Black Consciousness). An excerpt from the same piece in the Tribune:

> Bahia is the state with the highest number of cases of sickle cell disease (SCD) in Brazil, so the Bahian capital was chosen to host the VII Brazilian Symposium on Sickle Cell Disease. The event marks the Day of Black

> Consciousness mainly because it is a more prevalent disease in blacks, due to [it being a] hereditary condition.

The three-day event began with much fanfare. The opening ceremony included lengthy introductions from State officials, a 30-minute film, and a performance from the *Grupo de Teatro da Polícia Militar da Bahia* (Theatre Group of the Bahian Military Police). The performance, *Se não fosse a África* (If not for Africa) provided an overview of the history of blacks in Brazil, and referenced slavery, the Malê revolt of 1835[33], and Zumbi dos Palmares[34]. The start of the conference falling on the Day of Black Consciousness was no coincidence. The organizers (compiled of personnel from federal, state, and municipal administrators and participants from the sickle cell associations from across the country) wanted to link the Symposium and the related disease symbolically to blackness.

A month after the symposium, I spoke with Joice Aragão de Jesus about the significance of having the event in Salvador, Bahia and she echoed the information in the news media:

> Considering that Bahia has the highest incidence of the disease, the biggest black population and African representation in Brazil, and due to sickle cell having these origins [in Africa], we did [the symposium] in Salvador. In my opening speech I spoke about how Jessé Accioly was a genetics professor that studied [some of] the first families that had sickle cell

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[33] In 1835, a slave rebellion broke out in the city of Salvador, Bahia that came to be known as the Revolt of the Malês (Muslims). Though Africans were thought to be distinct from Afro-Brazilians, during this time, the imagery and actual representation of blacks in battle with white colonists to win freedom is used by Afro-Brazilians to link the two locations and to evoke the idea that Africans brought to Brazil paved the way to help fight (literally) for civil rights. See Kim Butler's (1998) *Freedoms Given Freedoms Won* for more.

[34] Zumbi dos Palmares is a leader of the quilombo Palmares located in Alagoas. He is central to the history and modern day struggle of Brazilians who recognize their African ancestry and he has attained near mythical status, particularly for Afro-Brazilians. Members of the *Movimento Negro* mobilized to eventually create the national SCD policy after the 300th anniversary of his death.

> anemia. He studied 12 families in Bahia. That work remained outside of the scientific community until another doctor from Bahia, Eliane [Azevêdo], took his work to the United States. Afterwards, Dr. Henilson Remi and Helena Pimental, also Bahians, introduced the newborn screening test for sickle cell anemia to the Minstry [of Health]…Afterwards, I [a Bahiana] humbly came to coordinate the [federal SCD] program. Sickle cell anemia is very much Bahian…Bahia is expressed a lot in the history [of SCD in Brazil]…Bahia has always had representation [in the history of SCD]. Now, Bahia begins to grow in relation to programs and policies to attend to the afflictions of a city that has the biggest presence of sickle cell. That also has a significance.

What Joice is trying to relay to me in this statement takes place in both the past and the future. Brazilians now recognize the work of Jessé Accioly, then Associate Professor of Medicine at the *Universidade Federal da Bahia,* who is credited with formulating the inheritance mechanism of sickle anemia in 1947 independent of James Neel, a renowned US-based geneticist who is recognized in the medical literature as the pioneering scientist to provide this information (also in 1947). In a letter to the editor, Eliane Azevêdo (also a Brazilian geneticist) writes to the *Journal of Human Genetics* to notify its readership of this omission in the medical literature—blamed on the limitations of language and poor journal circulation (Azevêdo, 1973). Joice bookends her remarks with the promise that lies within the regional boundaries of Bahia. "Now, Bahia begins to grow…" The regional differences in advancement for SCD are evident in program development and municipality and state commitment to the disease. Leaders within Bahia, a historically poorer state, were poised at this meeting to bring attention to the state's contributions to those who might help position the political and scientific priority at a higher level. Currently, despite the influence

of doctors like Dr. Gildasio Daltro, who is a Bahian-based, internationally recognized expert on the treatment of necrosis of the bone (a SCD related ailment) and leaders like Altair Lira and Maria Cândida Quiroz, who have assisted in the promotion and awareness of the disease—SCD remains a low clinical and public health priority. In fact, it was in Salvador that several interlocutors told me that there was a perception of a different genetic reality due to the specific haplotype profile found in people living with SCD in this region of the country when compared to the rest of the nation. I heard from several municipal programmatic personnel in Salvador that advances in SCD were stunted in this region in comparison with other regions in Brazil as a result of this perception.

Compare this with Brasília, a place in the embryonic stages of development for SCD. Though this site has recently initiated the development of a district-based clinical patient registry, it has not yet made a recognizable and distinctly Brasílian contribution to the national profile of the SCD. The regional imaginaries of Brazil intersect with the genetic imaginaries of sickle cell disease. Consider further a comparison with the south of Brazil, in particular Rio Grande do Sul, where the prevalence of sickle cell disease is nearly four times less than that of Bahia. Migratory patterns from this region include an influx of people from Italy, Germany, and Poland (Lesser, 2013), and with these migrations, an imaginary of the Gaucho—distant in location and cultural significance from the African influenced Bahia and consequently the disease.

Gieryn (2000) asks, “How do geographic locations, material forms, and the cultural conjurings of them intersect with social practices and structures,

norms and values, power and inequality, difference and distinction?" Bahia evokes simultaneous imaginaries of promise and challenges for those living with and fighting for SCD in Brazil.

Conclusion

As highlighted by Aureliano (2015), the Brazilian historical and sociocultural contexts must be considered when members of patient groups mediate with other actors regarding the "political economy of hope" (Novas, 2007). Instead of pushing for increased research and potential cures from doctors, scientists, and the pharmaceutical industry, those in patient-based associations campaign for public health policies that offer care and treatment. However, "the biological material needed to make these hopes concrete is … simultaneously a vector of health and wealth." I argue that many of my study participants with SCD (whether they actively campaign for greater access to drugs or increased number of specialty clinics or not) have differential relationships with the practice of hope, based on skin color, class, and consequent power. Though under a U.S.-based construct of race, anthropologist Cheryl Mattingly (2010) demonstrates through her study of African-American families of children with serious diseases, that the landscape of hope is inequitable and is instead negotiated in particular ways. So too, for this study can we see how certain actors with SCD—usually those with darker skin color—choose to locate their site of negotiation in both their genotype and access to the African continent; drawing on both biology and culture to help authenticate their claims to the State. Further, those who cannot fit firmly into either of these biological

(Zaira) or cultural (Flávio) constructs often find themselves in contestation with themselves and less legitimized by the State and others—at least for SCD related purposes. In life external to SCD, particularly for actors who may find themselves outside of or interstitially located in SCD membership, other forms of belonging, recognition, and respect take place in general Brazilian society. Often the exclusion these (typically lighter-skinned) actors may feel from full membership in the SCD community is counteracted by affirmations of inclusion in other aspects of their lives. These affirmations take shape in access to healthcare and education, better employment opportunities, less societal discrimination, and upward mobility. In essence, I found the darker skinned you were the more you relied on the health policy to help legitimize you as a citizen. Those who were lighter-skinned devalued the policy, not just because they did not see themselves in it, but because there was less of a need for it.

Using the example of SCD in Brazil helps us contextualize the framework of biocultural citizenship. As noted by Clarke (2013), scholars have "suggested that despite assumptions of membership and rights in relation to citizenship, the reality is that there are multiple layers of engagement and claim-making and that various other ethnic, cultural, and linguistic differences are at play" (465). The use of biology to help legitimate these cultural claims, especially in the black Atlantic, contributes a new and distinct way to think about how race and skin color are used as tools of agency for diasporic communities. The fact that the State has responded by legitimizing these cultural claims shows the impact that these strategies have had on greater society and will be discussed more in depth in the next chapter.

CHAPTER FOUR

Bicultural Competence and Policy Formation: A Story of Elite Engagement

Introduction

At the center of the contemporary story of sickle cell disease in Brazil, is a 66-year-old woman named Dr. Joice Aragão de Jesus, the national coordinator for SCD in the Ministry of Health from 2004 to 2014. Although she had started the transition towards retirement near the end of my fieldwork, her political legacy was already evident within the national sickle cell program, throughout the state and municipal programs, in the sickle cell associations, and among the individuals who have blended into an amalgamation of friend, family, and professional associate. For many in her vast network, there were no real boundaries. Her ex-husband, a journalist, traveled from Rio de Janeiro in November 2013 to attend the national SCD symposium in Salvador, Bahia and was helping to produce a pamphlet for SCD for the Ministry. Joice became upset when she learned from someone else that Gilberto and Sylvia, persons living with SCD in Rio who were prominent members of the local SCD association, were in financial need. She adopted her son's girlfriend when she learned that she came from an abusive family, funded her schooling, and Lidiane now trains to be a hematological dentist[35]. Joice is proud, independent, unafraid to speak her mind, strong-willed, and committed. Despite the amount of distrust her presence

[35] Brazil has a niched dental service in some of its treatment centers serving people with SCD. There is academic scholarship and training programs around the specific oral health needs for people with SCD. See Takahashi et.al., 1993, Rosa and Magalhaes, 2002, Franco et. al., 2007, and Batista and Andrade, 2008.

caused during the embryonic stages of policy development, she was unwavering in her commitment to the *rights* of people living with SCD. Her dedication to *Sistema Único de Saúde* or SUS, the public health infrastructure and the tenets it represents: universality, completeness, and equity (*universalidade, integralidade, equidade*) –was evident in the interviews she gave me and countless others, in her presentations to different parts of the government and organizations across the nation, and in the testimonies she offered at congressional hearings.

I met Joice during my first trip to Brazil at a small café in Ipanema. We sat in the back where she instantly opened up about her frustrations and hopes for the sickle cell program and the people living with the disease. Over the course of three years, and certainly during the five months I lived with her in the mostly middle to upper class neighborhood of Tijuca in Rio de Janeiro, I saw many different sides of this complex woman whose narrative brings the sickle cell story in Brazil into sharp focus. I witnessed anger, exhaustion, joy, hardheartedness, humor, disappointment, confidence, and worry. I accompanied her to meetings, workshops, and conferences with her colleagues and adversaries, but also to malls, beaches, and bars with her family, friends, and off-again-on-again partner. According to Schatz (2009), "if the study of justice, freedom, democracy, or order is to mean anything, it must take into account individuals' lived experiences and how they perceive these abstractions" (10). This chapter revolves primarily around Joice and examines how she and a handpicked team across the country have helped shape Brazil as an activist state specifically for its primarily black constituents living with SCD. If, as suggested by Dirks, Eley, and Ortner (1994)

politics is the attempt to corral different identities in a centralized manner, Joice contested this aim in her work as the national coordinator of the sickle cell program. She specifically and simultaneously lifts race- and health-based identities to the forefront of all other identities. At the center of this action is her attention to and care for Afro-Brazilians whom she believes have a right to health.

> Before the transition within the healthcare system with a new constitution, I was really unhappy as a doctor. I didn't like what I did. I was kind of lost. But after the new constitution, a democracy and a new public health system were created; I found myself and understood what I wanted. I wanted to work for all that.

The new constitution and public health system were created in 1988, in part to address the country's deep-rooted problem with inequalities. But it was not until 2000 that Joice began working for the government under the auspices of sickle cell disease. Her network of family members, partners, friends, and co-workers served as discursive political actors in the formation of who Joice was to become, even before her lifework was recognized as a political act.

Repression and Liberation

Joice was born on September 11, 1949 in the Liberdade neighborhood in Salvador, Bahia. If Salvador is imagined to be the blackest city in all of Brazil, Liberdade is considered the blackest neighborhood within the city boundaries. This is due to size— (it holds the most black inhabitants within Salvador)—and symbolism as well, for Liberdade is home to the headquarters of *the Movimento Negro Unificado* (MNU) or Unified Black Movement, as well as the African-centric carnival groups such as Ilê Ayiê and Olodum. To some scholars this placement helped solidify Bahia's identification as "African" (Covin 2006,

Alberto, 2011, Williamson, 2012). When Joice recounted to me the importance of Salvador to the Sickle Cell Movement, she attaches herself to Liberdade as not only her place of birth, but as the place that contributed to her eventual participation in the movement and authenticated her involvement with the disease. Joice lived in Salvador until she completed elementary school and was raised by her grandmother, whom she recalls with intense fondness, until the age of five.

> I was raised by my grandma, my father's mother. And I remember her, she was my mom really because my mom left me with my grandma when I was 15 days old and I lived with my grandma until I was five years old. I was really spoiled. I was the queen of the house. My grandmother treated me with a lot of love and care. I was the joy of the house…she spoiled me a lot. She would make dresses for me. For *carnaval*, I would wear a costume and dance and spray perfume.

At age five, she moved with her father from Liberdade to Engenho de Dentro, a middle and lower-middle class neighborhood in the northern zone of Rio de Janeiro. She recalls, "It was a good neighborhood with sanitation and buses. It was better than where we lived in Salvador in terms of quality of life." But improved public infrastructure did little to compensate for the drastic changes in Joice's home-life. She remembered:

> When I went to my dad's house, everything changed. It was a different environment. My dad went to my stepmother, who didn't like me I assume. And it was different. There wasn't that happiness that was in my grandma's house. I wasn't a queen. I was another daughter outside of my father's marriage. He had 5 daughters with that woman. It was really awful there. I wasn't happy there. I missed my grandma, but it was ok, I think I put up with it well. I studied, I lived here, but it wasn't a happy house where there was joy, or celebration and love. I didn't have that. But it's ok. It wasn't a tragedy.

Joice's father was in the Brazilian Navy and had aspirations to become an officer. Officer status would theoretically allow his family to join the middle-class, a space occupied by "literate, white-collar employees and professionals … who did not engage in manual labor and who were overwhelmingly white or light-skinned" (Owensby, 1999: 8). Joice's father placed a high value on education and a strong work ethic. He studied, took the placement exam, passed, and asked for a transfer to Rio de Janeiro. His studious nature was passed down to Joice, perhaps without choice, and she learned how to read by age four.

> My dad was a very intelligent man and he would study a lot and he would motivate us to study a lot. We didn't have money to buy books, but whenever he could, my dad would win books from the Navy, he would bring them and I would read. He would say that the most important thing was to study. I never had problems with school, I would pass exams, and life took its course.

Joice expressed a resigned passivity in discussing this part of her life course with me. In her recounting, the normally animated woman seems at times saddened by her memories, and often counters a troubling recollection with a quick phrase of comfort—either to convince me or herself that the moment was not that bad. She never lingers in the narrative about her past, or the present day. Often, she would shake brief moments of vulnerabilities away with a sigh and verbal commitment to move on. When I asked her if she misses parts of her childhood she replied: "I keep that memory as something good. I don't want to be a 5-year-

old girl. I think that time when I was 5 years old was good for me as an adult. It's not *saudades*. I like to remember. It's not *saudades*, which is different[36]".

The deference Joice gives her father continued throughout her childhood even until it was time for her to choose a profession. When I asked her how she decided to study medicine, she relayed to me that she had little to do with the decision:

> I didn't want to. My dad would say to me, 'you need to be a doctor because you are black, a woman and you're poor. If you want to get out of this [poverty], you need to be a doctor. You will study medicine.' I didn't challenge my dad's decision. I am a doctor because my dad wanted me to be. I studied and studied and the time came to take the entrance exam, which was very difficult because it was 5000 candidates for 120 spaces. You had to take a prep course. My father didn't have the money, those courses are very expensive, but those courses gave scholarships. You had to take a test and I qualified for a scholarship. So I studied, I took the public exam twice to get into the University. I wanted to be a journalist. I liked chemistry and thought about becoming a chemist. When I got the scholarship to do the prep course, he paid the fees. I got into a public university and there was no choice to be a doctor. It was my dad's story more than mine and I accepted.

Joice likens her father to a dictator; his house "was full of rules, moralism, and repression." She entered medical school in 1973, at the end of the presidency of Emílio Médici, arguably during the most repressive period of military dictatorship (sources). The tyranny in both her external and internal worlds likely jointly contributed to her political life, which started once she left for university and moved out of her father's house.

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[36] The term *saudades* is a Portuguese term that has no English translation. It is closely translated to mean a yearning or longing for a person or place, often associated with feelings of nostalgia. It's ubiquitous in Brazilian speech about loved ones, distance from home, and sometimes even for times gone by.

> When I started university, Brazil was already a military regime, a military dictatorship. So I got close to people at school that were against the dictatorship. Generally they were students that had more knowledge than me, and were from other social classes. They had better conditions in their families. So I became friends with them, and those friends helped me a lot…You didn't have the freedom to say what you thought…development in Brazil for poor populations were things you didn't talk about in terms of race, gender or class. So as a young person at that time looking for knowledge to understand Brazil, it was very closed, there was a lot of censorship. I hung out with politically active people. We would read, discuss and try to get information. I was part of the resistance to the military dictatorship. We would meet in groups and do a lot of political activities.

At 21, she married her first husband and divorced a year and a half later. Soon after, she informally married her second husband, a journalist who wrote for an anti-military regime newspaper during the time of dictatorship. As anthropologist Jessica Gregg (2003) describes in her monograph about Brazilian women with cervical cancer, "Strictly defined, marriage in Brazil as the result of a legal ceremony between a man and a woman…[However], in the favela marriage was generally defined less in terms of civil or religious unions and more in terms of economic and sexual ties." It should be noted that even though Joice, is a middle to upper class physician, her practices for partnership are in line with the fluid nature of marriage in Brazil.[37] During this time, Ernesto Geisel served as president (1974-1979) and facilitated the beginning of a very gradual opening (*abertura*) of the government towards eventual democratization. This opening of the political system towards more democratic practices in Brazil allowed for more social participation in health. Leading up to this time period, doctors in Brazil

[37] See Scheper-Hughes (1992), Green & Rao, 1995, and Covre-Sussai et. al., 2015 for more on marriage in Brazil.

reacted negatively to the current health model that was implemented by the authoritarian regime, which rejected the idea of preventive medicine and neglected poorer citizens. In hopes of spreading their preventive health message, they created the *Sanitarista* movement (Arvitzer, 2009). The Geisel administration declared a commitment to better health as a way to gain support for his rule and more members of the movement began to assume health related positions (Davies and Loveman, 1978, Weyland, 1996, Macedo, 2006,). As a result of increasing political pressure and cries for more liberalization by students, intellectuals, civilian and business leaders, the government set in place a number of actions to further liberalize the regime. Under Figueiredo's presidency (1979-1985), new parties formed and direct elections were allowed in the states. These actions would prove advantageous to the associations and individuals who were beginning to mobilize around health, gender, and civil rights (Loveman, 1978, Hanchard, 1994, Weyland, 1996, Parker, 2003, Htun, 2004).

This new openness allowed for the strategically placed *sanitaristas* to campaign ardently for decentralization within the health sector of government (Weyland, 1996, Parker, 2003, Cohen, 2005). According to Nunn (2009), although the physicians were not using the buzzword of "human rights," their platform today would be considered a rights-based approach to health. These premises, which integrated slogans of "participation," "inclusion," and "equity," served as the backdrop to bottom-up policy development and the creation of *Sistema Único de Saúde* (SUS), Brazil's Unified Health System in 1988 (Nunn, 2009).

Leading up to the creation of SUS, *sanitaristas* used the 8th National Health Conference in 1986 as a vehicle to propose a reorganization of the public health infrastructure. Political processes sat at the federal level and states had to wait for them to trickle down to their level. In order to have more control over initiatives for their constituencies, *sanitaristas* fought to decentralize the health sector and called for the state to be the main health provider (Avritzer, 2009). These strategies worked and Article 198 in the 1988 Constitution called for public health services that consisted of an integrated, regionalized, and hierarchical network and constituted a single system organized by decentralization, comprehensive care with a preventive focus, and community participation (Brazilian Constitution, 1988). The role of the community became more formalized two years later in 1990 when legislation established national health councils and conferences at the three levels of government: Brazil has one national, 27 state, and more than 5500 municipal health councils (Victora et. al., 2011).

Capital Building and Investment

During these transformations in Brazil's government, Joice went through her own personal and professional transitions. She graduated from medical school, gave birth to her first son Pedro, took the *concurso publico* (public exam)[38], re-married, received appointments to the Ministry of Health, had João, her second son, and by 1986—the same year that SUS was being proposed—she

[38] *Concurso publicos* are examinations given by the federal government to recruit and employ for the civil service. Unlike the CDC where a subject expert is utilized to review potential applicants to match prior experience with job duties, no prior experience is needed for some jobs within the public health apparatus (Graham, 1968, Geddes, 1990, Castor, 2002).

began working within the federal university system. From her training to her medical practice, Joice always attended to poorer populations throughout the state of Rio de Janeiro:

> I never worked in the private sector; I never had my own practice. You needed the resources to have an office to attend patients. I didn't have that, and I had a child, so I worked in various places. I had 3 or 4 jobs in clinics, in hospitals, in Novo Iguacu, Duque de Caxias, etc. I worked in many places. In 1980, I got into the ministry so I worked there and other locations too. In '86, I got into the university…At the university, it was public, so it was always poor people who [sought care]. The clinics I worked at were within poor populations. I never had any contact with the rich population.

The transitions within the healthcare system helped facilitate the development of Joice's career and her becoming a different kind of physician.

> That shift from private clinics and health insurance to the government was really good for me because I took a long time to take on an identity as a doctor. During that period, I was a doctor but I wasn't happy. I worked at the hospitals with poor people, but it didn't make me happy. I did the work I had to do. It was my profession. But when I began to work in the ministry, I began to change and saw that I could perform better…when I went to the ministry [in 1980], we were still in a transition to a democracy. It still wasn't a democracy.

In 1980, Joice was at the beginning of her career with the Ministry of Health, as a practicing physician. She began work on SCD with the Rio de Janeiro state government in 2000, and her policy work on the Federal level started in 2004. During this slow evolution in her career, she attended to patients in first-aid posts as a pediatrician, her specialty, but she always had an interest in public policy. She took courses as she could on public health and in 1983 was asked by the government of Leonel Brizola, to be the health secretary of São João de Meriti—a small but dense city approximately 30 kilometers away from Rio de

Janeiro. Brizola, considered a leftist, founded the Democratic Labor Party (*Partido Democrático Trabalhista* or PDT) in 1979. Using the platform he dubbed *Socialismo Moreno* (Mixed-race Socialism), as governor he sent two Afro-Brazilians to the national congress and in addition to Joice's appointment he appointed blacks to head the state secretariats of social affairs, labor and housing, and the military police (Andrews, 1991). Joice, who self-identified as a member of the worker's party, as well as an activist in the women's movement (but not the Black Movement) was eager to serve, but due to political pressure and patronage practices left the post in a short amount of time. Catching the attention of Dr. Nildo Aguiar, a renowned *sanitarista*, who was familiar with her work, she was recruited to work full-time in the regional office of INAMPS for the state of Rio de Janeiro in 1984. Despite the reluctance of the then-authoritarian regime, Dr. Aguiar directed the first universal care program in the state of Rio de Janeiro (http://smsdc-cfnildoaguiar.blogspot.com.br/p/quem-somos.html). Under his mentorship, Joice became more committed to universal healthcare and earned a masters degree in Collective Health. In 1988, she participated in the formal implementation of SUS for Rio de Janeiro. Working throughout Rio to help create the new infrastructure for the health system, over the next decade, she worked with the Health Education program, maternal mortality program, and the family health program. It was in the family health program that her interest in SCD became solidified.

> It was a political moment. I worked in the secretariat with public policy in the family health program. I also worked in the department of collective health in the state secretariat of Rio de Janeiro. I was part of the ministry, but I was able to work here in Rio. In SUS, you can work in city or state

> departments. I worked where all the public policies happen. And there, there was a woman, her name was Ulca, who worked with us and had sickle cell disease. And she would say that a sickle cell disease program should be implemented.

Prior to this, Joice had interactions with the SCD patient population as a physician, but was not yet aware of the policy concerns surrounding the disease. She also had personal connections to SCD. A woman who worked in Joice's house when her children were young had a son who had SCD and received treatment at the Federal University of Rio de Janeiro where Joice worked. One of her step-sisters had a daughter who died and the autopsy revealed that she had SCD. The fact that Joice's step-sister (with whom she was not close) was a carrier of the trait did not seem a significant motivating force for her future work in SCD, but by 1999 her interest was piqued enough for her to start gathering information about the disorder. By this time, race and racialized policies were being promoted within the administration of President Fernando Henrique Cardoso.

Race Gets a Promotion

Sickle cell disease received rapid and growing attention after President Cardoso came into power at the federal level, though at the local level SCD had been taken up by a group of black women who felt that health could not be ignored as part of theur human rights years before (Fry,2005, Macedo, 2006, Barbosa, 2012). In 2001 Edna Roland, member of the Black Movement, scholar and director of *Fala Preta* (an organization that focuses on black women's health issues), discussed in an interview with the Brazilian journal *RedeSaúde*, the work

done by the women's movement and the link between women's health and SCD: "I think we managed to popularize the term "sickle cell" inside the Black Movement. This is an improvement, if you think that a decade ago the Black Movement spoke nothing about health" (Roland, 2001). With the work of her and other women, the federal government eventually recognized SCD.

Cardoso's administration quickly set up a *Grupo Interministerial para Valorização da População Negra* (Interministerial Group for the Valorization of the Black Population) or GTI (Grupo Interministerial para Valorização da População Negra, 1998), announcing it on Black Consciousness Day, November 20, 1995. The GTI Health subgroup met in April 1996 with the participation of scientists, civil society activists, doctors and technicians from the Ministry of Health (Grupo Interministerial para Valorização da População Negra, 1998, Roland, 2001). A few months later a *Programa Nacional de Direitos Humanos* (National Human Right Program) or PNDH was created to support the actions of the GTI which included not only health concerns, but burgeoning affirmative action directives. With Presidential backing, the PNDH proposed strong measures to curb racism (Macedo, 2006, Lima, 2010). The GTI promoted what would eventually become the *Programa de Anemia Falciforme* (Sickle Cell Program) or PAF. Though recognized by the federal administration, PAF did not get picked up as a national program at this time, but is implemented on the state level in São Paulo. Because SCD is packaged as a "black disease" it did get parceled with other disorders (infant and maternal mortality, violent deaths, sexually-transmitted diseases and HIV/AIDS, tuberculosis, Hansen's disease (leprosy), cervical cancer, breast cancer, and mental health issues) as the rise in

attention for *saúde da população negra* continued to grow on the federal level. The 2001 World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance in Durban, South Africa is considered a pivotal moment for Cardoso's agenda on race. Brazil ratified the "Durban Declaration" which stated the recognition of the need to adopt special measures for the victims of racism, racial discrimination, xenophobia and related intolerance. The areas of education, health, and work were listed as priority areas of development (Macedo, 2006, Lima, 2010, Barbosa, 2012). In 2001, the Ministry of Health (MOH) published a "Manual of Diseases Most Important, for Ethnic Reasons, to the Brazilian Population of African Descent" and "National Health Policy of the Black Population: A Question of Equity." Maria Inês da Silva Barbosa wrote the "Manual of Diseases" and although SCD was included, it was not yet taken up as official policy (Macedo, 2006, Barbosa, 2012). With the creation of the *Secretaria Especial de Políticas para a Promoção da Igualdade Racial* (Special Secretariat for Policies to Promote Racial Equality) or SEPPIR in 2003 under Lula's administration, however, a series of events took place that led to health policy for the black population being created on a national level. This policy was approved in 2006 and an action plan to implement the policy was initiated in 2008, the policy was formally publicized on May 14, 2009 in the *Diário Oficial da União*—the Brazilian official press that serves to publicize new laws and normative orders. Nevertheless, implementation has remained scattered amongst state and municipal governments (Aragão de Jesus, 2011, Barbosa, 2012, Pagano, 2012).

Growing Pains

Before the federal policy was approved and before Joice arrived to help implement the policy, her interest started on the state level and was aided by political processes put into place by Benedita da Silva, the first female senator in Brazil (1994-1998) and later first Afro-Brazilian and female governor of Rio de Janeiro (2002-2003). In 1998, Benedita helped establish a law that would institute a monitoring and preventive genetic counseling program for those living with sickle cell trait and disease. The law provided free medication, genetic counseling, prenatal programming, and full medical care for anyone with SCD or sickle cell trait. In addition the law called for the development of a surveillance system to monitor and control cases of disease and trait and aimed to increase awareness within the state to medical providers as well as develop research initiatives and public health campaigns targeted to "communities of black origin" (http://gov-rj.jusbrasil.com.br/legislacao/143734/lei-3161-98). Spurred by a law already put in place and encouraging colleagues, she started an information-gathering mission: "I started talking and looking for information as I knew it was a right. I began to get interested and asked around and tried to inform myself. I was surprised with the estimates on the disease; I didn't know any of that. I knew sickle cell disease existed, but I didn't have any idea of the magnitude." She approached her then-supervisor Dr. Carlos Eduardo Aguilera Campos and suggested they meet with the Black Movement, but he jokingly called it "her problem" and dismissed the idea. She described Carlos to me as white in her discussion about this time and presumed he was attaching her blackness to the problem, subsequently allowing his whiteness to not be involved. She reached

out to the network of people she knew worked in the Secretary of State's office—health-related and otherwise—but no one seemed interested in sickle cell disease: "I went looking and asking how to do this program and nobody wanted to touch it. One day I was really nervous because I couldn't find one person, one professional that had the capacity to take this on." She continued to work on other initiatives within the Secretary of Health, but continued making inquiries to Carlos and others. In a state of frustration, she sat down with him one last time to report that she could not locate any officials to work on sickle cell health policy.

> I told him I wasn't finding anyone. He looked at me and said, 'Joice, stop with that. Don't you realize you're the one that's going to have to do this?' And I said, me? How? He said, 'there isn't anyone interested, and no one would stop to do this, this is yours'. And he left. And I thought, *oh my God*. I was anxious for days.

Afterwards, she sought advice from her ex-husband who provided her with enough encouragement to move her from the position of finding someone to initiate a program, to becoming the person to do it. In addition to speaking with more people, she approached members of the Rio based sickle cell association, the first being Gilberto dos Santos, a senior level member in AFARJ (*Associação dos Falcêmicos e Talassêmicos do Rio de Janeiro*). Weary and distrustful of government officials, he rebuffed her. She reached out to Dr. Heloisa Helena Arantes Gallo, a hematologist who worked at *HemoRio*, the state-based blood bank and hematological hospital where SCD patients received most of their care, and who had a relationship with people living with SCD who sought care there. Having a long history with the community, Gallo penned early articles about a

therapeutic approach to SCD and translated NIH-authored guidelines for medical providers. She asked for advice and daunted, but determined went back to Gilberto.

> I said you guys need to talk with me so I can understand the disease. I don't have any experience with people with sickle cell disease. I am a general pediatrician. I need you guys to tell me what that is like. I need to hear from you. It was a bit difficult because they didn't want to, they didn't like me; they wanted Heloisa [Gallo]. There was some resistance. They weren't into me, thinking that I had some personal interest... [but] I started thinking, working, bringing people together, looking for who had sickle cell disease, listening to them, calling them to ask what it was like, how they were doing, where they were going, all that information I organized.

In parallel to this, Clarice Lobo, the then-director of *HemoRio*, was attempting to implement a state-wide newborn screening program for SCD and their interests collided. With the help of Clarice and others she solidified the plan in 2000. Perhaps due to her novelty (she had no long history with hematology, the SCD Movement, or the Black Movement), she was turned away, particularly from those working on the ground for black and black health rights. The frustration the Rio-based SCD Movement had with Joice was mutual. She met with both these Movements in Brasilía at a meeting promoted by the Palmares Foundation: "I went and when I got there, it was the Black Movement debating, without any idea about what to do," she told me with exasperation. Throughout my time with Joice, she often expressed moments of disdain and annoyance with the Black (Health) Movement. When I asked about how well she worked with staff from the larger umbrella section of Health for the Black Population and how the SCD program was integrated into the larger concerns of the department, her

responses alluded to a lack of coordination and ignorance on their part—likely due to the membership of the Black Health Movement having little to no actual public health experience. Even the head of the technical committee for the MOH appointed to lead the program for the Health of the Black Population was an anthropologist who worked in the campaigns for rights for *quilombos* in the south of Brazil. The 1996 creation of the *Programa de Anemia Falciforme* (PAF) was another example of this for her. As mentioned above, the PAF was successfully created as a result of the efforts of the Black Health Movement, but lacked budgetary support and any plans for implementation. When Joice arrived at the meeting to discuss SCD with the Movement, she read the report in which the PAF described proposed activities "whose main objective is to promote and implement actions to improve the quality of life of people with sickle cell disease and disseminate information about the disease" (Guimarães, 2010) and noted that the program would be unsuccessful if not implemented by SUS. Frustrations grew between Joice and the Movement. She insisted on the need for a public health apparatus, but because Movement activists were unaware of what such an infrastructure could and could not do, the representatives of the Movement were not interested: "What they wanted couldn't be because the SUS has norms, and the norms of the system facilitated everything. The movement doesn't have any idea of the SUS structure."

Joice returned from that meeting holding the Movement in even less regard, but still determined to create a program for Rio de Janeiro state in what she thought was the right way. She reached out to her powerful network, contacting the then-Secretary of Health, Dr. Gilson Cantarino, whom she had

worked with in the family health program, and his advisor Dulce Scheverini. In addition, she consulted Dr. Roberto Chabo, an iconic leader of the physician union movement. Everyone advised her about the same thing: "…you have to do it in a way where it doesn't depend on being passed by parliament. You won't be able to make changes if it goes through parliament. You have to structure it to where it happens within the secretariat without going through other powers. I learned, heard and did this."

She was also advised not to attempt to create a division or coordination body and instead to consider the development of a working group, but a working group carefully named as the naming of this group could cause great delays from community members or "the group of militants."[39] In early 2001, a resolution was passed to create a working group for the control of SCD (Resolução SES nº 1588). In 2004, the Brazilian Ministry of Health, along with the country's Special Secretariat for the Promotion of Racial Equality (SEPPIR) and PAHO, signed a declaration expressing their intent to develop *saúde da população negra*, or the black population's health, as a special area within the Brazilian public health system (SUS). Joice was appointed to lead the activities for SCD under the umbrella of this interest and left Rio de Janeiro for Brasilía that year.

Bicultural Competency

Though Joice expressed frustration with the SCD Movement time and again, she served as an intermediary between them and the government once political actions started to take shape. She understood that the marginalized

[39] description of militant in Brazilian sense and references

group was not used to interacting with the government for their benefit and were distrustful. U.S.-based sociologist Ruha Benjamin[40] asks, "How, if at all, do people's experiences of everyday policing relate to their trust of other social institutions?" (Benjamin, 2013: 136). Benjamin's study on patients living with SCD and their interactions with the clinical research and medical system, based in the United States, provides examples that are both similar to and divergent from the Brazilian case. In *People's Science: Bodies and Rights on the Stem Cell Frontier*, an interviewee explains differential expectations between Asian-Americans with Thalassemia and African-Americans with SCD suggesting that African-Americans believe they have no control over their course of disease and in tandem, do not trust the medicine or science, in contrast to Asian-Americans. While African-Americans and Afro-Brazilians share many societal experiences[41] "in which racism, both at the institutional level and at the interpersonal level, is ever-present" (Dressler and Bindon, 2000), the insertion of *controle social* or social control in the development and maintenance of federal policy has provided a tool for Afro-Brazilians to feel more in control than their African-American counterparts. Not to be confused with Foucault's idea of social control[42] as described in his many works about the penal system, sexuality, governmentality, and bio-power, the Brazilian term was produced as a result of the tension between a citizenry (as expressed via social movements) distrustful of an

[40] see Benjamin's People Science Chapter 5 for a thorough investigation of distrust for Af-Ams wthin the medical system in her California based study ….
[41] See Harburg's socioeconomic stress model, Dressler 2000, status incongruence model
[42] deeper description of Foucault's contribution to the idea of social control especially as its been discussed for medicalization and knowledge production. Link these contributions to how the inclusion of "society" as part of health reform creates new forms of knowledge production that must be considered by the State.

authoritarian and inaccessible regime and the motives of health reformers bent on addressing Brazil's inequalities (Cornwall, 2008, Fleury, 2011, Foucault, 1963 1965, 1977). Joice stood between the state and its citizens for the development and maintenance of SCD policy and understood that her experience with the public health apparatus as well as her blackness aided and abetted the process.

> The important thing was that a relationship with people with sickle cell disease [in AFARJ] was being built with respect and trust…they didn't have a reason to trust…because they were abandoned. There was no program…there was nobody responsible, so they were really tense. They would fight with people and managers [from institutions] and then I came along. When we started to think that it would be a law and that it would be a program, you have to shift the perspective. We needed change and they didn't agree. I understood this because if the society isn't heard, if people with sickle cell disease aren't heard, and there isn't any listening, you aren't going to have a harmonious situation between patients and management. The situation was difficult. Everyone fought. I had an easier time because I was more connected to social movements. I began to live with those people. Meet with them, listen, find out what it was like. I started hearing what everyone was saying and it was a lot of complaints, a lot of suffering, hours of complaining, and I heard a lot. One day I said let's not complain anymore. Lets get to work.

Rather than discussing Joice's role in the political process of getting SCD recognized by the federal public health apparatus in more detail, I would like to take some time to talk about the psychological processes, social experiences, and individual challenges that allowed her to be the person who was able to get SCD recognized.[43] Joice is able to inhabit two distinct cultures within a communal and institutional space while performing a non-linguistic code switching. Here I

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[43] A rich body of literature has covered the promise and perils of the National Comprehensive Policy for the Health of the Black Population and it is not my intent to recreate the entire nuance here. I have provided a brief timeline in this chapter as it relates to SCD, but for more detail see Oliveira (2001), Lopes and Kalckmann (2005), Macedo (2006), Monterio et.al. (2005), Maio and Monteiro (2005), Monteiro and Maio (2008), Cruz (2010), Pagano (2011), Pagano (2014), Teixeira and de Araújo (2014).

define communal as the informal realm inhabited by the SCD Movement, but specific to persons with SCD with African ancestry and institutional as more formal space occupied by state actors within the public health apparatus on the national, state, and municipal level. Code switching, as defined by Heller (1988) is "the use of one or more language in the course of a single communicative episode" (1). Linguistically, this could take the form of a bilingual child speaking in his parent's native tongue at the kitchen table in one instance while responding to a visiting friend in another language completely. Code switching could also be portrayed by a person speaking the same language, but without an accent at work and with one at home. Taken out of the context of language, I define non-linguistic code switching as the ability to shift from one distinct milieu to another, speaking in diverse cultural languages instead. In order to accomplish this, Joice possesses bicultural competence (LaFromboise et. al., 1993) that allows her to "maintain a positive relationship with both cultures without having to choose between them" (399). Joice's ability to communicate appropriate cultural languages to both groups bridges the needs of each. She uses social capital, cultural capital, and racial fluidity to navigate the mostly white world of public health management in order to successfully advocate for sickle cell-related resources, health promotion, pharmaceuticals, and subsidization of travel to ensure the participation of people living with SCD in related events, while still working closely with the predominately Afro-Brazilian advocacy community in order to get them to express their needs. These distinct but interrelated constructs that are read in multiple ways are guided by Joice's understanding of self, as well as her insights about how different groups perceive her.

Many scholars have provided rich commentary on the topics mentioned above. My goal is to briefly frame Joice's life experiences using these tools to explain why she has been pivotal to the development of SCD policy in Rio de Janeiro and throughout Brazil. As per LaFromboise (1993): "there are a number of individual characteristics that may be considered significant in the development of bicultural competence. These include personal and cultural identity, age and life stage, gender and gender role identification, and socioeconomic status, among others." For the purpose of this chapter, I focus on social and cultural capital, and racial fluidity as the key factors of Joice's bicultural navigation. These three, interwoven in their own right, encapsulate many of the variables mentioned by LaFromboise, but still deserve distinct attention in how they influence Joice's position within various networks. The placement of Joice within the public health system during the timing of administrations willing to pay attention to race-based health policies positions her to be one of a key state-distributor of services. Her commitment to restorative justice is based on her public acknowledgement of the legacy of slavery, facilitated by her expert navigation of neoliberal health reform. Her communal and institutional identities balance to serve a largely Afro-Brazilian constituency in the wake of societal and institutional neglect.

Lovell and Wood (1998) studied the life course of Brazilians of African decent across the life span (childhood mortality, attaining an education, entering the labor market, wage discrimination) and found that color-based disparities start early and continue until one dies. The variable social capital within this population is a cause for these disparities. Joice throughout her lifetime has

maneuvered through various levels of social capital. Her childhood demonstrates mobility from lower to middle class and an adulthood that brings her into higher-class status. This transition occurs partly due to intentional life choices made by her father for both himself and for her. It is also facilitated by skin color. There have been many definitions of social capital since the term was made popular by Bourdieu (references). The definitions by Hunter (2002) and Lin (2000), are especially useful in helping to explain how Joice is able to operate as she does. Hunter situates social capital through the lens of skin color stratification while Lin provides his definition in context with inequality. For Hunter, social capital is "a form of prestige related to things such as social status, reputation, and social networks" and is linked to light-skinned privilege. Lin's, more nuanced definition is conceptualized as follows: 1.Quantity and/or quality of resources that an (individual, group, or community) actor can access or use through 2. Its location in a social network. (786). As noted by Lin and others, not all individuals acquire social capital in the same way. The inequality seen across individual and groups can be linked to differential socioeconomic positions. Just as citizenship can be considered differentiated as per Holston (2011), so too is the notion of social capital. If high correlates of social capital include education, health, confidence in political institutions, and satisfaction with government and political engagement, then Joice and members of the SCD Movement are at extremes on the continuum (Garson, 2006).

Putnam (1995) as parsed by Minkoff (1997) suggests a link between collective identity seen in social movements and social capital in his statement that "a grassroots political movement…is a social capital-intensive form of

political participation" (611). High levels of social capital are required for political effectiveness. In the case of the SCD Movement, a movement that constitutes individuals who decry their neglect and attribute that neglect to racism, discrimination, and lack of access to social capital, Joice's presence (wanted or not) offsets the group's low level of social capital with her abundance. Here we are placed at the juncture of Joice's "double-consciousness" (DuBois, 1903) and the SCD Movement's "matrix of domination" (Collins, 1990). Joice's bicultural nature (her internalization of two cultures) must be framed in the context of double-consciousness to help describe how her blackness is put at odds with an oppressive society led by a white dominant group. It is important to note, however, that Joice is distinct from the character DuBois described in the following quote: "One ever feels his twoness, an American, a Negro; two souls, two thoughts, two unreconciled strivings; two warring ideals in one dark body, whose dogged strength alone keeps it from being torn asunder" (DuBois, 1903: 45). Of course, we must transpose the context from a U.S. setting to Brazil-which has a number of implications. We move from a situational duality of the American and Negro to a Brazilian trinity. I asked my research participants to answer an open-ended question: *Qual é a sua raça/cor?* or what is your race or color? While almost all of my respondents answered with only one response, Joice was the only one to respond with two: "*raça = negra cor = parda"* (race = black color = brown). In this response she demonstrates a keen understanding of self and of politics. She recognizes her color as how she is seen in Brazilian society (*parda*/brown), which calls to question another distinction from DuBois' quote. The warring ideals are not two, but three, and occur in a brown or *light*

body. Further, her recognition of her blackness is a politically charged one reflected in her decision to collapse her brownness into blackness per the instructions of the Black Movement (see Chapter Two, page 53). Joice may very well understand how her light skin affords her the social capital that many who inhabit a dark skin deem inaccessible.

Although I spoke with persons living with SCD of all hues, the visual representation of SCD by the State and other entities in Brazil is primarily that of a dark-skinned black body (Fry, 2005). In the last four years, the state-sponsored national symposium's logo consisted of a woman's head, distinctly adorned with African garb or accessories and shaded jet-black. In the last three years, the continent of Africa was associated with the logo (see image compilation below).

As discussed in the last chapter, dark skin is often associated with Africa for some Brazilians. The presence of this darkness for some Brazilians contributes to Collins' matrix of domination. In her study on the issues and strategies of

advocacy groups who serve racial minorities, low socioeconomic populations, and women, Strolovitch (2007) notes that advocacy groups can be disenfranchised along several axes:"…they might lack financial resources; they might now be or have been in the past the objects of de jure facto discrimination; they might lack electoral power and therefore have no or few elected representatives; or they might lack 'cultural capital' because they a socially stigmatized by the broader society or dominant culture" (24). Though Joice acknowledges both her blackness and brownness, it is her cultural whiteness that accommodates for her ability to navigate the institutional spaces of policy development. Twine (1998) found that white middle-class Brazilians tended to identify both light- and dark-skinned Brazilians of African descent as black (*pretos*). Despite this, Joice capitalizes on the cultural markers of whiteness (high education, high-skilled employment, high income) that allow for learned savvy in institutional spaces, while also allowing her white counterparts in the public health system to have distance between themselves and a black cause associated with Black Movement members. The cultural capital earned here, as well as the cultural capital she holds as a member of the black community, allows her to navigate effectively, with precision and finesse, between communal and institutional spaces.

Thomas Abel (2008), a medical sociologist who studies cultural capital and the production of health, uses the definition of cultural capital as: "people's symbolic and informational resources for action. Those resources (values, behavioral norms, and knowledge) are acquired mostly through social learning, with learning conditions varying across the social classes, status groups or milieus…Cultural capital refers to the operational skills, linguistic styles, values

and norms that one accrues through education and life- long socialization. It comprises people's social abilities and competence for action, including their perceptions, values, norms, cognitive and operational skills" (1,2). Joice's high level of social capital can be attributed to her acquirement and sustainment of cultural capital, especially as a government official who has a long history of working within governmental constraints. Her frustration with the SCD Movement and its lack of effectiveness is based on their lack of cultural capital—as framed by the government. That is not to say that the SCD Movement has no cultural capital of its own. The capital valued for the development of policies and programs is owned by the State. However, the mechanism of social control forces the State to maneuver within the less formal boundaries drawn by the mostly Afro-Brazilian SCD Movement. Abel continues, "sharing similar values, knowing how to approach other members properly, the ability to use appropriate language and communication styles are examples of non-material conditions and cultural techniques required for people to enter those networks" (3). Both sides, in effect, need Joice. The government relies on Joice's cultural capital to interact with the SCD Movement and the Movement needs Joice's social capital to effectively move policies and programs forward within the public health system. Joice sits in the middle as an intermediary who translates both of these cultural languages.

Cultural capital is expressed through collective lifestyles and can exist in three forms: embodied, objectified, and institutional (Bourdieu, 1986). While Joice's long career within the public health apparatus—nearly 30 years—allowed her to learn the cultural ways of the State and with it the ways of dominant

Brazilian society, the "hereditary transmission" (49) of embodiment received from her African ancestors contributes greatly to her life experiences and accumulated cultural capital from within the SCD Movement communal space. Her acknowledgement of her African ancestry, her participation in *Candomblé*—a religion strongly influenced by African culture, and material artifacts showcased in her house that signify links to Afro-Brazilian culture represent both the embodiment and objectification of cultural capital from this space. Though she is situated in both spaces, tension is still present as she navigates between the public health apparatus and the SCD Movement to create policy for SCD. This is evident in her conflict in convincing members from within the SCD Movement to move away from the event based model of disjointed program implementation, to a centralized implementation plan that involved integration into SUS.

> …anytime there was a racial event, they would collect blood samples from people to see if there were people with the trait and the disease. They did that before the program. After the program, I said we aren't going to do that anymore. We are going to work towards everyone being able to go to a health post and there they can give a sample and get a result. If there was a party or conference on sickle cell, they wanted to collect. So in the beginning, they didn't like it. Afterwards I said look we will either need to make it a law and place it in the health system or we continue doing the same thing, bringing it to congresses and events.

Joice's confidence in political institutions is a marker for high levels of social capital, but the unequal distribution of that capital in the realm of the SCD Movement contributed to their lack of trust in the State. Though results from a number of studies have shown that participation in cultural activities is associated with lower mortality risk and perceived health (Bygren et. al., 1996, Glass, et. al., 1999, Franzini and Fernandez-Esquer , 2004, Abel, 2008, Hansen

et. al., 2015,), the profile of these health concerns was not genetic. That notwithstanding, cultural capital takes shape in the form of health values, knowledge, and behavior for groups to develop healthy lifestyles and while the SCD Movement was resistant to what seemed like an untrustworthy process to attain these items, it is now an unquestioned norm. The current state of SCD as parsed through the State reflects a balance between institutional and communal space. Joice's eventual acceptance by the SCD Movement allowed for a state representative to fulfill the sanctions of a relatively new reformed health system for a reluctant community, while also allowing that community a say in how policy is created and maintained.

An Unstable Seat at the Table

The new health system called for integration between the State and society. It recognized the social rights of its citizenry and called for co-management of multi-leveled (municipal, state, and federal) government and society, which would provide social control via mechanisms for negotiation and consensus building. Although Joice had been embedded in health reform practices and believed in the good that SUS could do, her inside access and connection to high-level reformers facilitated a trust that many citizens did not possess, not especially those who felt the most abandoned and marginalized. The operationalization of citizen participation, as mentioned above, took place in health councils (*Conselhos de Saúde*) and periodic health conferences (*conferências)*, which took place at every level of government (Cornwall, 2008, Fleury, 2011,Victora, 2011). There is growing literature on the effectiveness of

these councils (Labra, 2002, Cohelo, 2004, Wendhausen, 2006, Júnior and Sampaio, 2008, Batagello et. al., 2011). Given the long history of complex patronage-based bureaucracy, in addition to vast health and social inequalities, it is of no surprise that there have been challenges in the capability of these citizen-engaged councils. Cornwall (2008) and others have outlined three complexities that inhibit council performance: 1) The lack of accountability that the state with its complicated web of processes and personnel has to designated councils; 2) The legitimacy of a truly heterogeneous makeup of council members that accurately represent the interests at hand; 3) The imbalance of social capital (knowledge and power) between members of the community and public health administrators (Labra and Figueiredo, 2002, Cohelo, 2004, Labra et. al., 2005, Arviter, 2009). This "residual bureaucratic arrogance" and presumption on the part of health workers that civil society was in fact, *incivil* (uncivil) is evident in these challenges (Cornwall, 2008: 2182). I saw examples of this time and again both displayed directly to constituents with physical eye rolls and other disparaging body language as well as more indirectly through minor bureaucratic decisions. In Brasilía, during the 2nd National Exhibition of Experiences in Strategic and Participative Management in SUS, I witnessed conference room delegation where three days worth of meetings about the implementational progress of the National Comprehensive Health Policy of the Black Population (NHPBP) was held in a small auditorium instead of integrated into the general program and discussed in the large main plenary room.

The NHPBP was approved by a participatory National Health Council in 2006, and became official on May 13, 2009 as a *portaria*. A *portaria* carries the

force of a law in some cases, but is issued by a Minister of State (in this case, the Health Minister) rather than decreed by the President or legislated by Congress (Pagano, 2009). The text of the policy starts with general principles:

> … This policy is grounded in constitutional principles of citizenship and human dignity, the rejection of racism, and equality. It is also consistent with the fundamental objective of the Federative Republic of Brazil "to promote the good of all, without prejudice as to origin, race, sex, color, age and any other forms of discrimination"… To these come the joining of popular participation and social control, key tools for the formulation, implementation, evaluation and possible redirection of public health policies. These are developments of the principle of "community participation" and main object of Law 8,142 of December 28, 1990, which established the conferences and health advice as collegiate management bodies SUS, with community participation guarantee.

As Pagano (2011) explains, "The Policy thus establishes equity, or compensatory justice, as a necessary pre-condition for the fulfillment of equality" (100). Further, though this policy was created nearly a decade after the mandate of community participation, it was in alignment with the social policy project which was SUS. The linkage of SCD via this policy implemented by a socialist health system during the time of a socially minded administration, allowed Joice to attach herself the messaging of SCD policy as a spokesperson: The Brazilian state owes its Afro-Brazilian citizens the policies and programs for SCD due to the legacy of slavery and origin of SCD. If it were not for Brazil's participation in this institution, the disease would not be the public health problem that it is today.

A Social and Political Convergence

At the beginning of this chapter, I placed Joice at the center of this story, and there she remains. Her central position can be seen even more clearly once

we zoom out and see how she connects two entities on opposing sides: the State and the SCD Movement. Over the years Joice has coached these unwilling dance partners to perform in tandem and work together. From the time of her initial interest in SCD in 1998 to her retirement in 2014, she has transformed how people think about SCD and how workers within SUS and the SCD Movement work together. It is still not a perfect scenario. In our time together, Joice expressed deep levels of frustration about both sides. The sources of her angst have changed over the past 12 years, but have never subsided for new problems constantly emerge. Her dedication to *controle social* has meant a dedication to people living with SCD, as well as one to the governmental processes that in theory make the concept work. As a result, people in both the public health apparatus and the Movement hold her in high regard. Consider the following narratives.

Luana, living with sickle cell and part of the SCD Movement in Brasilía told me,

> Joice is someone that gives me courage. When she called me to participate on the board of directors [for ABRDFAL] and said she was happy I was there, I saw that she also has a mission for sickle cell disease too. I don't know why my role is so big at ABRDFAL, but I think it gives me more courage to face life.

Margareth, member of the *Assessoramento Técnico em Doença Falciforme* (ATDF) or Technical Assistance in Sickle Cell Disease team lead by Joice within the Ministry of Health said,

> I know that it [NHPBP] was a policy created with a lot of effort and vigor from Dr Joice. It had to be a policy that was installed in more or less an imposing way. You couldn't open it up for much conversation within the ministry because the policy would then otherwise not happen. So I think it

> was a policy created with a lot of gusto. It took Dr Joice's will to make it happen and take care of people she saw needed it and that asked for it. And if it wasn't for her enthusiasm, for Joice's strength, I don't think the policy would exist in the ministry. And I know that we need to organize the policies inside the states and the municipalities and make the policy happen. To make it known and recognized within the ministry itself so that from here, there is an effort to have it recognized externally.

Danila, who did not work with Joice directly in the Ministry of Health, but in parallel with her as member of a wider hemoglobinoathies team in the Pan American Health Organization (PAHO) relayed in an interview,

> I deeply respect Joice's work. I think she is doing work that managed to give another dimension of sickle cell within the SUS. Different from hemophilia work, she brought a social control with a lot of strength inside the ministry, for the development and perception of that policy. This was the big difference in understanding how to craft a strong articulation in order to implement a policy... she is the motor of the program at the ministry

Each of these narratives provides a different perspective on Joice and the programmatic work she represents, but they are woven with the same threads of high regard and respect. And though reflexivity prompts us to think about the construction of each of these narratives—I represented a U.S.-based researcher who would tell the story of SCD in Brazil, after all—Joice's transition from an untrusted governmental official who early on, left interactions with the SCD community defeated, to a beloved champion of rights for those with SCD seems evident. This same reflexivity allows me to contemplate not just the performance of all these particular actors, but of Joice as well. In the wake of our interviews, I would immediately journal the moods, the interruptions, and intonation of our interactions—matching these with her voice and the written text of interview transcripts during analysis. It was during these times, back in the U.S., that I

would later note the casualness in which she would mention names of people along her experiential path to becoming "the motor." Secretaries of health, icons in the health reform & physician rights' movement were never discussed at length; their importance not just to her but to larger efforts were never mentioned. I wondered if this was explained, in part, by performativity on her part—a downplaying of others in order to focus more on herself. I came to the conclusion that the she downplays her role in the elevation of attention for SCD for the same reason she downplayed these important interlocutors. To Joice, if programs were sustainable only in connection to certain people, there would be no sustainable programs, for personnel change is inevitable. For her, it is the momentum, behavior change, and tangible activities that are important. While there is truth in these beliefs, as this chapter has elucidated, people do indeed matter. Leading up to her retirement, her colleagues within SUS and many members of the SCD Movement across the country anguished over who would replace her. Would she or he care as much about the population? Would he or she be as effective in conveying the needs of the population to their counterparts within SUS? Would they take the time and patience to sit and learn from a majority Afro-Brazilian population as Joice did when she first came to the work? Would, or could, her replacement recognize and respect the significance of racism? If she left, would the SCD program evaporate without her leadership? These fears were allayed when Cândida Maria Quiroz was appointed to replace Joice. Embedded in the public health system on the municipal level in Salvador, Bahia and mother of a child with SCD, both she and her husband were key in the transformation of promotion of SCD for the city. Perhaps coincidentally, she too

is of light complexion, so light that she might pass for white in some areas of the United States. Despite this, when I met her and asked her why she felt the work of SCD was important and why she did it, she told me "Eu sou negra!" (I am black). It will be interesting to observe over time if Cândida has enough social and cultural capital to be as effective as Joice, , if not more—especially from within the institutional and federal space of the State. While her skin color will be an asset, her regional attachment to a state considered backwards, brown, and poor, at least at first may impede her access to immediate resources and networks.

On the closing day of the last National Sickle Cell Symposium that Joice attended as national coordinator for the SCD Program in 2013, she was interviewed by a journalist and known SCD activist, president of the Paraibana Association of Carriers with Hereditary Anemia. In his last prompt, he asked her to "send a message to the directors and the social controllers, especially to the movement of men and women with sickle cell." Joice replied,

> For the managers and directors [of SUS], I would say that they need to think with more care, about the implementation of their programs. The SCD population is a population that is suffering and dying and we need to rescue, even if for the symbolism, this disease among us. The homework is done, now let's try to remove the obstacles that exist in the health care system regarding sickle cell. For the users (people with SCD), I would really like to say thank you for the trust in me, especially as a manager, for the respect that they have always had and to say that this fight is theirs, it's a fight for their own lives and that I am one of those people who truly believe that a united people will never be defeated. So this is a short message I have for all of those loving individuals who have worked these nine years in the ministry with me. This is a big thank you because if we think about it, I think I as an individual, as a citizen, have probably gained more in maturity and in citizenship in this process while working with users.

This quote encapsulates just how personal Joice's politics are. Her reference to the symbolism of SCD is a powerful one. Here she urges her fellow public health workers to align themselves with the programs and policies of SCD out of principal if nothing else. She believes that the forced migration of slaves left Brazil with an inheritance of disease and abandonment. Her choice of the word "rescue" speaks to how she views her role amongst those with SCD. Though she positions herself with those who have SCD, significant power dynamics play out in this narrative. It is the State that has the responsibility and she reminds those within SUS of this duty as written in the Constitution. Joice has made great strides, but there is obviously much more work to be done as Cândida grabs the theoretical baton. Lastly, we are reminded about how civic-minded Joice is. From the very beginning, Joice has been drawn to democracy and what it could do for all people, but especially for the marginalized: women, blacks, and the poor. For her, working with both the Movement and the government to help distribute claims based on biocultural citizenship has been both a personal and professional, as well as a social and political mission.

CHAPTER FIVE

CONCLUSION | Strategies in Belonging

> *This particular disease [SCD] is not only a disease that affects only us black people but it's a disease of the general population and a geographical disease… Since the black movement raised the [SCD] flag to work for health… it's something that we're owed. It is a disease that came with the black population that came involuntarily to our country here… I don't want to work within the idea that it's a black disease, [but] if what is black is not* bonito*, then we will never have space. If what is associated as black is playing soccer or to be a* pagodeiro *or a* mulatta *dancing in* carnaval*, we will never have spaces…I have my profile, I have my rights, I am Brazilian, my origins are African, but I am a Brazilian woman, I am a Black Brazilian woman! I have rights like everyone else to come and go and these [policies associated with SCD] are rights under the Federal Constitution.*

-Nilcea, SCD Organization President, parent of person living with SCD, self-identified as *negra*

The day before a national symposium, in a workshop organized exclusively for people living with Sickle Cell Disease (SCD), Nilcea stood impassioned – almost yelling into the microphone – about the rights for this population. When I saw her next I asked if she would talk with me before the close of the meeting. We sat in a room closed off from the bustling activities of the symposium where, so full of opinions, I asked her one opening question and she talked without pause for 38 minutes. Her initial response covered a wealth of personal-political experience and the fraught role of sickle cell policy: acknowledgement that SCD is not solely a black disease, her reticence regarding the black movement's use of the disease as a platform, her desire for legitimization beyond the cultural contribution of the black population, and the claiming of rights vis-à-vis the

disease. Nilcea's critical, reflexive reflections speak to the tensions inherent in the marshaling of biocultural citizenship. Referencing nationality, ancestry, geography, and biology, Nilcea's entangled narrative points to the complexity of the relationships my research participants have with the State, with civil societies, and with themselves. Their words and stories help us make sense of these imperfect relationships: full of misunderstandings and contradictions, yet important for the understanding of the internal and external contestations.

If we tease apart Nilcea's statement, we are alerted to the complex ways in which she relates with the State. Discourses of universality and difference coexist as she conceptualizes the provision of health care, and more broadly this tension shapes struggles both by actors in the Sickle Cell Movement and those in governmental positions. When Nilcea says, "… I have my rights, I am Brazilian…", she lets us know she is keenly aware of her rights as a citizen. In this framing, she is afforded a universal set of privileges. However, she also draws on the notion of what sets her and others like her apart from fellow citizens. When she says, "I have rights like everyone else to come and go and these [policies associated with SCD] are rights under the Federal Constitution," she echoes the views of many within the SCD Movement whom I spoke with that situate their difference in the context of universalism. The 2009 National Comprehensive Policy for Black Population Health (NPBPB) was the first piece of legislation from the Ministry of Health that officially recognized black Brazilians as a vulnerable population warranting separate consideration. In her proclamation, Nilcea shows she understands this recognition.

Furthermore, this recognition was, in many ways, structured by the process of redemocratization and the construction of the new public health system. Like many others whose work and words appear in this study, Nilcea is well informed about the historical significance of the Constitution of 1988 and the associated reformist public health system that was implemented as a result, the *Sistema Único de Saúde* (SUS) or Unified Health System. In addition, those in the SCD Movement understood the implications of this system for the SCD community when it came to social control (*controle social).* This political process embedded within the public health system, to allow community participation in the development, maintenance, and evaluation of health policy, was something that was used with intentionality both by activists and government agents. Joice Aragão de Jesus, as a member of the nation-state health apparatus, was so committed to this practice that those who collaborated with her remarked on what little exposure they had to health communities prior to working with her. I attended workshops and training modules that promoted this concept to community members and medical practitioners alike. *Controle social* meant that community members could exercise their right to engage with public policy both under the banner of their universal rights and as a differentiated, vulnerable population.

Both the SCD Movement and the state link vulnerability and blackness. However, Nilcea pushes back against limited ideas about blackness, that confine the possibilities for blackness to a few tired tropes. When Nilcea told me, “If what

is associated as black is playing soccer or to be a *pagodeiro*[44] or a *mulata*[45] dancing in *carnaval*, we will never have spaces," she refers to the cultural associations affiliated with the definition of Brazilian blackness. She also speaks to the frustration I heard from some about the value of Afro-Brazilians lying only in the spaces of sports, dance, and music. In this part of the narrative, Nilcea may recognize the cultural contributions of Afro-Brazilians, and in her mind these may warrant an acknowledgement for cultural distinction. Perhaps more importantly, the State recognized and incorporated certain aspects of cultural difference into the national fabric, but in a bounded way. As discussed in Chapter Two, cultural definitions of blackness are often used in conjunction with biological ones for many of my study participants. Biologically, Nilcea recognizes, at least for SCD, that it's a "geographic disease," one of the "general population." This also came across in interviews with study participants across region—Brazil is a country where much racial mixture has taken place, and they held it was not accurate to associate SCD exclusively with blackness. This may seem contradictory to the messaging of the Black Movement, SCD Movement, and some members of the public health apparatus. However, within this contradiction is a cognizance that SCD's association to the African continent and

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[44] *Pagodeiro* could be defined as a young black man who frequents *pagode* clubs. *Pagode* is a subset of samba music and men associated with these spaces are also sometimes associated with promiscuity, flashiness, and a dangerous lifestyle. Nilcea references the culturally acceptable version of *pagodeiro*, which is an Afro-Brazilian man who dances well and is highlighted in carnival for his dancing skills.

[45] *Mulatas* are Afro-Brazilian women who have historically been portrayed as racially mixed (and thusly lighter in phenotype). The typical *mulata* is a woman who is irresistibly attractive, musically talented, and extremely sensual. See Gilliam and Gilliam, 1998, 1999, Pravaz, 2003, and Caldwell, 2007 for more. High dancing skills are associated with one of the key characters of carnival—the beautiful and scantily clad dancers seen throughout the internationally televised carnival parade that takes place every year in Brazil.

subsequent diasporic movement to Brazil demands a sub-set of the population to be recognized and provided with resources from the State to address its presence.

The preceding chapters explore the practices of actors on the individual, organizational, and State level. I argued that despite the potentially problematic typological thought that historically was used to restrict inclusion, the Brazilian state in contemporary times uses racial classification to open up routes of access to resources and citizenship—specifically to its Afro-Brazilian citizens. Brazilians in this study draw on their African heritage (vis-à-vis SCD) to further enhance or legitimize their blackness in claims for health rights. This deep entanglement of biology and culture as shown through Brazilian actors who attempt to gain access to fuller citizenship is what I call biocultural citizenship. It is a flexible mode of enacting belonging that varies depending on skin color, social class, and other identifiers. I have shown the many iterations of biocultural citizenship enacted across the phenotypic continuum. Narrators with different skin color, from different regions across Brazil, and with different social class status, illustrate the myriad ways in which claims are being understood for individuals with a sickle allele.

If we turn to the visual representation biocultural citizenship via my model, it is seen as divided into equal parts; every piece is distinct and has the potential to interact with any other pieces within the model. Imagine pushing a pin in the center and moving the parts around the circle to understand the relationality of the model. Further, though I have highlighted a number of biological, cultural, and societal factors that I thought were most important for this Brazilian study, I recognize that there are many potential identifiers that

people living with sickle cell disease or trait can draw from. The ones represented in my model rose to the top as having the most significance for my actors.

The concept of bounded justice explains the futility of the distribution of health-based rights once they impinged upon by societal forces. There are two sides working in conjunction to produce this notion of bounded justice. On one side is a marginalized population who draw upon both the sickle gene and African heritage to make competing claims upon the State via biocultural citizenship and on the other is the State, which helps, distribute programs, education, and pharmaceuticals. This relationship is being facilitated by the political processes of a relatively new democracy determined to help give power to the historically powerless. In theory, these health reparations seek "to nurture the group's self-empowerment, and thus aid in the nation's social and cultural transformation" (Brooks, 2013:269). In reality, the unequal and ineffective practices of the government in conjunction with the lack of experience and exposure that Afro-Brazilian citizens have in handling political power contributes to the bounded quality of the justice they are offered.

This concept encapsulates the tension that I heard from those in the Black Health movement who felt as if though SCD had received its fair share of attention and it was now time to focus on other issues related to black health: most remarkably concerns around violent deaths. In this declaration, members of the Black Health Movement understand violence as a social determinant of health and a real concern for the Afro-Brazilian population. Violence, in addition to a cadre of other societal forces such as discrimination, lack of access to education and consequently reduced income—have been reported to

disproportionately impact blacks in Brazil. Bounded justice then, captures this essence of day-to-day injustices that occur within the black Brazilian population, inequalities that remain unpacified with the distribution of health rights. That is not to say that those in the SCD community take these rights for granted. They are, in fact, very grateful—especially because the larger black health policy promoted by the State has translated into general health promotion for SCD. Before 2009, many will tell you of the lack of information that was in circulation within SUS about SCD. As a result, care and treatment have improved and parts of the lives of people living with SCD have been improved. For those outside this rare genetic circle, there is still much to be done.

I have also introduced the term interstitial biosocial space as a way of negotiating authenticity claims. If biosocial identities and groupings are based on shared genetic knowledge and even shared genetic material even, how does one reconcile the space in which Zaira resides? Having sickle cell trait and heavily involved in the SCD Movement in Rio (SCD organization president), she is not accepted as authentic and must fight for her sea at the table. I draw upon Gibbon's (as found in Gibbon and Novas, 2008) concepts of "gendered modes of identity making" and "memorialization" to help capture the tension caused by Zaira's role as mother and sickle cell gene carrier, by her *côr* (skin color), and by the resistance of others in the SCD organization who have the actual disease and are weary of her representation. Her lack of reliance on SCD to serve as a main identifier in her life positions her interstitially with this group.

In an in-depth biographical analysis of Joice Aragão de Jesus, the director of the national SCD program for the Ministry of Health, I illustrated how a key

elite actor utilized bicultural competence in order to balance the relationships she has with both the State public health apparatus and her primarily Afro-Brazilian constituents. By interweaving Joice's professional trajectory with the development of a reformist public health system, I demonstrated how she uses social capital, cultural capital, and racial fluidity to biculturally navigate the SCD public health world. Her commitment to both the SCD community and the role of SUS for the public creates a situation in which she serves two populations. Her ability to culturally translate for the both of them does not preclude her from conflict on both sides. On one side is an entity legislatively mandated to enact inclusiveness, and on the other a population affronted with high levels of trauma. There is the trauma that bears to mind the notion of biological citizenship, as classically defined by Adriana Petryna (see Chapter Two) in which biological trauma is used to justify actions from the state. In this case, the biological trauma could be considered the inheritance of the S allele. Further, the inheritance of the S allele is situated in the context of cultural trauma via the slave trade, which, by my actors' accounts, brought SCD to Brazil in the first place (e.g. "It is a disease that came with the black population that came involuntarily to our country here.")

According to sociologist, Jeffrey Alexander, "cultural trauma occurs when members of a collectivity feel they have been subjected to a horrendous event that leaves indelible marks upon their group consciousness, marking their memories forever and changing their future identity in fundamental and irrevocable ways" (Alexander et.al., 2004:1). Slavery is embedded in the national conversation about science, policy, and sickle cell disease. Consider the sampling of scientific

text below, one taken from an American author, the other from a Brazilian author. Brazilian author Lervolino (2011) states:

> Originally from Africa and brought to the Americas by the forced immigration of slaves, it is more frequent where the proportion of African descendants is greater (the northeastern region and the States of São Paulo, Rio de Janeiro and Minas Gerais). In these regions, we observe new cases of sickle cell disease in every 1000 births and sickle cell trait carriers in every 27 births. It is estimated that approximately 2500 children are born every year with sickle cell disease in Brazil (49).

Consider a similar description of SCD for the United States by American author Hassell (2010):

> The number of individuals with sickle cell disease (SCD) in the U.S. is unknown. Thirty years ago, the U.S. sickle cell anemia population was estimated to be 32,000–50,000, based on reported gene frequencies derived from testing of African-American neonates. Subsequent population estimates of over 50,000–80,000 for both SCD and sickle cell anemia (a common form of SCD) are noted in a variety of publications, usually without a specific reference. Specific methods used to obtain these figures are not provided but are usually discussed in the context of the frequency of sickle cell anemia in the U.S. African-American population as determined by newborn screening data (S512).

Though both authors accurately describe what the estimated prevalence is for their respective countries, there is a difference in how the retrospective populations are mentioned. Scientists' training and views are shaped in particular ways based on a number of variables, including national identity. The production of science in nineteenth century Brazil was heavily linked to nation building and race. The intellectual and political elites in Brazil believed that their national makeup and consequent scientific contributions were bolstered by the African contribution to the population. This may explain why even in contemporary times, slavery is mentioned in this typical Brazilian scientific text.

National conceptions of racial identity are key factors in how people understand SCD. The NHPCP is in part, a political response to the cultural trauma imparted to Afro-Brazilians. As stated earlier, the diasporic spread of Africans to Brazil via the slave trade and subsequent gene transmission allows us to connect the cultural aspects of African descent to genetics.

By focusing an analytical lens on Brazil, we can interrogate the different ways in which sickle cell can be interpreted outside of the U.S.-based setting in which it is usually examined. . Though the presence of the one-drop rule can be felt in both countries, Brazil's long and storied history with miscegenation changes the conversation to one that *might* encapsulate narratives around SCD as a "Brazilian" disease. Instead, we witness the ways that knowledge is produced for a marginalized group as a way of resistance. In 2016, Brazil's economic boom gave way to a serious financial downturn. Along with this transformation will come changed priorities for public health. As the Zika virus steals the current spotlight, how might we see the notion of bounded justice enact itself on a primarily poor and nonwhite population who may be offered certain health rights as they form new biosocial groupings?

This study broadens the definition of biosociality to marginal communities. By inserting this framework into the Brazilian context, we are able to observe the contestation between a social group of biological citizens who have organized themselves by both disease and culture, and the scientific or medical elite who hold the epistemic authority. Current thinking situates the biological as something that inherently breeds solidarity. Biocultural citizenship shows us that biology is still stratified along cultural lines. Furthermore, a commonality is

formed only when we take into account the stratification of embodied suffering and the limits of existing political will to attend to that suffering. Alexander Weheliye (2014) argues that black studies and other formations of critical ethnic studies are often overlooked or neglected in the discourse of biopolitics. He stresses that race be prioritized in these biopolitical considerations, "not as a biological or cultural classification but as a set of sociopolitical processes of differentiation and hierarchization which are projected onto the putatively biological human body" (5). I argue that biocultural citizenship captures a set of processes that take all three into consideration: the biological, cultural, and sociopolitical (as represented in the societal layer of my model). We are forced to contend with all three.

If we turn back to the narrative highlighted at the beginning of this chapter, we are confronted with contradiction, indignation, pride, entitlement, anger, and awareness—an astute awareness of political process, societal reality, historical nuance and selfhood. Citizenship is hierarchical. Afro-Brazilians have strategically transformed themselves into exceptional bodies that deserve exceptional rights. Nonetheless, even as race becomes biology and we bear witness to how exclusion gets mapped into biological processes, we must remember the hope that many in this study have enacted for the embodiment of belonging.

APPENDICES

APPENDIX A: RESEARCH PARTICIPANT INFORMATION SHEET

Emory University Graduate School of Arts and Sciences
Research Participant Information Sheet

Title: Race, Policy, and Culture: An Identity Crisis for Sickle Cell Disease in Brazil

Principal Investigator: Melissa Creary

Funding Source(s): Institute of International Education

Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. The decision to join or not join the research study will not cause you to lose any benefits, nor will you be coerced to rejoin.

The study itself will last between 10 and 12 months, but your commitment would likely be between 1-3 hours over one day. There will be an approximate total of 50 adult (over 18) particpants.The basis of your selection to participate will be based on falling into this age range, having a diagnosis of sickle cell disease, being a family member of someone who has been diagnosed with sickle cell disease, serving as a medical provider to those who have sickle cell disease, recognized as a leader the sickle cell movement, or sevring as a health officlal in the public health system.

Purpose

The purpose of this study is to look at the differing experiences of different kinds of people who interact with sickle cell disease. The study is interested in the relationships between the government, civil societies, and individuals.

Procedures

This project seeks to have people tell their story of how they interact with sickle cell disease in their own words. Interviews will take place face-to-face and the interviewer will record your responses verbatim. Photographs will be taken of you at the time of the interview with your permission. If photographs include persons other than the participantss in non-public settings, consent will be sought from those individuals or the material will be deemed unusable.

Risks and Discomforts

There are no major risks, discomfort or side effects from the study activities that are known at this time, but it is understandable that some conversations could result in a certain amount of stress. If at any time you feel the need to stop an interview or to withdraw completely from the project, then you are free to do so with no resulting negative consequences.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about the different experiences of sickle cell disease. Though taking part in this research study may not benefit you personally, we may learn new things that will help others or help improve care options or policy

Compensation

If the interview takes place at the Brazilian Symposium for Sickle Cell Disease (Salvador, Bahia, November 2013), you will be entered at the conclusion of the interview for a Kindle® E-Reader with WiFi. If the interview takes place outside of this setting, you will not be compensated. You will be allowed to withdraw at any time in the study.

Confidentiality

The primary purpose of this research is to contribute to a Ph.D. dissertation and as such, the primary audience for the work will be academic and the use of images will be restricted to the dissertation and it's audience. However, there are other potential audiences for the project in different forms. The photographic narrative produced can stand alone in exhibition. This option allows for direct

and immediate interaction with a public audience. This allows the project to continue the production of knowledge. Any additional uses will be subject to consent by the participants involved. If the participant declines public exhibition, the use of images will be restricted to the dissertation.

Certain offices and people other than the researchers may look at your study records. Government agencies, Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board, the Emory Office of Research Compliance, and members of the Institute of Liberal Arts, Department of History, and the School of Public Health at Emory. Emory will keep any research records we produce private to the extent we are required to do so by law.

A pseudonym (fake name) rather than your name will be used on study records when requested and the same done for any names you might mention in the course of interviews. All information gathered from the study will be stored on a personal harddrive that will remain in the possesion of the study. This data itself will be password protected. If there is any information that is deemed too personal by the participant it will be left out. Survey information will only be used together as a group with other participant information, to assure confidentiality. Raw data will be stored until the dissertation is completed and then deleted. Only the information generated from the raw data that has been used in the final product or has agreed to be used further will be kept.

Voluntary Participation and Withdrawal from the Study

Participation in this study is totally voluntary. You have the right to leave the study at any time without penalty, except that you will only receive a portion of the compensation. This decision will not affect in any way your current or future care/services or any other benefits to which you are otherwise entitled.

The investigators have the right to stop your participation in this study without your consent if they believe it is in your best interest.

Questions

Contact Melissa Creary at (55) 71 9280-2317, pesquisadorafalciforme@gmail.com, or at www.facebook.com/pesquisadorafalciforme.

- If you have any questions about this study or your part in it, or
- If you have questions, concerns or complaints about the research

We will give you a copy of this information sheet to keep. If you have questions about your rights as a research participant or if you have questions, concerns or complaints about the research, you may contact the Emory Institutional Review Board at +1 404 712 0720 or irb@emory.edu. You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

APPENDIX B: SURVEY INSTRUMENT

Tell me your story: A Research Study on Sickle Cell Disease

Name (Fake Name): _____

Date: _____

Location: _____

Please answer the following questions. This information will NOT identify you as an individual unless you want it to. It will only be used together as a group with other participant information, to assure confidentiality.

1. What is your age? -
   _____
2. What is your gender?
   _____
3. What is your race/color?
   _____
4. What is your religion? Please circle any that apply.
   a. Catholic
   b. Protestant
   c. Pentecostal
   d. Latter-day Saints
   e. Umbanda
   f. Candomblé
   g. Buddhism
   h. Judaism
   i. Islam
   j. Hinduism
   k. Bahai

l. Other:
_____

5. What is the highest level of education you have finished? Please circle one (1).

a. I never went to school
b. Fundamental
c. Intermediate
d. Higher Education
    i. Undergraduate
    ii. Graduate

6. What is your occupation?
_____

7. Are you married?

a. Yes
If yes, what is the race/color of your spouse?

_____

b. No

8. Do you have any children?

a. Yes
If yes, what is the race/color of ALL your children?

_____

_____

_____

b. No

Sickle Cell Information

9. What type of sickle cell do you have? Please circle one (1).

a. I don't have sickle cell
   If you don't have sickle cell, STOP 

   here.
b. Sickle Cell Anemia (HbSS)
c. Sickle Cell SC Disease (HbSC)
d. Sickle Cell Beta Thalassemia Disease (HbSβ-thal)
e. Sickle Cell Trait

10. What age did you find out you had sickle cell?

_____

11. How many times did you interact with the SUS this year? Please circle one (1).
    a. 0
    b. 1-5
    c. 6-10
    d. 11-15
    e. 15-20
    f. more than 20

12. How many times did you go to the hospital or clinic this year? Please circle one (1).
    a. 0
    b. 1-5
    c. 6-10
    d. 11-15
    e. 15-20
    f. more than 20

13. How many times did you manage your sickle cell at home this year? Please circle one (1).
    a. 0
    b. 1-5
    c. 6-10
    d. 11-15
    e. 15-20
    f. more than 20

14. If you managed your pain at home, please explain why:

_____

_____

_____

_____

15. How many times did you interact with the sickle cell movement (at conferences, organizational meetings, support group sessions) this year?
    a. 0
    b. 1-5
    c. 6-10
    d. 11-15
    e. 15-20
    f. more than 20

APPENDIX C: INTERVIEW DISCUSSION GUIDE

Oral History Interview Discussion Guide in English and Portuguese

Introduction:

My name is [ ]. Today is [month/day/year]. I am interviewing for the [first, second, etc.] time [full name of narrator]. This interview is taking place at [address; may include description, such as home of, office of] in [town, state].

Meu nome é [ ]. Hoje é [dia / mês / ano]. Estou entrevistando para o [primeiro, segundo, etc] tempo [nome completo do narrador]. Esta entrevista está ocorrendo em [endereço; pode incluir descrição, tais como casa de escritório de] em [cidade, estado].

Opening Question:

1. Tell me about where you come from?

   Conte-me sobre de onde você vem?

Family History Questions:

2. What city did you grow up in?

   Que cidade você cresceu em?

3. What are some memories you have about when you lived there?

   Quais são algumas das lembranças que você tem cerca de quando viveu lá?

4. Can you describe your childhood neighborhood to me?

   Você pode descrever o seu bairro de infância para mim?

5. How did you get to the city you live in now?

   Como você chegou à cidade em que vive agora?

6. Do you remember your grandparents?

   Você se lembra de seus avós?

7. What are some things you remember about them?

   Quais são algumas coisas que você lembra sobre eles?

8. What did they do for work?

   O que eles fizeram para o trabalho?

9. Were you close to them?

   Você estava perto deles?

10. Were there any family members that were influential to you?

    Houve membros da família que foram influentes para você?

11. Where were your parents born? Can you describe your mother and father to me?

    Onde estavam seus pais nasceram? Você pode descrever a sua mãe e pai para mim?

12. What about any brothers or sisters? Can you tell me about them?

    E sobre irmãos ou irmãs? Você pode me dizer sobre eles?

13. Did you go to school?

    Será que você vai para a escola?

14. Can you tell me about your experiences in school?

    Você pode me dizer sobre as suas experiências na escola?

15. Tell me about the kinds of jobs you've had?

Diga-me sobre os tipos de trabalhos que você já teve?

16. What do you do for fun? Do you have any hobbies?

O que você faz para se divertir? Você tem algum hobby?

17. Do you practice a religion or belong to a church? How important is faith to you?

Você pratica uma religião ou pertencer a uma igreja? Quão importante é a fé para você?

18. Are you married or have a long-time partner?

Você é casado ou tem um parceiro de longa data?

19. Why did you get married?

Por que você se casou?

20. Can you tell me about your spouse?

Você pode me dizer sobre o seu cônjuge?

21. Do you want to get married? Why or why not?

Você quer se casar? Por que ou por que não?

22. What kind of work does your partner do?

Que tipo de trabalho é que o seu parceiro faz?

23. Do you have any children?

Você tem filhos?

24. Tell me about them?

Diga-me sobre eles?

25. Where do they live now?

Onde eles vivem agora?

26. What do they do?

O que eles fazem?

Race:

27. Tell me what you think about race or color?

Diga-me o que você pensa sobre a raça ou cor?

Sickle Cell Disease:

28. What does your family think about sickle cell disease?

O que sua família pensa sobre a doença falciforme?

29. Do you do anything in the sickle cell movement? If so, why did you decide to be an activist?

Você faz qualquer coisa no movimento de anemia falciforme? Se sim, por que você decidiu ser um ativista?

Identity:

30. How do you identify yourself?

Como você se identifica?

Ancestry:

31. Tell me where your family comes from.

Diga-me onde sua família vem.

32. What does blood mean to you?

O que o sangue significa para você?

Policy:

33. What do you know about the sickle cell policy from the Ministry of Health?

O que você sabe sobre a política de anemia falciforme do Ministério da Saúde?

34. Why do you think the Ministry of Health decided to package sickle cell as a black health problem?

Porque você acha que o Ministério da Saúde decidiu empacotar anemia falciforme como um problema de saúde negra?

35. Can you tell me about what you know about sickle cell disease and the policy created for it in 2006?

Você pode me dizer sobre o que você sabe sobre a doença falciforme e a política criado por ele em 2006?

Care:
(For people with SCD)

36. Tell me about your experiences of getting treated for SCD.

Diga-me sobre suas experiências de serem tratados por anemia falciforme.

(For medical providers)

37. Tell me about your experience treating people who live with SCD.

Diga-me sobre sua experiência no tratamento de pessoas que vivem com anemia falciforme.

Concluding Question:
Thanks for meeting with me for this interview. I've asked everything I've wanted but is there anything else you think I should know?

Obrigada por se encontrar comigo para esta entrevista. Eu pedi tudo o que eu queria, mas há alguma coisa que você acha que eu deveria saber?

BIBLIOGRAPHY

Abel, Thomas. “Cultural Capital and Social Inequality in Health.” *Journal of Epidemiology and Community Health* 62, no. 7 (2008): e13–e13.

Alberto, Paulina L. “Of Sentiment, Science and Myth: Shifting Metaphors of Racial Inclusion in Twentieth-Century Brazil.” *Social History* 37, no. 3 (2012): 261–96.

———. *Terms of Inclusion: Black Intellectuals in Twentieth-Century Brazil*. 1st New edition edition. Chapel Hill: The University of North Carolina Press, 2011.

Alcoff, Linda. “The Problem of Speaking for Others.” *Cultural Critique*, no. 20 (1991): 5.

Alexander, Jeffrey C., Ron Eyerman, Bernard Giesen, Neil J. Smelser, and Piotr Sztompka. *Cultural Trauma and Collective Identity*. University of California Press, 2004.

Almeida, Maria Inez, Rosemeire Cristina Moretto Molina, Tereza Maria Mageroska Vieira, Ieda Harumi Higarashi, and Sonia Silva Marcon. “Being Mother of Child with Chronic Disease: Accomplishing Complex Cares.” *Escola Anna Nery* 10, no. 1 (April 2006): 36–46.

Amaral, Júlia Lamese, Nívea Aparecida Almeida, Paula Silveira Santos, Patrícia Peres Oliveira, and Fernanda Moura Lanza. “Socio-Demographic, Economic and Health Profile of Adults with Sickle-Cell Disease.” *Revista Da Rede de Enfermagem Do Nordeste* 16, no. 3 (July 21, 2015): 296–305.

Andrews, George Reid. *Blacks & Whites in São Paulo, Brazil, 1888-1988*. Madison, Wis: University of Wisconsin Press, 1991.

Ansari, Zahid, Norman J. Carson, Michael J. Ackland, Loretta Vaughan, and Adrian Serraglio. "A Public Health Model of the Social Determinants of Health." *Sozial-und Präventivmedizin /Social and Preventive Medicine* 48, no. 4 (July 1, 2003): 242–51.

Aragão de Jesus, Joice. 2011. Personal Interview. Rio de Janeiro, Brazil, August 5, 2011.

Arcand, Jean-Louis, and Béatrice D'hombres. "Racial Discrimination in the Brazilian Labour Market: Wage, Employment and Segregation Effects." *Journal of International Development* 16, no. 8 (November 1, 2004): 1053–66.

Atkinson, Paul, Peter Glasner, Margaret Lock, Sahra Gibbon, Professor of Sociology and Politics of Bioscience Barbara Prainsack, and Stephen Hilgartner. *The Handbook of Genetics & Society: Mapping the New Genomic Era*. Routledge, 2009.

Aureliano, Waleska de Araújo. "Health and the Value of Inheritance: The Meanings Surrounding a Rare Genetic Disease." *Vibrant: Virtual Brazilian Anthropology* 12, no. 1 (June 2015): 109–40.

Avritzer, Leonardo. "Civil Society in Brazil: From State Autonomy to Political Interdependency." *DCP/UFMG, Spring*, 2009. Accessed November 20. http://orecomm.net/

———. *Participatory Institutions in Democratic Brazil*. Washington, D.C. : Baltimore: Woodrow Wilson Center Press ; Johns Hopkins University Press, 2009.

Azevedo, E. "Historical Note on Inheritance of Sickle Cell Anemia." *American Journal of Human Genetics* 25, no. 4 (1973): 457.

Bacelar, Jeferson. *Etnicidade: Ser Negro Em Salvador*. Penba, 1989.

Badziak, Rafael Policarpo Fagundes, and Victor Eduardo Viana Moura. "Determinantes Sociais Da Saúde: Um Conceito Para Efetivação Do Direito À Saúde." *Revista de Saúde Pública de Santa Catarina* 3, no. 1 (2010): 69–79.

Baer, Roberta D., Erika Arteaga, Karen Dyer, Aimee Eden, Rosalyn Gross, Hannah Helmy, Margaret Karnyski, Airia Papadopoulos, and Doug Reeser. "Concepts of Race and Ethnicity among Health Researchers: Patterns and Implications." *Ethnicity & Health* 18, no. 2 (April 2013): 211–25.

Bailey, Donald B., Debra Skinner, Arlene M. Davis, Ian Whitmarsh, and Cynthia Powell. "Ethical, Legal, and Social Concerns About Expanded Newborn Screening: Fragile X Syndrome as a Prototype for Emerging Issues." *Pediatrics* 121, no. 3 (March 1, 2008): e693–704.

Bailey, Stanley R. "Group Dominance and the Myth of Racial Democracy: Antiracism Attitudes in Brazil." *American Sociological Review* 69, no. 5 (2004): 728–47.

Bairros, Fernanda Souza de, Stela Nazareth Meneghel, Juvenal Soares Dias-da-Costa, Diego Garcia Bassani, Ana Maria Baptista Menezes, Denise Petrucci Gigante, and Maria Teresa Anselmo Olinto. "Racial Inequalities in Access to

Women's Health Care in Southern Brazil." *Cadernos de Saúde Pública* 27, no. 12 (December 2011): 2364–72.

Bala, Poonam. *Biomedicine as a Contested Site: Some Revelations in Imperial Contexts*. Lanham, MD: Lexington Books, 2009.

Barbarin, Oscar A., Charles F. Whitten, Sandy Bond, and Rhonda Conner-Warren. "The Social and Cultural Context of Coping with Sickle Cell Disease: III. Stress, Coping Tasks, Family Functioning, and Children's Adjustment." *Journal of Black Psychology* 25, no. 3 (August 1, 1999): 356–77.

Barbosa, Maria Inês da Silva. Personal Interview, Salvador, Bahia, Brazil. July 16, 2012.

Barsaglini, Reni Aparecida, Késia Marisla da Paz, and Patricia Lima Lemos. "Qualidade de Vida E Cuidado Às Pessoas Com Doença Falciforme." *Interface-Comunicação, Saúde, Educação* 19, no. 52 (2015): 195–200.

Bartholdson, Orjan. "The Ambiguous Discourse of Afro-Brazilian Identity among NGOs in Salvador," n.d.

Batagello, Rodrigo, Luciana Benevides, and Jorge Alberto Cordón Portillo. "Conselhos de Saúde: Controle Social E Moralidade." *Saúde E Sociedade* 20, no. 3 (September 2011): 625–34..

Batista, Amanda, and Tania Cristina Andrade. "Anemia Falciforme: Um Problema de Saúde Pública No Brasil." *Universitas: Ciências Da Saúde* 3, no. 1 (April 1, 2008).

Baumann, Gerd. *Contesting Culture: Discourses of Identity in Multi-Ethnic London*. Cambridge Studies in Social and Cultural Anthropology 100. Cambridge ; New York: Cambridge University Press, 1996.

Benjamin, Ruha. *People's Science: Bodies and Rights on the Stem Cell Frontier*. Stanford, California: Stanford University Press, 2013.

Bennett, Tony, John Frow, Sage Publications, and Sage eReference (Online service). *The Sage Handbook of Cultural Analysis*. Los Angeles: Sage, 2008.

Ben-Zeev, A., T. C. Dennehy, R. I. Goodrich, B. S. Kolarik, and M. W. Geisler. "When an 'Educated' Black Man Becomes Lighter in the Mind's Eye: Evidence for a Skin Tone Memory Bias." *SAGE Open* 4, no. 1 (January 14, 2014).

Biehl, João. "Technologies of Invisibility." *Anthropologies of Modernity: Foucault, Governmentality, and Life Politics. West Sussex: Blackwell Publishing* 248 (2005): 271.

Biehl, João Guilherme. "The Activist State: Global Pharmaceuticals, AIDS, and Citizenship in Brazil." *Social Text* 22, no. 3 (2004): 105–32.

Biehl, João, Adriana Petryna, Alex Gertner, Joseph J Amon, and Paulo D Picon. "Judicialisation of the Right to Health in Brazil." *The Lancet* 373, no. 9682 (June 2009): 2182–84.

Borges, Dain. "'Puffy, Ugly, Slothful and Inert': Degeneration in Brazilian Social Thought, 1880–1940." *Journal of Latin American Studies* 25, no. 02 (1993): 235–56.

Borrell, Luisa N., Catarina I. Kiefe, David R. Williams, Ana V. Diez-Roux, and Penny Gordon-Larsen. "Self-Reported Health, Perceived Racial Discrimination, and Skin Color in African Americans in the CARDIA Study." *Social Science & Medicine* 63, no. 6 (September 2006): 1415–27.

Bourdieu, Pierre. "The Forms of Capital (1986)." Cultural Theory: An Anthology. John Wiley & Sons, 2010.

Brasil Ministerio da Saude Secretaria de Politicas de Saude. *Manual de Doenças Mais Importantes, Por Razões Étnicas, Na População Brasileira Afro-Descendente*. Brasil. Ministerio da Saude, 2001.

Braun, Lundy, Anne Fausto-Sterling, Duana Fullwiley, Evelynn M. Hammonds, Alondra Nelson, William Quivers, Susan M. Reverby, and Alexandra E. Shields. "Racial Categories in Medical Practice: How Useful Are They?" *PLoS Med* 4, no. 9 (2007): e271.

Brooks, Roy L. "Postconflict Justice in the Aftermath of Modern Slavery." *Geo. Wash. Int'l L. Rev.* 46 (2013): 243.

Bunton, Robin, and Alan Petersen. *The New Genetics and The Public's Health*. Routledge, 2002.

Burchard, Esteban González, Elad Ziv, Natasha Coyle, Scarlett Lin Gomez, Hua Tang, Andrew J. Karter, Joanna L. Mountain, Eliseo J. Pérez-Stable, Dean Sheppard, and Neil Risch. "The Importance of Race and Ethnic Background in Biomedical Research and Clinical Practice." *New England Journal of Medicine* 348, no. 12 (2003): 1170–75.

Burnes, David P. R., Beverley J. Antle, Charmaine C. Williams, and Lisa Cook. "Mothers Raising Children with Sickle Cell Disease at the Intersection of Race, Gender, and Illness Stigma." *Health & Social Work* 33, no. 3 (August 1, 2008): 211–20.

Butler, Judith. *Gender Trouble: Feminism and the Subversion of Identity*. Routledge, 2011.

Butler, Kim D. *Freedoms Given, Freedoms Won: Afro-Brazilians in Post-Abolition, São Paulo and Salvador*. Rutgers University Press, 1998.

Bygren, L. O., B. B. Konlaan, and S. E. Johansson. "Attendance at Cultural Events, Reading Books or Periodicals, and Making Music or Singing in a Choir as Determinants for Survival: Swedish Interview Survey of Living Conditions." *BMJ : British Medical Journal* 313, no. 7072 (December 21, 1996): 1577–80.

Caldwell, Kia Lilly. *Negras in Brazil: Re-Envisioning Black Women, Citizenship, and the Politics of Identity*. New Brunswick, N.J: Rutgers University Press, 2007.

Calvo-González, Elena. "Genetics and Racial Difference in Contemporary Brazil: Haemoglobinopathies, Whiteness and Admixture in Biomedical Literature." *Bulletin of Latin American Research*, July 1, 2015.

Calvo-González, Elena, Elena Calvo-Gonzáles, and Vera Rocha. "'Está No Sangue': A Articulação de Ideias Sobre 'raça', Aparência E Ancestralidade Entre Famílias de Portadores de Doença Falciforme Em Salvador, Bahia." *Revista de Antropologia*, 2010, 277–320.

Campbell, Dave. "Anthropology's Contribution to Public Health Policy Development." *McGill Journal of Medicine* 12, no. 1 (2011): 76.

Campbell, Sue, Letitia Meynell, and Susan Sherwin, eds. *Embodiment and Agency*. University Park, Pa: Pennsylvania State University Press, 2009.

Campos de Sousa, Leone, and Paulo Nascimento. "Brazilian National Identity at a Crossroads: The Myth of Racial Democracy and the Development of Black

Identity." *International Journal of Politics, Culture, and Society* 19, no. 3–4 (June 2008): 129–43.

Cançado, Rodolfo D., and Joice A. Jesus. "A Doença Falciforme No Brasil." *Revista Brasileira de Hematologia E Hemoterapia* 29, no. 3 (September 2007).

Carolan, Brian V. *Social Network Analysis and Education: Theory, Methods & Applications*. Los Angeles: SAGE, 2014.

Castor, Belmiro V. *Brazil Is Not for Amateurs: Patterns of Governance in the Land of Jeitinho*. Xlibris Corporation, 2003.

Caudill, William. *Applied Anthropology in Medicine*. University of Chicago Press, n.d.

Cavalcanti, Juliana Manzoni, and Marcos Chor Maio. "Between Black and Miscegenated Population Groups: Sickle Cell Anemia and Sickle Cell Trait in Brazil in the 1930s and 1940s." *História, Ciências, Saúde-Manguinhos* 18, no. 2 (2011): 377–406.

Chaitin, Julia. "Oral History." In *The SAGE Encyclopedia of Qualitative Research Methods*, edited by Lisa Given. 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc., 2008.

Chiseri-Strater, Elizabeth. "Turning in upon Ourselves: Positionality, Subjectivity, and Reflexivity in Case Study and Ethnographic Research." *Ethics and Representation in Qualitative Studies of Literacy*, 1996, 115–33.

Chor, Dóra. "Health Inequalities in Brazil: Race Matters." *Cadernos de Saúde Pública* 29, no. 7 (July 2013): 1272–75.

Clarke, Adele, Janet Shim, Sara Shostak, and Alondra Nelson. "Biomedicalising Genetic Health, Diseases and Identities." In *Handbook of Genetics and Society: Mapping the New Genomic Era*, edited by Paul Atkinson, 21–41. Genetics and Society. London: Routledge, 2013.

Coelho, Vera Schattan P. "Brazil's Health Councils: The Challenge of Building Participatory Political Institutions." *IDS Bulletin* 35, no. 2 (2004): 33–39.

Cohen, Jillian Clare, and Kristina M. Lybecker. "AIDS Policy and Pharmaceutical Patents: Brazil's Strategy to Safeguard Public Health." *The World Economy* 28, no. 2 (2005): 211–30.

Collins, Patricia Hill. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. Routledge, 1990.

Constituição Federal (Artigos 196 a 200). Accessed November 22, 2013. http://conselho.saude.gov.br/legislacao/index.htm.

Cooley, Thomas B. "Likenesses and Contrasts in the Hemolytic Anemias of Childhood." *Archives of Pediatrics & Adolescent Medicine* 36, no. 6 (1928): 1257.

Cornwall, Andrea. "Deliberating Democracy: Scenes from a Brazilian Municipal Health Council." *Politics & Society* 36, no. 4 (December 1, 2008): 508–31.

Costa, Ana Maria, and Tatiana Lionço. "Democracia E Gestão Participativa: Uma Estratégia Para a Eqüidade Em Saúde?" *Saúde E Sociedade* 15, no. 2 (August 2006).

Coupland, Christine. "Identities and Interviews." *Exploring Identity. Concepts and Methods. New York: Palgrave MacMillan*, 2007, 274–87.

Covin, David. *The Unified Black Movement in Brazil, 1978-2002*. McFarland, 2006.

Covre-Sussai, Maria, Bart Meuleman, Sarah Botterman, and Koenraad Matthijs. "Traditional and Modern Cohabitation in Latin America: A Comparative Typology." *Demographic Research* 32 (2015): 873–914.

Creary, Melissa, Dhelia Williamson, and Roshni Kulkarni. "Sickle Cell Disease: Current Activities, Public Health Implications, and Future Directions." *Journal of Women's Health* 16, no. 5 (2007): 575–82.

Cruz, I. C. F. "Saúde Da População Negra: A Construção Da Equidade No SUS Pela Implementação Da Política Nacional de Saúde Integral Da População Negra." *Online Braz J Nurs [Internet]* 9, no. 3 (2010).

Da Matta, Roberto. *Carnivals, Rogues, and Heroes*. University of Notre Dame Press, 1991.

Da Silva Martins, Sérgio, Carlos A. Medeiros, and Elisa Larkin Nascimento. "Paving Paradise: The Road From 'Racial Democracy' to Affirmative Action in Brazil." *Journal of Black Studies* 34, no. 6 (July 1, 2004): 787–816.

Dauphin-McKenzie, Nathalie, Jerry M. Gilles, Elvire Jacques, and Thomas Harrington. "Sickle Cell Anemia in the Female Patient." *Obstetrical & Gynecological Survey* 61, no. 5 (2006): 343–52.

Davies, Thomas, and Brian Loveman. *The Politics of Antipolitics: The Military in Latin America*. Rowman & Littlefield Publishers, 1978.

Dávila, Jerry. *Diploma of Whiteness: Race and Social Policy in Brazil, 1917–1945*. Duke University Press, 2003.

———. *Hotel Trópico: Brazil and the Challenge of African Decolonization, 1950–1980*. Duke University Press, 2010.

De Holanda, Sérgio Buarque. “Race, Colour, and Skin Colour in Brazil.” Accessed December 9, 2014. https://halshs.archives-ouvertes.fr/docs/00/71/46/28/PDF/FMSH-WP-2012-04_Guimaraes.pdf.

De Holanda, Sérgio Buarque. *Raízes Do Brasil: Edição Comemorativa 70 Anos*. Companhia das letras, 2006.

De Holanda, Sergio Buarque, and G. Harvey Summ. *Roots of Brazil*. University of Notre Dame Press, 2012.

De Macedo, Márcio José. “Abdias Do Nascimento: A Trajetória de Um Negro Revoltado (1914-1968).,” 2005.

De Paiva, Roberto B., Antonio S. Ramalho, Roosevelt MS Cassorla, and others. “A Anemia Falciforme Como Problema de Saúde Pública No Brasil.” *Revista de Saúde Pública* 27, no. 1 (1993): 54–58.

Dey, Ian. *Qualitative Data Analysis: A User-Friendly Guide for Social Scientists*. London: New York, NY : Routledge, 1993.

Diniz, Debora, and Cristiano Guedes. “Anemia Falciforme: Um Problema Nosso. Uma Abordagem Bioética Sobre a Nova Genética Sickle Cell Anaemia: A Brazilian Problem. A Bioethical Approach to the New Genetics.” *Cad. Saúde Pública* 19, no. 6 (2003): 1761–70.

Dirks, Nicholas B., Geoff Eley, and Sherry B. Ortner. *Culture/power/history: A Reader in Contemporary Social Theory*. Princeton University Press, 1994.

Dovidio, John F., Samuel E. Gaertner, Kerry Kawakami, and Gordon Hodson. “Why Can’t We Just Get along? Interpersonal Biases and Interracial

Distrust." *Cultural Diversity and Ethnic Minority Psychology* 8, no. 2 (2002): 88.

Dressler, William W. "Cultural Consonance: Linking Culture, the Individual and Health." *Preventive Medicine* 55, no. 5 (2012): 390–93.

———. "What's Cultural about Biocultural Research?" *Ethos* 33, no. 1 (2005): 20–45.

Dressler, William W., Mauro C. Balieiro, and Jose Ernesto Dos Santos. "Culture, Skin Color, and Arterial Blood Pressure in Brazil." *American Journal of Human Biology* 11, no. 1 (1999): 49–59.

Dressler, William W., Mauro C. Balieiro, Rosane P. Ribeiro, and José Ernesto Dos Santos. "Cultural Consonance and Arterial Blood Pressure in Urban Brazil." *Social Science & Medicine* 61, no. 3 (2005): 527–40.

Dressler, William W., and James R. Bindon. "The Health Consequences of Cultural Consonance: Cultural Dimensions of Lifestyle, Social Support, and Arterial Blood Pressure in an African American Community." *American Anthropologist* 102, no. 2 (2000): 244–60.

Dressler, William W., James R. Bindon, and Yasmin H. Neggers. "Culture, Socioeconomic Status, and Coronary Heart Disease Risk Factors in an African American Community." *Journal of Behavioral Medicine* 21, no. 6 (1998): 527–44.

Dressler, William W., José Ernesto Dos Santos, and Mauro Campos Balieiro. "Studying Diversity and Sharing in Culture: An Example of Lifestyle in Brazil." *Journal of Anthropological Research* 52, no. 3 (October 1, 1996): 331–53.

Driss, A., K. O. Asare, J. M. Hibbert, B. E. Gee, T. V. Adamkiewicz, and J. K. Stiles. “Sickle Cell Disease in the Post Genomic Era: A Monogenic Disease with a Polygenic Phenotype.” *Genomics Insights* 2009, no. 2 (July 30, 2009): 23–48.

Du Bois, W. E. B. *The Souls of Black Folk. Edited with an Introduction by David W. Blight and Robert Gooding-Williams*. Boston, MA: Bedford Books, 1903.

Duster, T. “MEDICINE: Enhanced: Race and Reification in Science.” *Science* 307, no. 5712 (February 18, 2005): 1050–51.

Duster, Troy. *Backdoor to Eugenics*. Routledge, 1990.

Duster, Troy, and Keith Wailoo. “Medicine, Culture, and Sickle Cell Disease.” *The Hastings Center Report* 32, no. 4 (July 2002): 46.

Elander, James, Mary Catherine Beach, and Carlton Haywood Jr. “Respect, Trust, and the Management of Sickle Cell Disease Pain in Hospital: Comparative Analysis of Concern-Raising Behaviors, Preliminary Model, and Agenda for International Collaborative Research to Inform Practice.” *Ethnicity & Health* 16, no. 4–5 (2011): 405–21.

El-Dahdah, Farès. *Lucio Costa: Brasilia’s Superquadra*. Prestel Munich, 2005.

El-Haj, Nadia Abu. “The Genetic Reinscription of Race.” *Annual Review of Anthropology* 36, no. 1 (September 2007): 283–300.

Epstein, Steven. *Inclusion the Politics of Difference in Medical Research*. Chicago: University of Chicago Press, 2007.

Espino, Rodolfo, and Michael M. Franz. “Latino Phenotypic Discrimination Revisited: The Impact of Skin Color on Occupational Status.” *Social Science Quarterly* 83, no. 2 (June 1, 2002): 612-623.

Evans, Monica. “Achieving a Racial Democracy in Brazil through Race Based Social Inclusion Higher Education Policy.” Michigan State University. Michigan. USA, 2011.

Falu, Nessette. “Lesbicas Negras’ Ethics and The Scales of Racialized Sexual Recognitions in Gynecology and Public Discourses in Salvador-Bahia.” Thesis, Rice University, 2015.

Farfán-Santos, Elizabeth. “‘Fraudulent’ Identities: The Politics of Defining Quilombo Descendants in Brazil.” *The Journal of Latin American and Caribbean Anthropology* 20, no. 1 (March 1, 2015): 110–32.

Felix, Andreza Aparecida, Helio M. Souza, and Sonia Beatriz F. Ribeiro. “Aspectos Epidemiológicos E Sociais Da Doença Falciforme.” *Revista Brasileira de Hematologia E Hemoterapia* 32, no. 3 (2010): 203–8.

Fernandes, APPC, José Nélio Januário, Camila Blanco Cangussu, Daniela Lino de Macedo, and Marcos Borato Viana. “Mortalidade de Crianças Com Doença Falciforme: Um Estudo de Base Populacional.” *J Pediatria (Rio de Janeiro)* 86, no. 4 (2010): 279–84.

Fleury, Sonia. “Brazil’s Health-Care Reform: Social Movements and Civil Society.” *The Lancet* 377, no. 9779 (2011): 1724–25.

Flores, William Vincent, and Rina Benmayor. *Latino Cultural Citizenship: Claiming Identity, Space, and Rights*. Beacon Press, 1997.

Forte, Maximilian C. *Who Is an Indian?: Race, Place, and the Politics of Indigeneity in the Americas*. University of Toronto Press, 2013.

Foucault, Michel. *Discipline and Punish : The Birth of the Prison*. New York: Pantheon Books, 1977.

———. *Madness and Civilization: A History of Insanity in the Age of Reason*. Vintage, 1965

———. *The Birth of the Clinic*. Routledge, 1963.

———. "The History of Sexuality, Volume I: An Introduction, Trans. Robert Hurley." *New York: Pantheon*, 1978.

Franco, Bruna de Melo, Juliana Cristina Hosken Gonçalves, and Cássio Roberto Rocha dos Santos. "Manifestações bucais da anemia falciforme e suas implicações no atendimento odontológico." *Arq. odontol* 43, no. 3 (September 2007): 92–96.

Franklin, I. M., and K. Atkin. "Employment of Persons with Sickle-Cell Disease and Sickle-Cell Trait." *Occupational Medicine* 36, no. 3 (1986): 76–79.

Franzini, Luisa, and Maria Eugenia Fernandez-Esquer. "Socioeconomic, Cultural, and Personal Influences on Health Outcomes in Low Income Mexican-Origin Individuals in Texas." *Social Science & Medicine* 59, no. 8 (October 2004): 1629–46.

Fraser, Nancy. "Social Justice in the Age of Identity Politics: Redistribution, Recognition, Participation." Discussion Papers, Research Unit: Organization and Employment. Social Science Research Center Berlin (WZB), 1998.

Freeman, Elizabeth Hordge. "Home Is Where the Hurt Is: Racial Socialization, Stigma, and Well-Being in Afro-Brazilian Families." Duke University, 2012.

Freitas, Anthony, Susan Kaiser, Davis Joan Chandler, Davis Carol Hall, Jung-Won Kim, and Tania Hammidi. "Appearance Management as Border Construction: Least Favorite Clothing, Group Distancing, and Identity Not!1." *Sociological Inquiry* 67, no. 3 (July 1, 1997): 323–35.

French, Jan Hoffman. *Legalizing Identities: Becoming Black Or Indian in Brazil's Northeast*. Univ of North Carolina Press, 2009.

Freyre, Gilberto. *The Masters and the Slaves: A Study in the Development of Brazilian Civilization*. New York, 1970.

Fry, Peter. *Divisões Perigosas: Políticas Raciais No Brasil Contemporâneo*. Editora Record, 2007.

———. "Remembering or Forgetting Mendel: Sickle Cell Anemia and Racial Politics in Brazil." In *Racial Identities, Genetic Ancestry, and Health in South America*, 155–74. Springer, 2011.

Fry, Peter H. "O Significado Da Anemia Falciforme No Contexto Da 'Política Racial' Do Governo Brasileiro 1995-2004." *História, Ciências, Saúde-Manguinhos* 12, no. 2 (August 2005): 347–70.

Fullwiley, D. "The Biologistical Construction of Race: `Admixture' Technology and the New Genetic Medicine." *Social Studies of Science* 38, no. 5 (October 1, 2008): 695–735.

Fullwiley, Duana. "Biosocial Suffering: Order and Illness in Urban West Africa." *BioSocieties* 1, no. 04 (December 2006): 421–38.

———. "Revaluating Genetic Causation: Biology, Economy, and Kinship in Dakar, Senegal." *American Ethnologist* 37, no. 4 (November 1, 2010): 638–61.

———. *The Enculturated Gene: Sickle Cell Health Politics and Biological Difference in West Africa*, 2011.

Gardner, P. "Oral History." In *The SAGE Dictionary of Social Research Methods*, edited by Jupp, Victor, 207–9. London; Thousand Oaks, Calif.: SAGE Publications, 2006.

Geddes, Barbara. “Building ‘State’ Autonomy in Brazil, 1930-1964.” *Comparative Politics* 22, no. 2 (January 1, 1990): 217–35.

Gibbon, Sahra, and Carlos Novas. *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*. Routledge, 2007.

Gibbon, Sahra, Ricardo Ventura Santos, and Mónica Sans. *Racial Identities, Genetic Ancestry, and Health in South America : Argentina, Brazil, Colombia, and Uruguay*. 1st edition. New York: Palgrave Macmillan, 2011.

Gieryn, Thomas F. “A Space for Place in Sociology.” *Annual Review of Sociology* 26 (January 1, 2000): 463–96.

Giles-Vernick, Tamara. “Oral Histories: Oral Histories as Methods and Sources.” In *A Handbook for Social Science Field Research: Essays & Bibliographic Sources on Research Design and Methods*, edited by Ellen Perecman and Sara R. Curran. Thousand Oaks, Calif: Sage Publications, 2006.

Gilliam, Angela, and Onik’a Gilliam. “Odyssey: Negotiating the Subjectivity of Mulata Identity in Brazil.” *Latin American Perspectives* 26, no. 3 (May 1, 1999): 60–84.

Glaser, Barney G. “The Constant Comparative Method of Qualitative Analysis.” *Social Problems* 12, no. 4 (April 1965): 436–45.

Glass, Thomas A., Carlos Mendes de Leon, Richard A. Marottoli, and Lisa F. Berkman. “Population Based Study of Social and Productive Activities as Predictors of Survival among Elderly Americans.” *BMJ* 319, no. 7208 (1999): 478–83.

Godreau, Isar P. “Blanqueamiento and the Celebration of Blackness as an Exception in Puerto Rico.” In *Globalization and Race: Transformations in the Cultural Production of Blackness*, 171, 2006.

Goldsmith, Arthur H., Darrick Hamilton, and William Darity Jr. “Shades of Discrimination: Skin Tone and Wages.” *The American Economic Review* 96, no. 2 (May 1, 2006): 242–45.

Gordon, Colin. “Government Rationality: An Introduction.” In *The Foucault Effect: Studies in Governmentality: With Two Lectures by and an Interview with Michel Foucault*, edited by Michel Foucault, Graham Burchell, and Peter Miller, 1–52. Chicago: University of Chicago Press, 1991.

Graham, Lawrence S. *Civil Service Reform in Brazil: Principles Versus Practice*. University of Texas Press, 1968.

Gravlee, Clarence C. “How Race Becomes Biology: Embodiment of Social Inequality.” *American Journal of Physical Anthropology* 139, no. 1 (February 18, 2009): 47–57.

Greene, Margaret E., and Vijayendra Rao. “The Marriage Squeeze and the Rise in Informal Marriage in Brazil.” *Social Biology* 42, no. 1–2 (March 1, 1995): 65–82.

Gregg, Jessica L. *Virtually Virgins: Sexual Strategies and Cervical Cancer in Recife, Brazil*. Stanford University Press, 2003.

Grupo Interministerial para Valorização da População Negra. 1998. “Saúde” Accessed November 22. http://www.biblioteca.presidencia.gov.br/ex-presidentes/fernando-henrique-cardoso/publicacoes-1

Guell, Cornelia. “Candi(e)d Action: Biosocialities of Turkish Berliners Living with Diabetes.” *Medical Anthropology Quarterly* 25, no. 3 (September 1, 2011): 377–94.

Guimarães, Cínthia Tavares Leal, and Gabriela Ortega Coelho. “The Importance of Genetic Counseling at Sickle Cell Anemia.” *Ciência & Saúde Coletiva* 15 (June 2010): 1733–40.

Guimarães, Tania MR, Wagner L. Miranda, and Márcia MF Tavares. “O Cotidiano Das Famílias de Crianças E Adolescentes Portadores de Anemia Falciforme.” *Rev. Bras. Hematol. Hemoter* 31, no. 1 (2009): 9–14.

Guizardi, Francini L., Grasiele Nespoli, Maria Luiza Silva Cunha, Felipe Rangel de Souza Machado, Márcia Cavalcanti Raposo Lopes, and others. “Políticas de Participação E Saúde,” 2014.

Hacking, Ian. “Genetics, Biosocial Groups & the Future of Identity.” *Daedalus* 135, no. 4 (2006): 81–95.

Hanchard, Michael George. *Orpheus and Power: The“ Movimento Negro” of Rio de Janeiro and Sao Paulo, Brazil 1945-1988*. Princeton University Press, 1998.

Hansen, Elisabeth, Erik Sund, Margunn Skjei Knudtsen, Steinar Krokstad, and Turid Lingaas Holmen. “Cultural Activity Participation and Associations with Self-Perceived Health, Life-Satisfaction and Mental Health: The Young HUNT Study, Norway.” *BMC Public Health* 15 (2015): 544.

Haraway, Donna. “Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective.” *Feminist Studies* 14, no. 3 (1988): 575–99.

Harper, Ian, and Parvathi Raman. “Less than Human? Diaspora, Disease and the Question of Citizenship.” *International Migration* 46, no. 5 (December 1, 2008): 3–26.

Harris, Michelle, Bronwyn Carlson, and Evan Poata-Smith. “Indigenous Identities and the Politics of Authenticity.” *Faculty of Law, Humanities and the Arts - Papers*, January 1, 2013, 1–9.

Hassell, Kathryn L. “Population Estimates of Sickle Cell Disease in the US.” *American Journal of Preventive Medicine* 38, no. 4 (2010): S512–21.

Hauskeller, Christine. “Race and the Genetic Revolution: Science, Myth and Culture.” *Ethnic and Racial Studies* 37, no. 10 (August 24, 2014): 1946–48.

“Healthy People 2020.” Accessed April 5, 2016. https://www.healthypeople.gov/.

Heller, Monica. *Codeswitching: Anthropological and Sociolinguistic Perspectives*. Walter de Gruyter, 1988.

Herek, G.M. “Illness, Stigma, and AIDS.” In *Psychological Aspects of Serious Illness: Chronic Conditions, Fatal Diseases, and Clinical Care.*, edited by Paul T. Costa and Gary R. VandenBos, 107–50. Washington: American Psychological Association, 1996.

Hill, Shirley. *Managing Sickle Cell Disease: In Low-Income Families*. Temple University Press, 2010.

Holanda, Sérgio Buarque de. *Roots of Brazil*. From the Helen Kellogg Institute for International Studies. Notre Dame, Ind: University of Notre Dame Press, 2012.

Holland, Dorothy, and Kevin Leander. “Ethnographic Studies of Positioning and Subjectivity: An Introduction.” *Ethos* 32, no. 2 (2004): 127–39.

Holston, James. “Contesting Privilege with Right: The Transformation of Differentiated Citizenship in Brazil.” *Citizenship Studies* 15, no. 3–4 (June 1, 2011): 335–52.

———. *Insurgent Citizenship: Disjunctions of Democracy and Modernity in Brazil*. Princeton University Press, 2008.

———. *The Modernist City: An Anthropological Critique of Brasilia*. University of Chicago Press, 1989.

Hordge Freeman, Elizabeth. “Home Is Where the Hurt Is: Racial Socialization, Stigma, and Well- Being in Afro-Brazilian Families.” Dissertation, Duke University, 2012.

Hordge-Freeman, Elizabeth. *The Color of Love: Racial Features, Stigma, and Socialization in Black Brazilian Families*. University of Texas Press, 2015.

Houtzager, Peter P., Adrián Gurza Lavalle, and Arnab Acharya. “Who Participates?: Civil Society and the New Democratic Politics in São Paulo, Brazil,” 2003.

Htun, Mala. “From "Racial Democracy" to Affirmative Action: Changing State Policy on Race in Brazil.” *Latin American Research Review* 39, no. 1 (2004): 60–89.

Hunter, Margaret. “The Persistent Problem of Colorism: Skin Tone, Status, and Inequality.” *Sociology Compass* 1, no. 1 (September 1, 2007): 237–54.

Hunter, Margaret L. “‘If You’re Light You’re Alright’ Light Skin Color as Social Capital for Women of Color.” *Gender & Society* 16, no. 2 (April 1, 2002): 175–93.

Hunter, Tera W. *To'Joy My Freedom: Southern Black Women's Lives and Labors after the Civil War*. Harvard University Press, 1997.

Jasanoff, Sheila, ed. *Reframing Rights: Bioconstitutionalism in the Genetic Age*. Cambridge, Mass: The MIT Press, 2011.

Jones, Camara P. "Systems of Power, Axes of Inequity: Parallels, Intersections, Braiding the Strands." *Medical Care* 52 (2014): S71–75.

Jones, Camara Phyllis. "Levels of Racism: A Theoretic Framework and a Gardener's Tale." *American Journal of Public Health* 90, no. 8 (2000): 1212.

———. "The Impacts of Racism on Health." *Department of Health and Social Behavior. Publisher Unknown*, 2000.

Jones, Camara Phyllis, Clara Yvonne Jones, Geraldine S. Perry, Gillian Barclay, and Camille Arnel Jones. "Addressing the Social Determinants of Children's Health: A Cliff Analogy." *Journal of Health Care for the Poor and Underserved* 20, no. 4A (2009): 1–12.

Jordan, Lanetta, Paul Swerdlow, and Thomas D. Coates. "Systematic Review of Transition From Adolescent to Adult Care in Patients With Sickle Cell Disease:" *Journal of Pediatric Hematology/Oncology* 35, no. 3 (April 2013): 165–69.

Júnior, José Patrício Bispo, and José Jackson Coelho Sampaio. "Participação Social Em Saúde Em Áreas Rurais Do Nordeste Do Brasil." *Rev Panam Salud Publica* 23, no. 6 (2008): 403.

Kadushin, Charles. *Understanding Social Networks: Theories, Concepts, and Findings*. New York: Oxford University Press, 2012.

Kahn, Jonathan. “Misreading Race and Genomics after BiDil.” *Nature Genetics* 37, no. 7 (2005): 655–56.

Kaizu, T., and H. S. Margolius. “Studies on Rat Renal Cortical Cell Kallikrein. I. Separation and Measurement.” *Biochimica Et Biophysica Acta* 411, no. 2 (December 5, 1975): 305–15.

Kalckmann, Suzana, Claudete Gomes dos Santos, Luís Eduardo Batista, and Vanessa Martins da Cruz. “Institutional Racism: A Challenge to Equity in the National Health System (SUS)?” *Saúde E Sociedade* 16, no. 2 (August 2007): 146–55.

Kent, Michael, Ricardo Ventura Santos, and Peter Wade. “Negotiating Imagined Genetic Communities: Unity and Diversity in Brazilian Science and Society.” *American Anthropologist* 116, no. 4 (2014): 736–48.

Kent, M., and P. Wade. “Genetics against Race: Science, Politics and Affirmative Action in Brazil.” *Social Studies of Science* 45, no. 6 (December 1, 2015): 816–38.

Key, Nigel S., and Vimal K. Derebail. “Sickle-Cell Trait: Novel Clinical Significance.” *ASH Education Program Book* 2010, no. 1 (2010): 418–22.

Kikuchi, Berenice A. “Nursing of Sickle Cell Disease in Basic Healthcare Services.” *Revista Brasileira de Hematologia E Hemoterapia* 29, no. 3 (2007): 331–38.

Koenig, Barbara A., Sandra Soo-Jin Lee, and Sarah S. Richardson. *Revisiting Race in a Genomic Age*. Rutgers University Press, 2008.

Krieger, Nancy. “Discrimination and Health Inequities.” *International Journal of Health Services* 44, no. 4 (January 1, 2014): 643–710.

———. “Embodying Inequality: A Review of Concepts, Measures, and Methods for Studying Health Consequences of Discrimination.” *International Journal of Health Services* 29, no. 2 (April 1, 1999): 295–352.

Labra, Maria Eliana. “Social Capital and Health Councils in Brazil: A Virtuous Circle?” *Cadernos de Saúde Pública* 18 (January 2002): S47–55.

Labra, Maria Eliana, and Jorge St Aubyn de Figueiredo. “Associativism, Participacion, Civic Culture and Health Councils in Brazil.” *Ciência & Saúde Coletiva* 7, no. 3 (January 2002): 537–47.

Labra, Maria Eliana, Silvia Gerschman, Flavio Coelho Edler, and Julio Manuel Suárez. “Conselhos de saúde: dilemas, avanços e desafios,” 2005, 353–83.

Laclau, Ernesto, and Chantal Mouffe. *Hegemony and Socialist Strategy: Towards a Radical Democratic Politics*. Verso, 2001.

LaFromboise, Teresa, Hardin L. Coleman, and Jennifer Gerton. “Psychological Impact of Biculturalism: Evidence and Theory.” *Psychological Bulletin* 114, no. 3 (1993): 395–412.

Laguardia, Josué. “No Fio Da Navalha: Anemia Falciforme, Raça E as Implicações No Cuidado À Saúde.” *Revista Estudos Feministas* 14, no. 1 (April 2006): 243–62.

LaRossa, Ralph. “Grounded Theory Methods and Qualitative Family Research.” *Journal of Marriage and Family* 67, no. 4 (November 2005): 837–57.

Laux, Lothar. *A Self-Presentational View of Coping with Stress*. Springer, 1986.

Leavy, Patricia. *Oral History*. Oxford; New York: Oxford University Press, 2011.

Lee, Sandra Soo-Jin, Joanna Mountain, and Barbara A. Koenig. "Meanings of Race in the New Genomics: Implications for Health Disparities Research, The." *Yale J. Health Pol'y L. & Ethics* 1 (2001): 33.

Lemke, Thomas, Monica J. Casper, and Lisa Jean Moore. *Biopolitics: An Advanced Introduction*. NYU Press, 2011.

Lervolino, Luciana Garcia, Paulo Eduardo Almeida Baldin, Silvia Miguéis Picado, Karina Barreto Calil, Ana Amélia Viel, and Luiz Alexandre Freixo Campos. "Prevalence of Sickle Cell Disease and Sickle Cell Trait in National Neonatal Screening Studies." *Revista Brasileira de Hematologia E Hemoterapia* 33, no. 1 (2011): 49–54.

Lesser, Jeffrey. *Immigration, Ethnicity, and National Identity in Brazil, 1808 to the Present*. Cambridge University Press, 2013.

Lima, Márcia. "Desigualdades Raciais E Políticas Públicas: Ações Afirmativas No Governo Lula." *Novos Estudos - CEBRAP*, no. 87 (July 2010): 77–95.

Lima, Nísia Trindade. "Public Health and Social Ideas in Modern Brazil." *American Journal of Public Health* 97, no. 7 (July 2007): 1168–77.

Lin, Nan. "Inequality in Social Capital." *Contemporary Sociology* 29, no. 6 (2000): 785–95.

Livingston, Julie. *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic*. Duke University Press, 2012.

Lock, Margaret. "Cultivating the Body: Anthropology and Epistemologies of Bodily Practice and Knowledge." *Annual Review of Anthropology* 22 (1993): 133–55.

Lopes, Fernanda. “Beyond the Numbers Barrier: Racial Inequalities and Health.” *Cadernos de Saúde Pública* 21, no. 5 (October 2005): 1595–1601.

Lopes, Fernanda, and Suzana Kalckmann. “Experiências desiguais ao nascer, viver, adoecer e morrer: tópicos em saúde da população negra no Brasil.” *Temas em Saúde Coletiva* 3 (2005): 53–101.

Lovell, Peggy A. “Gender, Race, and the Struggle for Social Justice in Brazil.” *Latin American Perspectives* 27, no. 6 (November 1, 2000): 85–102.

Lovell, Peggy A., and Charles H. Wood. “Skin Color, Racial Identity, and Life Chances in Brazil.” *Latin American Perspectives* 25, no. 3 (May 1, 1998): 90–109.

Loveman, Mara, Jeronimo O. Muniz, and Stanley R. Bailey. “Brazil in Black and White? Race Categories, the Census, and the Study of Inequality.” *Ethnic and Racial Studies* 35, no. 8 (August 2012): 1466–83.

Macedo, Luciana de Oliveira. “A Política de Saúde Da População Negra No Brasil: O Caso Da Anemia Falciforme (1996-2004),” 2006.

Maher, Frances A., and Mary Kay Tetreault. “Frames of Positionality: Constructing Meaningful Dialogues about Gender and Race.” *Anthropological Quarterly* 66, no. 3 (July 1993): 118.

Mahtani, Minelle. *Mixed Race Amnesia: Resisting the Romanticization of Multiraciality*, UBC Press, 2014.

Maia, Rousiley. “Democracia E a Internet Como Esfera Pública Virtual: Aproximando as Condições Do Discurso E Da Deliberação.” *Universidade de Brasília*, 2001.

Maio, Marcos Chor. “UNESCO and the Study of Race Relations in Brazil: Regional or National Issue?” *Latin American Research Review*, 2001, 118–36.

Maio, Marcos Chor, and Simone Monteiro. “Tempos de racialização: o caso da ' saúde da população negra ' no Brasil.” *Hist. Ciênc. Saúde-Manguinhos*. 12, no. 2 (August 2005): 419–46.

Maio, Marcos Chor, and Ricardo Ventura Santos. “Raça, Doença E Saúde Pública No Brasil: Um Debate Sobre O Pensamento Higienista Do Século XIX.” In *Raça Como Questão: História, Ciência E Identidades No Brasil*, 51–82. Fiocruz, 2010.

Marques, Larissa Nascimento, Alessandra Cavalcanti, and Andrea Ruzzi-Pereira. “O Viver Com a Doença Falciforme: Percepção de Adolescentes.” *Revista de Terapia Ocupacional Da Universidade de São Paulo* 26, no. 1 (April 24, 2015): 109.

Marshall, Thomas H. *Citizenship and Social Class*. Vol. 11. Cambridge, 1950.

Marsland, Rebecca. “(Bio) Sociality and HIV in Tanzania: Finding a Living to Support a Life.” *Medical Anthropology Quarterly* 26, no. 4 (2012): 470–85.

Mason, Jennifer. *Qualitative Researching*. 2nd ed. London ; Thousand Oaks, Calif: Sage Publications, 2002.

Mattingly, Cheryl. *The Paradox of Hope: Journeys through a Clinical Borderland*. University of California Press, 2010.

May, Tim, ed. “Narrative In Social Research.” In *Qualitative Research in Action*. London: SAGE, 2002.

McLaughlin, John P. “Cultural Analysis.” In *The A-Z of Social Research: A Dictionary of Key Social Science Research Concepts*, 61. SAGE Publications, Inc., 2003.

McPherson, Marianne, Lisa Thaniel, and Caterina P. Minniti. “Transition of Patients with Sickle Cell Disease from Pediatric to Adult Care: Assessing Patient Readiness.” *Pediatric Blood & Cancer* 52, no. 7 (July 1, 2009): 838–41.

Mendonça, João Maia de. “Comentários À Tese de Carlos E. Frimm.” *Revista Brasileira de Medicina* 5, no. 7 (1948): 553.

Mercer, Colin. *Towards Cultural Citizenship: Tools for Cultural Policy and Development*. Stockholm; Hedemora: Bank of Sweden Tercentenary Foundation ; Gidlunds Förlag, 2002.

Miller, Robert Lee. *Researching Life Stories and Family Histories*, 1999.

Minkoff, Debra C. “Producing Social Capital: National Social Movements and Civil Society.” *The American Behavioral Scientist* 40, no. 5 (April 1997): 606–19.

Miranda, Vítor. “A Resurgence of Black Identity in Brazil? Evidence from an Analysis of Recent Censuses.” *Demographic Research* 32, no. 59 (June 18, 2015): 1603–30.

Mitchell, Bruce L. “Sickle Cell Trait and Sudden Death–bringing It Home.” *Journal of the National Medical Association* 99, no. 3 (2007): 300.

Mol, Annemarie. “Ontological Politics. A Word and Some Questions.” *The Sociological Review* 47, no. S1 (May 1999): 74–89.

Monteiro, Simone, and Marcos Chor Maio. “Cor/Raça, Saúde E Política No Brasil (1995-2006).” *Raçanovas Perspectivas*, 2008, 121.

Monteiro, Simone, Marcos Chor Maio, M. C. De Souza Minayo, and C. Coimbra. “Etnicidade, Raça E Saúde No Brasil: Questões E Desafios.” *Críticas E Atuantes: Ciências Sociais E Humanas Em Saúde Na América Latina*, 2005.

Montoya, Michael J. *Making the Mexican Diabetic Race, Science, and the Genetics of Inequality*. Berkley, Calif.: University of California Press, 2011.

Moritz Schwarcz, Lilia. “A Mestizo and Tropical Country: The Creation of the Official Image of Independent Brazil.” *European Review of Latin American and Caribbean Studies | Revista Europea de Estudios Latinoamericanos Y Del Caribe* 0, no. 80 (April 15, 2006): 25.

Morning, A. “Does Genomics Challenge the Social Construction of Race?” *Sociological Theory* 32, no. 3 (September 1, 2014): 189–207.

Mosby, Inc, ed. *Mosby’s Medical Dictionary*. 8th ed. St. Louis, MO: Mosby, 2009.

Murji, Karim, and John Solomos, eds. *Racialization: Studies in Theory and Practice*. Oxford ; New York: Oxford University Press, 2005.

Nelson, Alondra. *Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination*. U of Minnesota Press, 2011.

———. *The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome*. Beacon Press, 2016.

Ness, Daniel W. Van, and Karen Heetderks Strong. *Restoring Justice: An Introduction to Restorative Justice*. Routledge, 2010.

Nobles, Melissa. *Shades of Citizenship: Race and the Census in Modern Politics*. Stanford, Calif: Stanford University Press, 2000.

Novas, Carlos. "Genetic Advocacy Groups, Science and Biovalue: Creating Political Economies of Hope." In *New Genetics, New Identities*, edited by Paul Atkinson and Peter Glasner, 11–27. London, UK: Routledge, 2007.

Nowicka, Magdalena, and Louise Ryan. "Beyond Insiders and Outsiders in Migration Research: Rejecting A Priori Commonalities. Introduction to the FQS Thematic Section on' Researcher, Migrant, Woman: Methodological Implications of Multiple Positionalities in Migration Studies.'" In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, Vol. 16, 2015.

Nugent, David, and Joan Vincent. *A Companion to the Anthropology of Politics*. John Wiley & Sons, 2004.

Nunn, A. S., E. M. da Fonseca, F. I. Bastos, and S. Gruskin. "AIDS Treatment In Brazil: Impacts And Challenges." *Health Affairs* 28, no. 4 (July 1, 2009): 1103–13.

O'Connor, Tom. "Qualitative Research Methodologies." presented at the MegaLinks in Criminal Justice, n.d. Accessed March 4, 2013.

Ohara, Daniela G., Gualberto Ruas, Shamyr S. Castro, Paulo RJ Martins, and Isabel AP Walsh. "Musculoskeletal Pain, Profile and Quality of Life of Individuals with Sickle Cell Disease." *Brazilian Journal of Physical Therapy* 16, no. 5 (2012): 431–38.

Oliveira, F. *Saúde Da População Negra: Brasil Ano 2001. Organização Pan-Americana Da Saúde*. Brasília, 2003.

O'neill, Onora. "Bounded and Cosmopolitan Justice." *Review of International Studies* 26, no. 05 (December 2000): 045–060.

Ong, Aihwa. "Cultural Citizenship as Subject Making: Immigrants Negotiate Racial and Cultural Boundaries in the United States." *Race, Identity, and Citizenship: A Reader*, 1999, 262–93.

Ong, Aihwa, Virginia R. Dominguez, Jonathan Friedman, Nina Glick Schiller, Verena Stolcke, David Y. H. Wu, and Hu Ying. "Cultural Citizenship as Subject-Making: Immigrants Negotiate Racial and Cultural Boundaries in the United States [and Comments and Reply]." *Current Anthropology* 37, no. 5 (December 1, 1996): 737–62.

Owensby, Brian P. *Intimate Ironies: Modernity and the Making of Middle-Class Lives in Brazil*. Stanford University Press, 1999.

Ownby, Terry. "Critical Visual Methodology: Photographs and Narrative Text as a Visual Autoethnography." Accessed February 20, 2015.

Pagano, A. "Afro-Brazilian Religions and Ethnic Identity Politics in the Brazilian Public Health Arena." *Health, Culture and Society* 3, no. 1 (August 14, 2012): 1–28.

Pagano, Anna. "Health in Black and White: Debates on Racial and Ethnic Health Disparities in Brazil." Dissertation. University of California, San Diego, 2011.

Paim, Jairnilson, Claudia Travassos, Celia Almeida, Ligia Bahia, and James Macinko. "The Brazilian Health System: History, Advances, and Challenges." *The Lancet* 377, no. 9779 (2011): 1778–97.

Parker, Richard. “Building the Foundations for the Response to HIV/AIDS in Brazil: The Development of HIV/AIDS Policy, 1982–1996.” *Divulgação Em Saúde Para Debate* 27 (2003): 143–83.

Parra, Flavia C., Roberto C. Amado, José R. Lambertucci, Jorge Rocha, Carlos M. Antunes, and Sérgio DJ Pena. “Color and Genomic Ancestry in Brazilians.” *Proceedings of the National Academy of Sciences* 100, no. 1 (2003): 177–82.

Peard, Julyan G. *Race, Place, and Medicine: The Idea of the Tropics in Nineteenth Century Brazilian Medicine*. Durham, NC: Duke University Press, 1999.

———. “Tropical Disorders and the Forging of a Brazilian Medical Identity, 1860-1890.” *The Hispanic American Historical Review* 77, no. 1 (February 1997): 1.

Pellegrini Filho, Alberto. “Public Policy and the Social Determinants of Health: The Challenge of the Production and Use of Scientific Evidence.” *Cadernos de Saúde Pública* 27 (2011): s135–40.

Pena, Sérgio DJ. “Razões Para Banir O Conceito de Raça Da Medicina Brasileira.” *Hist. Ciênc. Saúde-Manguinhos* 12, no. 2 (2005): 321–46.

———. “Reasons for Banishing the Concept of Race from Brazilian Medicine.” *História, Ciências, Saúde-Manguinhos* 12, no. 2 (2005): 321–46.

Pena, Sérgio DJ, and Maria Cátira Bortolini. “Pode a Genética Definir Quem Deve Se Beneficiar Das Cotas Universitárias E Demais Ações Afirmativas?” *Estudos Avançados* 18, no. 50 (2004): 31–50.

Pena, Sérgio DJ, Giuliano Di Pietro, Mateus Fuchshuber-Moraes, Julia Pasqualini Genro, Mara H. Hutz, Fernanda de Souza Gomes Kehdy, Fabiana Kohlrausch, et al. "The Genomic Ancestry of Individuals from Different Geographical Regions of Brazil Is More Uniform than Expected." *PloS One* 6, no. 2 (2011): e17063.

Pereira, Sônia Aparecida dos Santos, Stela Brener, Clareci Silva Cardoso, and Anna Bárbara de Freitas Carneiro Proietti. "Sickle Cell Disease: Quality of Life in Patients with Hemoglobin SS and SC Disorders." *Revista Brasileira de Hematologia E Hemoterapia* 35, no. 5 (2013): 325–31.

Perry, Keisha-Khan Y. *Black Women against the Land Grab: The Fight for Racial Justice in Brazil*. Minneapolis: Univ Of Minnesota Press, 2013.

Petruccelli, José Luis. *A Cor Denominada: Estudos Sobre a Classificação Étnico-Racial*. LPP/Uerj, 2007.

Petryna, Adriana. "Biological Citizenship: The Science and Politics of Chernobyl-Exposed Populations." *Osiris*, 2nd Series, 19 (January 1, 2004): 250–65.

———. *Life Exposed: Biological Citizens after Chernobyl*. With a New introduction by the author edition. Princeton, NJ: Princeton University Press, 2003.

Perreira, Krista M., and Edward E. Telles. "The Color of Health: Skin Color, Ethnoracial Classification, and Discrimination in the Health of Latin Americans." *Social Science & Medicine* 116 (2014): 241–50.

Platt, Allan F., and Alan Sacerdote. *Hope and Destiny: The Patient and Parent's Guide to Sickle Cell Disease and Sickle Cell Trait*. Hilton Pub, 2002.

Pollock, Anne. *Medicating Race: Heart Disease and Durable Preoccupations with Difference*. Duke University Press, 2012.

Pravaz, Natasha. “Brazilian Mulatice: Performing Race, Gender, and the Nation.” *Journal of Latin American Anthropology* 8, no. 1 (March 1, 2003): 116–46.

Purvis, Trevor, and Alan Hunt. “Identity versus Citizenship: Transformations in the Discourses and Practices of Citizenship.” *Social & Legal Studies* 8, no. 4 (1999): 457–82.

Rabinow, Paul. “Artificiality and Enlightenment: From Sociobiology to Biosociality.” In *Incorporations*, edited by Jonathan Crary and Sanford Kwinter, 236–52. Zone 6. New York, NY: Zone, 1992.

———. *Essays on the Anthropology of Reason*. Princeton University Press, 1996.

Rabinow, Paul, and Nikolas Rose. “Biopower Today.” *BioSocieties* 1, no. 2 (June 2006): 195–217.

Raco, Mike. “Neoliberal Urban Policy, Aspirational Citizenship and the Uses of Cultural Distinction.” In *Contradictions of Neoliberal Planning: Cities, Policies, and Politics*, edited by Tuna Taşan-Kok and Guy Baeten, 43–59. The geoJournal Library, v. 102. Dordrecht ; New York: Springer, 2012.

Ramalho, Antonio Sérgio, and Luís Alberto Magna. “A Portaria No 822/01 Do Ministério Da Saúde E as Peculiaridades Das Hemoglobinopatias Em Saúde Pública No Brasil Government Directive MS# 822/01: Unique Aspects of Hemoglobinopathies.” *Cad. Saúde Pública* 19, no. 4 (2003): 1195–99.

Rapp, Rayna, Deborah Heath, and Karen-Sue Taussig. "Genetic Citizenship." *Companion to the Handbook of Political Anthropology* (2004).

Rawls, John. *A Theory of Justice*. Harvard University Press, 1971.

———. *Political Liberalism*. Columbia University Press, 1993.

———. *The Law of Peoples: With, The Idea of Public Reason Revisited*. Harvard University Press, 2001.

———. "Themes in Kant's Moral Philosophy (1989)." In *Collected Papers*, edited by Samuel Richard Freeman, 497–528. Cambridge, Mass: Harvard University Press, 1999.

Reardon, Jenny. *Race to the Finish: Identity and Governance in an Age of Genomics*. Princeton University Press, 2009.

———. "The Democratic, Anti-Racist Genome? Technoscience at the Limits of Liberalism." *Science as Culture* 21, no. 1 (March 2012): 25–47.

Rees, David C, Thomas N Williams, and Mark T Gladwin. "Sickle-Cell Disease." *The Lancet* 376, no. 9757 (December 2010): 2018–31.

Reiter, Bernd, and Gladys L. Mitchell. *Brazil's New Racial Politics*. Boulder, Colo.: Lynne Rienner Publishers, 2010.

Ricoeur, Paul. *Time and Narrative, Translated by K. McLaughlin and D. Pellauer. Vol. 1*. Chicago: University of Chicago Press, 1984.

Riessman, Catherine Kohler. "Narrative Analysis." *In: Narrative, Memory & Everyday Life.*, 2005, 1–7.

Risch, Neil, Esteban Burchard, Elad Ziv, and Hua Tang. "Categorization of Humans in Biomedical Research: Genes, Race and Disease." *Genome Biol* 3, no. 7 (2002): 1–12.

Roland, Edna. "PAF: Um Programa Que Ainda Não Saiu Do Papel." *Jornal Da Rede Feminista de Saúde* 23 (2001): 1–4.

Rosaldo, R. “Cultural Citizenship, Inequality, and Multiculturalism.” In *Latino Cultural Citizenship: Claiming Identity, Space, and Rights*, edited by William Vincent Flores and Rina Benmayor, 27–38. Boston: Beacon Press, 1997.

Rosa, Luciane de Jesus, and Marina Helena Cury Gallottini de Magalhäes. “Aspectos gerais e bucais da anemia falciforme e suas implicaçöes no atendimento odontológico.” *Rev. Assoc. Paul. Cir. Dent* 56, no. 5 (October 2002): 377–81.

Rose, Nikolas, and Carlos Novas. “Biological Citizenship”. Global Anthropology. Blackwell Publishing, 2002.

Rouse, Carolyn Moxley. *Uncertain Suffering: Racial Health Care Disparities and Sickle Cell Disease*. University of California Press, 2009.

Royal, Charmaine D., Charles R. Jonassaint, Jude C. Jonassaint, and Laura M. De Castro. “Living with Sickle Cell Disease: Traversing ‘race’ and Identity.” *Ethnicity & Health* 16, no. 4–5 (August 1, 2011): 389–404.

Sansone, Livio. *Blackness without Ethnicity Constructing Race in Brazil*. New York: Palgrave, 2003.

Santos, Ricardo Ventura. “Guardian Angel on a Nation’s Path.” *Current Anthropology* 53, no. S5 (2012): S17–32.

Santos, S. A. d. “Who Is Black in Brazil? A Timely or a False Question in Brazilian Race Relations in the Era of Affirmative Action?” *Latin American Perspectives* 33, no. 4 (July 1, 2006): 30–48.

Schatz, Edward, ed. “Ethnographic Immersion and the Study of Politics.” In *Political Ethnography: What Immersion Contributes to the Study of Power*, 1–22. Chicago ; London: The University of Chicago Press, 2009.

Scheper-Hughes, Nancy. *Death Without Weeping: The Violence of Everyday Life in Brazil*. University of California Press, 1992.

Schotte, Simone. “The Role of Inequality in Economic Development-Implications from Brazil’s ‘New Middle Class,’” 2012.

Schwarcz, Lilia Moritz. *Not Black, Not White: Just the Opposite: Culture, Race and National Identity in Brazil*. Centre for Brazilian Studies, 2003.

———. *The Spectacle of the Races: Scientists, Institutions, and the Race Question in Brazil, 1870-1930*. Hill and Wang, 1999.

Schwarcz, Lilia Moritz, and John Gledson. *The Emperor’s Beard: Dom Pedro II and the Tropical Monarchy of Brazil*. 1st American ed. New York: Hill and Wang, 2004.

Schwartzman, Luisa Farah. “Does Money Whiten? Intergenerational Changes in Racial Classification in Brazil.” *American Sociological Review* 72, no. 6 (December 1, 2007): 940–63.

Shavers-Hornaday, V. L., C. F. Lynch, L. F. Burmeister, and J. C. Torner. “Why Are African Americans under-Represented in Medical Research Studies? Impediments to Participation.” *Ethnicity & Health* 2, no. 1–2 (June 1997): 31–45.

Shore, Cris, and Susan Wright. *Anthropology of Policy: Perspectives on Governance and Power*. Routledge, 2003.

Silberling, Louise S. “Displacement and Quilombos in Alcantara, Brazil: Modernity, Identity, and Place*.” *International Social Science Journal* 55, no. 175 (2003): 145–56.

Silva, Roberto B. de Paiva e, Antonio S. Ramalho, and Roosevelt M. S. Cassorla. “A Anemia Falciforme Como Problema de Saúde Pública No Brasil.” *Revista de Saúde Pública* 27, no. 1 (February 1993).

Skidmore, Thomas E. *Black into White: Race and Nationality in Brazilian Thought: With a Preface to the 1993 Edition and Bibliography*. Durham: Duke University Press, 1993.

Smedley, Audrey, and Brian D. Smedley. “Race as Biology Is Fiction, Racism as a Social Problem Is Real: Anthropological and Historical Perspectives on the Social Construction of Race.” *American Psychologist* 60, no. 1 (2005): 16–26.

Snow, David A., Sarah A. Soule, and Hanspeter Kriesi. *The Blackwell Companion to Social Movements*. John Wiley & Sons, 2008.

Stepan, Nancy. *Beginnings of Brazilian Science: Oswaldo Cruz, Medical Research and Policy, 1890-1920*. New York: Science History Publications, 1976.

———. *The Hour of Eugenics: Race, Gender, and Nation in Latin America*. Cornell University Press, 1991.

———. *The Idea of Race in Science: Great Britain, 1800-1960*. Hamden, Conn: Archon Books, 1982.

Sue, Christina A. *Land of the Cosmic Race: Race Mixture, Racism, and Blackness in Mexico*. OUP USA, 2013.

Sweet, Elizabeth. *Exploring the Early Development of Health Inequality Culture, Stress, and Health among African American Adolescents*. Dissertation. ProQuest, 2008.

Sydenstricker, V. P. "Elliptic Human Erythrocytes." *Journal of the American Medical Association* 81, no. 2 (1923): 113–14.

Takahashi, Claudia Regina Iumi, Santos Júnior, Décio Dos, Fabio Daumas Nunes, and Ney Soares de Araújo. "Atendimento odontológico ao paciente com anemia falciforme." *Rev. odontopediatr* 2, no. 4 (December 1993): 215–18.

Tannenbaum, Frank. *Slave and Citizen*. Boston: Beacon Press, 1992.

Tapper, Melbourne. *In the Blood: Sickle Cell Anemia and the Politics of Race*. University of Pennsylvania Press, 1999.

Tasan-Kok, Tuna, and Guy Baeten. *Contradictions of Neoliberal Planning: Cities, Policies, and Politics*. Springer Science & Business Media, 2011.

Taussig, Karen-Sue. *Ordinary Genomes: Science, Citizenship, and Genetic Identities*. 1st Edition. Durham NC: Duke University Press Books, 2009.

Telfair, Joseph, Jennifer Myers, and Sherree Drezner. "Transfer as a Component of the Transition of Adolescents with Sickle Cell Disease to Adult Care: Adolescent, Adult, and Parent Perspectives." *Journal of Adolescent Health* 15, no. 7 (November 1, 1994): 558–65.

Telles, Edward. *Pigmentocracies: Ethnicity, Race, and Color in Latin America*. 1 edition. The University of North Carolina Press, 2014.

Telles, Edward E. “Who Gets Formal Sector Jobs? Determinants of Formal-Informal Participation in Brazilian Metropolitan Areas.” *Work and Occupations* 19, no. 2 (May 1, 1992): 108–27.

Telles, Edward Eric. *Race in Another America: The Significance of Skin Color in Brazil*. Princeton, N.J: Princeton University Press, 2004.

Terreri, Josefina Aparecida P. “Qualidade de Vida Em Portadores de Doença Falciforme.” *Rev Paul Pediatr* 31, no. 1 (2013): 24–29.

Teixeira, Carmen Fontes, and Marcos Vinícius Ribeiro de Araújo. “Formulação Da Política De Saúde Da População Negra Em Salvador: Atores e Propostas.” *Revista Baiana de Saúde Pública* 37, no. 4 (July 31, 2014): 891.

“The Forms of Capital by Pierre Bourdieu 1986.” Accessed January 9, 2016.

Theobald, Douglas L. “A Formal Test of the Theory of Universal Common Ancestry.” *Nature* 465, no. 7295 (May 13, 2010): 219–22.

Thompson, Paul. *Voice of the Past: Oral History*. OUP Oxford, 1978.

Tilly, Charles. “Afterword: Political Ethnography as Art and Science.” In *New Perspectives in Political Ethnography*, 247–50. Springer, 2007.

Townsend, Peter. *Poverty in the United Kingdom: A Survey of Household Resources and Standards of Living*. University of California Press, 1979.

Travassos, Claudia, and David R. Williams. “The Concept and Measurement of Race and Their Relationship to Public Health: A Review Focused on Brazil and the United States.” *Cadernos de Saúde Pública* 20, no. 3 (2004): 660–78.

Tsaras, Geoffrey, Amma Owusu-Ansah, Freda Owusua Boateng, and Yaw Amoateng-Adjepong. “Complications Associated with Sickle Cell Trait: A

Brief Narrative Review." *The American Journal of Medicine* 122, no. 6 (June 2009): 507–12.

Twine-Dance, Frances. *Racism in a Racial Democracy*. New Brunswick: Rutgers University Press, 1998.

Twine, France Winddance. "Racial Ideologies and Racial Methodologies." *Racing Research, Researching Race: Methodological Dilemmas in Critical Race Studies*, 2000, 1–34.

Twine, France Winddance, and Jonathan W. Warren, eds. *Racing Research, Researching Race: Methodological Dilemmas in Critical Race Studies*. New York: New York University Press, 2000.

Veblen, Thorstein. *The Theory of the Leisure Class*. Dover Thrift Editions. New York: Dover Publications, 1918.

Victora, Cesar G., Mauricio L. Barreto, Maria do Carmo Leal, Carlos A. Monteiro, Maria Ines Schmidt, Jairnilson Paim, Francisco I. Bastos, et al. "Health Conditions and Health-Policy Innovations in Brazil: The Way Forward." *The Lancet* 377, no. 9782 (2011): 2042–53.

Wade, Peter. *Race and Ethnicity in Latin America*. 2 edition. London ; New York : New York: Pluto Press, 2010.

———. *Race, Nature and Culture: An Anthropological Perspective*. Pluto Press London, 2002.

Wade, Peter, Carlos López Beltrán, Eduardo Restrepo, and Ricardo Ventura Santos, eds. *Mestizo Genomics: Race Mixture, Nation, and Science in Latin America*. Durham: Duke University Press, 2014.

Wailoo, K. "'A Disease Sui Generis': The Origins of Sickle Cell Anemia and the Emergence of Modern Clinical Research, 1904-1924." *Bulletin of the History of Medicine* 65, no. 2 (1991): 185–208.

Wailoo, Keith. *Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health*. UNC Press Books, 2001.

Wan, H., and C. Horvath. "Behavior of Soluble and Immobilized Acid Phosphatase in Hydro-Organic Media." *Biochimica Et Biophysica Acta* 410, no. 1 (November 20, 1975): 135–44.

Washington, Scott Leon. "Hypodescent: A History of the Crystallization of the One-Drop Rule in the United States, 1880--1940." Dissertation. Princeton University, 2011.

Weber, Max. "Class, Status, Party." In *From Max Weber: Essays in Sociology*, edited by Hans Heinrich Gerth and C. Mills, Oxford University Press paperback, [Nachdr.]., 180–95. New York: Oxford Univ. Press, 1959.

Wedel, Janine R., Cris Shore, Gregory Feldman, and Stacy Lathrop. "Toward an Anthropology of Public Policy." *The ANNALS of the American Academy of Political and Social Science* 600, no. 1 (2005): 30–51.

Weheliye, Alexander G. *Habeas Viscus: Racializing Assemblages, Biopolitics, and Black Feminist Theories of the Human*. Duke University Press, 2014.

Weiner, A. S., and E. Sonn. "Pathogenesis of Congenital Hemolytic Disease." *Am. J. Dis. Child.* 7 (1946): 14.

Wendhausen, Agueda Lenita P. "[Power relations and democracy in health councils in Brazil: a case study]." *Revista Española De Salud Pública* 80, no. 6 (December 2006): 697–704.

Weyland, Kurt. *Democracy without Equity: Failures of Reform in Brazil*. University of Pittsburgh Press, 1996.

———. "The Brazilian State in the New Democracy." *Journal of Interamerican Studies and World Affairs* 39, no. 4 (1997): 63–94.

Whaley, Arthur L. "Cultural Mistrust of White Mental Health Clinicians among African Americans with Severe Mental Illness." *American Journal of Orthopsychiatry* 71, no. 2 (2001): 252.

White, Luise. "' They Could Make Their Victims Dull': Genders and Genres, Fantasies and Cures in Colonial Southern Uganda." *The American Historical Review*, 1995, 1379–1402.

Williams, Bill, and Paul Thompson. *The Voice of the Past: Oral History*. JSTOR, 1979.

Williams, Monnica, and Eric Turkheimer. "The Effects of Interviewer Race on Anxiety in African Americans." *Leading-Edge Health Education Issues. Berlin: Springer*, 2008.

Williamson, Kenneth. "Night Becomes Day: Carnival, Contested Spaces, and the Black Movement in Bahia." *The Journal of Latin American and Caribbean Anthropology* 17, no. 2 (2012): 257–78.

Wojciechowski, Elizabeth A., Anita Hurtig, and Louise Dorn. "A Natural History Study of Adolescents and Young Adults with Sickle Cell Disease as They Transfer to Adult Care: A Need for Case Management Services." *Journal of Pediatric Nursing* 17, no. 1 (February 2002): 18–27.