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Author

Dubbin, Leslie Anne

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Race, Place and Space: Illness Narratives of African Americans Living With Coronary Heart

Disease

By

Leslie A. Dubbin

DISSERTATION

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Race, Place and Space: Illness Narratives of African Americans Living with Coronary Heart Disease
By Leslie A. Dubbin

Abstract: Addressing racial inequalities in health requires attending to the multiple social mechanisms through which such inequalities are produced. By exploring the range of social factors that influences the experiences of African Americans living with coronary heart disease (CHD), this dissertation describes the processes through which race remains a powerful determinant of health status in the United States and why it continues to be so disproportionately consequential for African Americans in particular. From a methodological standpoint, I argue that critical interactionism provides an innovative approach to the study of racial inequalities by highlighting participants' health and illness experiences at the micro level while providing an analytical framework to study how meso and macro level social factors influence those experiences. Second, I demonstrate that for African Americans, the development and progression of CHD cannot be separated from their social, cultural and racial moorings and that most of the participants consider CHD a "black disease" that carries with it a strong historical and culturally sustaining legacy. Third, using Carpiano's Bourdieusian based framework of social capital, this dissertation takes account of within neighborhood variations of social capital, adding a more nuanced and in-depth understanding of the local conditions and contingent mechanisms through which social capital is generated. By focusing on the types of resources inhered within various forms of social capital, I demonstrate how the costs of cultivating and sustaining social capital can outweigh its potential health related benefits.   Fourth, through an extended narrative, I provide a portrait of how the lived environment shapes one's sense of place and how health is produced or undermined through everyday contexts, experiences and burdens. I employ the concepts of habitus and collective habitus as analytics to explore the ways in which bodies, place, and social space are linked together and the effect that linkage has on stress production, perception and experience. I demonstrate how even within the same geographically defined neighborhoods, different lived environments exist producing different types of collective habitus where different attributes, values, expectations and ways of being predominate. I argue that when one collective habitus intrudes upon another, social tensions are created and manifested bodily through stress production, perception and experience.   Lastly, I emphasize the importance of taking account of ongoing racial and social dynamics through which inequalities in health are created, sustained and reproduced.

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Chapter one

Introduction

It was only about 20 years ago that St. Sebastian Medical Center[1] began its interventional

cardiology program, offering a range of percutaneous coronary interventions for the treatment of

coronary heart disease (CHD). When the program began, I was already an experienced

cardiovascular critical care nurse, and I was absolutely enthralled with this new technology. At

every possible opportunity, I would follow my patients to the cardiac catheterization laboratory

and marveled at how quickly and seemingly easy it was for our interventional cardiologist to

open a blocked coronary artery of a patient suffering from an acute myocardial infarction (MI)

by simply inflating a balloon in it. Literally, within minutes, a patient went from dying of heart

disease to surviving it. It wasn't long before I put in a request to transfer from the Coronary Care

Unit (CCU) to the Cardiac Catheterization Lab. I threw myself into my new job and learned

every aspect of it. The job was fast paced, high stress, life and death, and adrenaline producing.

To be honest, it was fun!

Within the first year of my transfer, I worked very closely with our interventional

physician, Dr. Seton, to greatly expand our program. We developed an "on-call" system that

really comprised just the two of us and we responded to every cardiac emergency twenty-four

hours a day, seven days a week. On one particularly busy day, we were paged to the Emergency

Department (ED) that a 53-year-old white male had come in suffering from an acute antero-

lateral wall MI, endangering about two-thirds of his entire heart muscle. When we got to the ED,

the patient was critically ill. He was writhing with crushing chest pain, gray in color, diaphoretic

and had a deathly low blood pressure. His lungs were filling with fluid due to the poor pumping

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[1] Pseudonym

action of his left ventricle causing him to be extremely short of breath. Dr. Seton and I looked at each other knowing that this case was going to be touch and go; within minutes we had the patient in the cath lab, prepped and the procedure started. Once Dr. Seton was able to position the balloon in the artery and reestablish blood flow through it, the patient started to respond. His blood pressure rose to normal limits, his color and breathing improved and he quickly stabilized. Post procedure, the patient was admitted to the CCU and Dr. Seton and I shared a few much-deserved high-fives.

Close to the end of the day as we were finishing the last of our elective cases, our pagers went off again. Dr. Seton and I went back down to the ED together only to find this time the patient was a 55-year-old black woman suffering from the same type of MI as the previous patient. I remember remarking to Dr. Seton that her electrocardiogram abnormalities (indicating the affected territory of the heart) were identical to that of the patient we had treated earlier in the day. Except for the fact that she was black and female, she "looked" just like him. She was suffering from crushing chest pain, diaphoresis, and her severely low blood pressure was causing her nail beds to turn a deathly shade of blue.

Without thinking about it, I began to get her ready to take her upstairs to the cath lab when Dr. Seton said, "Les, let's wait. We are going to medically manage her instead". Seeing that I was a bit puzzled, Dr. Seton gestured to the patient and said, "Blacks, especially black women, don't do as well with PTCA [percutaneous transluminal coronary angioplasty—the balloon procedure described above]. We are going to treat her conservatively".

Stepping out into the hallway to discuss the case with the cardiology team in charge of her care, I argued forcefully that it made no difference that "blacks typically didn't do as well" and that clearly she would die if we didn't try to be more aggressive. I lost that argument and the

team instead ordered the appropriate "conservative" drug regimen and the patient was taken to the CCU. She was placed in a room next door to the white male we had treated earlier. For the next four days, I watched as the white male patient got steadily better while the black female patient got steadily worse. On the fourth day, as the white male patient was being transferred out of the CCU to a lower level of care, the black female patient had a cardiac arrest from which she could not be resuscitated.

That experience was a seminal event in my career as a Registered Nurse for it opened my eyes to the disparate treatment based on race that I shamefully never noticed before, and also to the disproportionate distribution of diseases that exist across various racial groups. And although it has taken me 20 years to get here, it is my hope that this dissertation contributes to the study and understandings of the dynamics that lead to racial inequalities in health.

Statement of the Problem

Although there has been a rapid decline on all-cause mortality rates in the United States over the last 60 years, a racial gap still exists between black and white Americans where black Americans suffer a disproportionate burden of death on nearly every measure of health compared to white Americans (Geronimus, Bound, & Colen, 2011; D. R. Williams & Rucker, 2000). This gap is most pronounced in the realm of coronary heart disease (CHD), where according to the latest statistics, the mortality rates (per 100,000 population) for CHD were 226.9 for white males and 286.3 for black males, and 147.5 for white females and 185.1 for black females (Centers for Disease Control and Prevention, 2013).

Coronary heart disease, coronary artery disease, acute myocardial infarction, and acute coronary syndrome provide the clinical context for some of the most elaborate studies of racial

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inequalities in health care and health outcomes. Coronary heart disease has a natural history and its physiology, risk factors, and complications are well understood (Geiger, 2003). However, investigating racial inequalities in health requires attending to the multiple social mechanisms and interactions through which such inequalities may be produced in the first place. Social factors such as the distribution of political, economic and labor forces, racial stratification, cultural ideologies and class hierarchies constitute racialized processes that may result in social inequalities along racial lines (Omi & Winant, 1994, 2008; Pinderhughes & Shim, n.d.). By better understanding how social structure "works" to produce racial inequalities in health, researchers and policy makers may glean insights into how social forces mold a group's collective health status and lead efforts toward the development of logical macro social interventions to improve population health. Such research also has implications at the micro level where we may gain a better understanding of the relationship between the development and progression of CHD and the social environment and the social conditions under which black Americans live.

To that end, I address the following research questions in this dissertation: What are the processes by which race remains such a powerful determinant of cardiovascular health status in the United States? And why has it been so disproportionately consequential for black Americans in particular? Specifically, the aims of this study are:

1. To explore the range of social factors that influences the experiences of black Americans living with CHD. This aim seeks to examine the power relations and social structures (education, housing, neighborhoods and health care) that facilitate or constrain what participants diagnosed with CHD believe they are able to do or to be, and the effect such structures have on their life's course.

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2.　　　　To explore black Americans' conceptualization of stress and how it is generated and manifested within various social fields. This aim seeks to describe how the perception of stress interacts with the development and progression of CHD.

Epistemological Foundation:　Critical Interactionism

This dissertation is grounded by the theoretical underpinnings of critical interactionism, a fusion of critical theory and symbolic interactionist approaches. Generally speaking, all forms of critical qualitative research involve the study of macro-social factors and are primarily concerned with social inequalities and the nature of social structure, power, culture, and human agency. Critical research is one genre of inquiry into the various aspects of social life that is premised on an assumption that society is inequitably structured and suppresses consideration and understanding of why things are the way they are, and what must be done for things to be otherwise (Simon & Dippo, 1986). Through a critical lens, the researcher examines the power relations that structure how everyday life is experienced within a particular lived environment and investigates the structures that regulate and legitimate specific ways of being, communicating, knowing and acting (Madison, 2005; Simon & Dippo, 1986). The goal of critical research is to illuminate and begin to address the structural processes that limit, constrain, define and redefine the boundaries of what one is able to do or to be.

Symbolic interactionism

As a distinctive approach to the study of human group life and conduct, symbolic interactionism primarily rests on three underlying assumptions, according to Blumer (1969) .

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First, we live in a symbolic world of learned meanings; that is, we act toward things based on the meanings those things have for us. Second, the meanings of those things are derived from the social interactions that we have with others. And third, we engage with, handle, and modify those meanings through an interpretive process as we encounter and interact with things and people. Foundational to the symbolic interactionist tradition is that whatever meanings we assign to things arise from the ways other people act toward us in relation to those things and our own responses in social interactions. In other words, how others act help to define the meaning of a thing for us. Therefore, meanings are social products, created and sustained or changed through people interacting with one another (Blumer, 1969). It is through such processes of constant interpreting and defining that symbolic interactionism demonstrates its strengths for study of human experiences and actions. Symbolic interactionism has, for example, illuminated how we come to identity with certain racial groups, how we experience our lives within the group, and how we interact with others outside that group based on our interpretations of the situations in which we find ourselves (Blumer, 1939, 1958, 1965; Omi & Winant, 1994).

Like criticalists, symbolic interactionists are also interested in human agency, the capacity of individuals to make decisions about who we are and what we do. From a symbolic interactionist view, individuals through their interactions create social structures. Therefore, social structures do not act upon individuals in a deterministic way. Social, racial and class relations, and divisions of labor are all constituted through communication and interaction (Pawluch & Neiterman, 2010). For symbolic interactionists, power, and the exercise of it, are processes played out in the course of interaction and whose definition of the situation prevails over others (Blumer, 1969). The criticism that symbolic interactionism is only interested in micro-level interactions with no regard for macro-structural influences and power relations on

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human experiences demonstrates a superficial understanding of the perspective (Lyman, 1984; Lyman & Vidich, 2000).

Critical interactionism

The main critique of critical research has been its preoccupation with broad structural and historical patterns of domination and oppression (Adkins & Gunzenhauser, 1999), leaving silent the voices of the individual people who live dominated and oppressed. However, when critical research is fused with the philosophical and theoretical insights of symbolic interactionism, a "critical interactionist" approach emerges allowing a more penetrating exploration of the relationship between macro-structural conditions and the concrete realities that people create and share (Lather, 1986a, 1986b; Sandstrom & Fine, 2003; Sandstrom, Martin, & Fine, 2001). A critical interactionist approach offers a way to probe the lived realities of human actors and the social conditions that inform their construction and possible transformation of such realities (Anderson, 1989; DiIorio, 1982; Sandstrom et al., 2001; Sundin & Fahy, 2008).

Critical interactionism therefore provides a solid theoretical grounding for this dissertation through which I was able to explore two key issues through the narrated experiences of my participants: 1) the actions of social institutions, entities, and the state where people are treated differently by race, shaping policy decisions and distributing resources accordingly; and 2) the individual or micro-level where racial dynamics operate at the everyday (often pre-reflexively) in the way we interact with one another (Omi & Winant, 1994). Through this approach, I was able to examine the power relations that structured how my participants' everyday lives were lived and highlight the effects of institutional structures such as education, housing, and neighborhoods on their experiences living with CHD.

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Methodological Approach

A key component of a critical interactionist project is the collection of detailed accounts of what goes on in the everyday lives of the participants. These accounts must be more than a litany of "things" that they do during the course of a day; they must also convey participants' distinctive interpretations of reality and the meanings that actions and events have for them in order to better understand how individuals live with CHD. Therefore, I used in-depth interviews and observations of neighborhoods for my primary data collection methods. A total of 22 primary participants and 10 family members participated in this study (see Table 1 for primary participant and family member demographics and characteristics). Fourteen participants were interviewed once, and eight were interviewed twice. The interviews took place between August 2010 and December 2013. With the exception of one participant who was living in a residential drug treatment facility, all interviews were conducted at the participant's home.

Recruitment

Using purposive sampling, participants were recruited from a multi-physician cardiology clinic at a large teaching hospital in San Francisco. A "Dear Doctor" letter was sent to attending cardiologists along with an information packet that included all of the study details. Study participants were recruited only from those clinics where the attending cardiologist gave permission to recruit. The attending cardiologist or clinic nurse identified potential participants during a particular clinic session.

Eligibility criteria included: 1) participant self-identified as black, black American or African American; 2) participant had been living with a diagnosis of CHD for at least 6 months; and 3) was over the age of 18 years. I approached potential participants either before or after the

clinic visit, as directed by the clinic staff or physician, and then explained the study. Written

consent was obtained only after all questions were answered and a date and time for the

interview was then established. Those participants who elected to have family members

participate gave signed consent to have them present at the interview; family members were

consented separately. All primary participants and family members were each given a $50 gift

card at the end of each interview. The University of California, San Francisco Committee on

Human Research approved this study.

In-depth Interviews

Interview data were collected through the use of a semi-structured interview guide.

During the interviews, I asked open-ended questions seeking in-depth responses about the

experiences of living with CHD. This method allowed new questions to emerge during the flow

of the interview. Probes and follow-up questions resulted in a thorough exploration of the

participants' experiences. Some of the topics covered included: the participants' thoughts and

feelings upon learning they had CHD; their explanations for the development of CHD and the

meanings they attached to it; experiences and meanings of stress and its influence on living with

CHD; experiences seeking medical help; the impacts having CHD had on their family, work and

social life, and relationships; descriptions of their neighborhoods and the influence the lived

environment had on the experience of living with CHD; the availability of social resources as

well as the meanings they attached to CHD and/or its symptoms. Interviews ranged in length

from 45 minutes to 2 hours and 20 minutes. All interviews were digitally recorded and

transcribed verbatim.   The semi-structured interview guide used during data collection is

included as Appendix A.

Eight participants agreed to participate in a follow-up interview, each lasting approximately one hour. The purpose of these interviews was to share with them the themes and concepts that emerged in the data to get their sense if they resonated with them. These interviews were particularly helpful in clarifying nuances with regard to the experience of stress production in the lived environment.

Neighborhood Observations

As part of my ethnographic fieldwork, I did extensive walk-throughs and observations of the different neighborhood environments in which my participants lived. Typically, I would start at or near my participant's address and map out a 6-square-block area in each direction to reconnoiter on foot. My interest in doing so was to get a "gestalt" of the neighborhood while noting any community resources such as churches, libraries, community centers, parks, full-service grocery stores, pharmacies, health clinics, police and fire departments, and public transportation that were possibly available to a participant within a relatively short distance. I also took note of any local industry in the neighborhood such as small businesses, cafes, restaurants, movie theatres and other sources of entertainment.

Data Analysis

In the foreground of this project were the participants' descriptions of how they experienced their life world, what they defined as desirable living, and what they saw as possible (or not) in terms of how they live. My role was to attempt to identify the subjective meanings they attributed to those experiences. Through their eyes and experiences, I explored how social organizations and institutions (like health care, education, and housing), distribution of

resources, social relations (racism, interpersonal interactions and work place environments), and different ways of living and knowing shaped their experiences of living with CHD.

Data analysis followed the conventions of a post-modern constructivist approach to grounded theory (Charmaz, 2005, 2007). I conducted data collection and analysis simultaneously, at the same time acknowledging that no qualitative study rests solely on induction; our grounded theories are constructed through our present involvements and interests, our perspective and past experiences, our interactions with others and our prior research practices (Charmaz, 2006).

In an iterative fashion, I read and re-read the entire transcript of each interview while listening to the audio recording, in order to identify emergent themes and concepts that emerged from the data. Listening to the audio recordings at the same time as reading the transcripts allowed me to pick up nuances in linguistic syntax as well as spoken emphases that may not have been clear solely from a transcribed text. I generated a code list as themes and concepts emerged from the data. Individual codes were then sorted into categories.

I wrote many memos on various codes as well as thick biographies of each participant, a narrative of each participant's life history as it was told to me including important historical and current events (Rehm, 2010). These thick descriptions (Geertz, 1973) of social and cultural contexts, emotions of participants and their thoughts and perceptions gave me a vivid picture of the events, actions and situations of their social context (Holloway & Wheeler, 2002). This proved to be extremely valuable as it allowed me to see experiences across participants where they were similar and where they were not. I also came to "know" my participants much more deeply through this process. Writing extensive memos allowed me to think through concepts, codes and contradictions in a narrative fashion. Additionally, I wrote field notes, extensive

analytic memos and kept a reflexive journal about my research experiences.   I primarily used MAXQDA 11 for data management and storage of text, field notes and memos as well as to facilitate the rapid extraction of coded text for further analysis.

Challenges

Clearly, as a white woman, the cross-cultural nature of this study has to be emphasized. That said, I perceived no difficulties in recruiting participants for this study—only one declined due to personal reasons. All of my participants were extremely gracious and welcoming and clearly interested in participating in this study.

One challenge I did have, and in fact I never succeeded in resolving, was convening focus groups. My original intent in conducting focus groups was to allow the participants the opportunity to share their insights, observations and experiences with each other as well as giving me the opportunity observe the interactional dynamics between the participants. Two focus groups of five participants each were scheduled at St. Sebastian Medical Center on two subsequent days. Each time when I made the confirmation calls, too many of the participants cancelled or said they were no longer interested, rendering continuing the focus groups ineffective. One participant gave some insight when she cancelled saying, "I already spend too much time at that hospital". Sensing that the idea of a focus group too much a burden on my participants, I did not proceed any further.

Overview of Chapters

In Chapter 2, I explore illness experiences of African American men and women living with CHD. While there exists a large body of literature on the disproportionate burden of CHD

and its related complications, there is little that actually explores African Americans' day-to-day

illness experiences living with the disease. Such explorations are important as they reveal a

broad range of micro, meso, and macro contextual factors that influence how people live with

chronic illnesses (Charmaz, 2000; Lawton, 2003). The purpose of this chapter is to offer a social

and cultural analysis of the illness experiences of my participants using an illness narrative

approach. I argue that, for my participants, the development of CHD and the behaviors that

facilitate or undermine health cannot be separated from their social, cultural and racial moorings.

I describe and demonstrate how the symptoms associated with CHD are more than physiologic:

they also function as symbolic guideposts pointing to the personal and social burdens associated

with the illness experience. There are also socially structured patterns in the ways in which

people think about their health and the behaviors that facilitate or hinder it. I demonstrate that

for African Americans in this study, CHD was a racially marked disorder—a "black" disease that

carried with it a historical and culturally sustaining legacy. An important part of participants'

illness experiences also included reexaminations of their lives prior to the onset of CHD as well

as their future plans and dreams and reconcile them to the practical logic of their current day-to-

day circumstances. Some participants, by redefining their current situation as more hopeful,

were able to forge new and more positive life paths.

In Chapter 3, I examine the concept of social capital and seek to address three main

issues as it relates to the health and illness experiences of my participants. First, I explore the

extent to which one's lived environment affects the forms, generation and mobilization of social

capital. I found that regardless of the type of living space a participant occupied, all of them

could access a source of social capital to cope with the daily challenges related to living with

CHD. Second, I describe the types of social networks that were most effective as sources of

social capital within contextually different lived environments, and find that the forms of social capital and the resources available varied depending upon the type of lived environment a participant occupied. Third, I demonstrate the extent to which the cost of cultivating and sustaining social capital can outweigh its potential health-related benefits. While social capital provided tangible and material benefits to the recipient, there was often a "pay-to-play" aspect where the one providing the resources, rather than those who needed them, acted as gatekeepers, rationing the types and amounts of resources available from which to draw as well as the nature and scope of the support. This had the effect of constraining individual choice that at times led to family tensions and discord.

In Chapter 4, I present an extended narrative of one African American woman that provides a portrait of how the lived environment shapes one's sense of place and how health is produced or undermined through everyday contexts, experiences and burdens. Drawing upon the works of Bourdieu (1977) and Casey (2001, 2009), I employ the concepts of habitus and collective habitus as analytics, exploring the ways in which bodies and place are linked together and the effects that linkage has on stress perception, experience and production. Through these concepts, I argue there is a temporal dimension through which our bodies become habituated over time through our biographical experiences to produce particular states of equilibrium or our "sense of place". When there is a mismatch between our habitus, which we develop over time and within a specific set of social conditions, and the actual and physical and social circumstances in which we find ourselves, our sense of place is disrupted and stress becomes the bodily manifestation of that mismatch. I also demonstrate how habitus is collectively constructed, reproduced and expressed, where the attitudes, behaviors and practices of those who live in a particular place seem to become naturalized and inherent characteristics of the places in

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which they occur. This creates a social space where we feel a sense of belonging—a sense of

place—where we fit within the social order. However, I found that even within distinct

geographically defined neighborhoods, different lived environments exist, producing different

types of collective habitus that encapsulate different values, expectations and ways of being.

This chapter argues that bodily experiences of stress may be the result of a habitus mismatch,

arising out of social and spatial oppositions when one type of collective habitus intrudes upon

another.

Finally, in Chapter 5, I summarize and synthesize this research and its findings and

elaborate on its contributions to the extent literature, as well as explore remaining questions,

policy implications and identify areas of further research. From a methodological standpoint, I

argue that critical interactionism provides an innovative approach to the study of racial

inequalities in health as it offers additional theoretical leverage and opportunities for nursing and

sociological research by simultaneously highlighting patients' health and illness experiences at

the micro level while providing an analytical framework to study how meso and macro level

social factors influence those experiences. Such an approach provides a multidimensional

window into the sociocultural nature of illness, an understanding of the local conditions and

contingent mechanisms through which meso-level dynamics like social capital are generated,

insight into the potential negative and constraining effects of social networks, and an expanded

exploration of how habitus, the lived environment, and the social conditions from which we

come can both help and hinder our health. I conclude by emphasizing the importance of taking

account of the ongoing racial and social dynamics at play through which inequalities are created,

sustained and reproduced.

CHAPTER 2

Illness Narratives of African Americans Living with CHD

How African American men and women manage, respond to and live with coronary heart disease (CHD) is not well understood. Despite the voluminous literature on the disproportionate burden of CHD and its related complications among African Americans, it is rather surprising that there is so little that explores their day-to-day illness experiences (Becker, 1994; Becker, Gates, & Newsom, 2004; Becker & Newsom, 2005; Liburd, Namageyo-Funa, Jack, & Gregg, 2004; Samuel-Hodge et al., 2000). Such explorations are important as they pave the way for an in-depth understanding of a broad range of micro, meso and macro-contextual factors that influence how people live with chronic disease (Charmaz, 2000; Lawton, 2003). As well, scholars have come to recognize that many of the issues in managing chronic illness are largely social in nature (Conrad, 1990; S. R. Kaufman, 1988; Kleinman, 1988; Kleinman, Eisenberg, & Good, 1978; Lawton, 2003; Liburd et al., 2004; Zola, 1966).

Between medicine and the social sciences, there is a conceptual difference between disease and illness. Where disease is considered the malfunctioning of the biological and physiological processes of the body, illness has been defined as the "innately human experience of symptoms and suffering" (Kleinman, 1988, p. 3) and refers to how individuals, their family and members of their wider social network perceive, live with, and respond to symptoms and disability. The illness experience includes the common-sensical ways in which we categorize and explain physiological distress caused by pathological processes, the difficulties that symptoms or disabilities cause in our lives, as well as the different behaviors or actions we adopt that help us best cope with illness or symptom distress (Charmaz, 2000; Kleinman, 1988; Kleinman et al., 1978).

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The purpose of this chapter is to offer a social and cultural analysis of the illness experiences of African American men and women living with CHD using an illness narrative approach. I argue that there is a broad range of micro, meso and macro-contextual factors that inform the multidimensionality of these experiences. First, I describe and demonstrate how the symptoms accompanying CHD are more than physiologic; they have a symbolic nature through which both the personal and social burdens associated with the illness experience can be revealed. Second, I argue that the ways in which people think about their health, and the behaviors that facilitate or hinder it, are socially, historically and culturally patterned, reflective of the social structure that produces them. Third, I demonstrate that for African Americans in this study, CHD was a normative experience—a racially marked disorder that carried with it a historical and culturally sustaining and replicative legacy. Fourth, living with CHD required participants to reexamine their past lives and future plans and reconcile them to the practical logic of their present day-to-day circumstances. And finally, through the illness experience, some participants were able to forge new and positive life paths, relationships and behaviors by redefining their current situations as more hopeful.

Over the last 30 years, a large and collective body of illness narratives has accrued, providing a "window into the life-worlds of people with a wide range of different diseases…at different stages in their illnesses and in a variety of contexts" (Lawton, 2003, p. 24). Most of this work is theoretically grounded in, or in conversation with, a symbolic interactionist perspective that assumes the self is fundamentally social in nature and constructed through the constant interaction with others. Because the self is social, socialization is a lifelong process; thus, symbolic interactionism permits us to examine how the ways in which we define ourselves can change during the life course (Blumer, 1969; Charmaz, 1983, 2005). In the next section I review

some of the earliest and most widely cited papers using illness narratives, and synopsize the central themes that have been previously developed.

Illness Narratives in Social Science Research

In one of the most heavily cited papers, Bury (1982) explores the problems of recognition and changes in the life situation and relationships as a chronic illness (rheumatoid arthritis) first emerges. He conceptualizes chronic illness as a "biographical disruption…where the structures of everyday life and the forms of knowledge that underpin them are disrupted" (p. 169). In other words, the onset of chronic illness not only disrupts the understandings an individual has of their biological selves and their self concept, but also of the normal every day rules and expectations of reciprocity and mutual support that individuals have between themselves, their families, and their wider social networks. In his analysis, Bury highlighted 3 elements of this disruption: First, the "what is going on here" stage where an individual's attention is refocused to their bodily state and to the decisions about when, where, and if to seek treatment; second, a re-thinking of one's biography and self-concept where physical pain and discomfort can bring about a new consciousness of the body and highlight the tenuous nature of one's existence; and third, one's ability to mobilize the necessary material and cognitive resources that may be crucial to the ways in which the illness is subsequently experienced. Bury's work describes the social nature of the illness experience by highlighting how disease disrupts the structure and meaning of illness as well as relationship, material and practical affairs as well.

Similarly, but confining her analysis to those who were severely debilitated and/or housebound from a variety of chronic illnesses, Charmaz (1983) uses the concept of "loss of self" to critique the very narrow medicalized view that suffering encompasses only physical

discomfort. Working from within a symbolic interactionist tradition, Charmaz reveals how chronically ill individuals frequently experience a "crumbling away of their former self images without simultaneous development of equally valued ones" (p. 168). As Charmaz beautifully illustrates, those with chronic illness are particularly concerned about the self they see they are becoming, while losing their moorings to the valued self that once was. Charmaz highlights how those with severe debilitating chronic illness negatively reflect upon and redefine themselves in self-discrediting ways, fostering an increasing dependence on others for their self-defining value, that in turn strains much needed social relationships. She also brings attention to how stigma, related to chronic disease, amplifies feelings of low-self esteem, prompting one to withdraw from social activities resulting in a more socially restricted life. With few opportunities for meaningful interactions where positive self-validation can occur, the feeling of "loss of self" is compounded and made more acute.

Building on the work of Bury (1982), Williams (1984) uses the concept of "narrative reconstruction" to capture the "structured self-image" of those "seasoned professionals" who have been living with rheumatoid arthritis for a number of years (p. 176). Through this concept he endeavors to understand how and why people living with chronic disease come to see their illness developing or originating in the way that it does and how they account for the disruptions the disease has brought to their lives. Narrative reconstruction refers to the strategies individuals use to create a sense of order and stability in the aftermath of a "biographical disruption" that serious illness creates (Lawton, 2003). The participants in Williams' study point to the significant experiences in their past—deaths or discriminatory work experiences—that constitute an attempt to find a legitimate and meaningful place for illness in their present lives. By understanding one's illness in terms of past social experiences, it reaffirms the individual's

impression that their life has had a course and the self has had a purpose. These "unfolding historical relationships" provide reference points to what Williams refers to as a "genesis of a misfortune…which imaginatively reconstructs the past so that it has meaning or purpose for the present" (p. 175).

Another corpus of work that highlights the complex and variable ways in which individuals experience and "live with" illness comes from Corbin and Strauss (1985, 1987; 1984). They offer the concept of "biographical work" to explore the relationship between illness and biography. Biographical work is the establishment of continuities between various aspects of a person's past and present life where the old self must be reconstituted and given new meaning. This work is not continuous, rather it is triggered by significant events, such as illness, where one rethinks their personal history in a different way and, at the same time, refashions their ideas of "futures to come" (Ville, 2005, p. 326). Biographical work refers to the ways in which coming to terms with a self altered by an illness ultimately determines the meaning of the illness. Thus, biographical work generates new meanings about the self.

Drawing on a case study of a woman who had suffered a stroke, Kaufman (1988) illuminates how biographical work is an individual's attempt to "reorder things" and hold onto the continuity of the self through which they can "keep going" despite great suffering and misfortune. This "maintenance" of the self requires its integration with new physical, social and moral conditions in order for the individual to make sense of their current circumstances.

This chapter also draws upon the extensive work of Becker and colleagues (1994; Becker et al., 2004; Becker & Newsom, 2005) as well as additional work from Charmaz (1990, 2000), all of whom describe illness narratives as an innovative and exciting way for examining individuals' assumptions about health and illness, disruption and continuity, defining illness, and

illness management strategies. Through illness narratives we can gain valuable insight into the perceptions and experiences of individuals living with chronic illness like CHD.

In what follows, I approach this chapter by loosely employing a framework proposed by Kleinman (1988) and subsequently utilized by Liburd et al., (2004) in their study exploring patients' perceptions of the psychosocial, cultural and behavioral impacts of African American men living with type 2 diabetes. The original framework comprised of 5 broad categories designed to capture an individual's understanding and perceptions of their current social, spiritual, cultural and psychological realities of living with chronic illness.   In this paper I organize the following sections around the following 5 major coding categories that emerged in the data that comprise my findings: 1) the symbolic nature of symptoms; 2) origin stories; 3) CHD as a racially marked disorder; 4) the illness odyssey; and 5) the personal and interpersonal significance of illness. I conceptualize these categories as layers, that when peeled back, expose the multidimensionality of the illness experience. Following the conventions of other illness narratives (Becker, 1994; S. R. Kaufman, 1988; Kleinman, 1988) I present the data in the form of thick vignettes or portraits of individual participants in order to explore the elements and concepts that comprise their unique illness narratives, drawing as well upon supplementary data from other participants when necessary in order to expand on emerging themes. I begin the findings section with the top layer that is, where the illness experience began for most of my participants—symptom onset.

The Symbolic Nature of Symptoms: "Living Scared"

With symptom onset, the body is morphed into a new kind of unfamiliar terrain that must be learned step-by-step; a new "shaky ground on which a new order—if there is to be order—

must be built" (Becker, 1994, p. 82). In this study, most of the participants reported the onset of cardiac symptoms as an insidious process defined by subtle physiological changes rather than an acute event. One participant reported, "Just symptoms I had that didn't make my body feel normal…it was a shock to me and probably all these years I had it and didn't know". Others described a sense of knowing that "something just wasn't right" but then complete surprise with the diagnosis was confirmed. Most participants reported a myriad constellation of symptoms of CHD that they described as "scary" and "unpredictable". They described a sense of "panic" and uncertainty that the shortness of breath, chest pain, palpitations, and/or "cold sweat" would not subside. In those moments participants described feelings of "not knowing what's gonna happen next"; questioning if the symptoms will subside or will "I just be dropping dead"?

How we interpret and give meaning to symptoms are dependent upon local knowledge of the body, its pathologies, the self, and their relationship to each other and the intimate aspects of our lives (Kleinman, 1988). In this study, I discovered that symptoms had a symbolic nature in which the participant had to interpret the changes in their bodies and determine whether these changes signaled a circumstance that required immediate treatment, a progression of a chronic disease state, or an instance that could be quickly resolved (and what means were necessary do so). Symptoms also had significant meanings for participants in terms of fears about the future, interpersonal relationships, perceptions of mortality and functioned as symbolic reminders of new limits to bodily abilities and of how their lives had changed. Here I explore the symbolic nature of symptoms through the experiences of a participant I call Michael.

Michael, aged 63, is a former environmental service worker for a large university. He was born in St. Thomas and moved to San Francisco following his discharge from the Navy where he served in the Vietnam War. He has a strong history of CHD; his father, in fact,

recently died from the disease. Michael describes himself as an avid "walker". He loves to walk

everywhere and prior to his illness onset, he walked several miles every day around the City. He

currently lives in a very hilly neighborhood and only infrequently does he take the cable car,

preferring instead to navigate the hills on foot. Michael's symptoms, in fact, first manifested

during one of his routine morning walks up a steep hill. Michael explains, "Everything used to

be going good, then all of a sudden I begin to get short of breath". He underwent a diagnostic

cardiac catheterization and understood from the results "that I had clogs up there in my

artery…but it didn't look like it's that bad", so his doctor told him. Michael did have a stent

placed yet despite this intervention, Michael's symptoms have continued. This has led him to be

rather skeptical that he has been treated properly or thoroughly saying,

> I have the feeling they didn't do the whole work on it. I still think cloggage up in
>
> there…I don't think it been taken care of…this is my body! I can tell what's going on! I
>
> don't think they finished what they really need done or they not telling me if up there is
>
> really OK or if it really messed up. You don't have my body. I should know what it is!
>
> Here, Michael defines the status of his illness through his continuing symptoms, but the

significance of those symptoms is being contested by his physician who does not give credit to

Michael's subjective account. The objective assessment of the diagnostician that Michael's

artery "didn't look like it's that bad" trumps his every day experience, local knowledge of his

own body and his perception that something is still very much wrong. This creates a private

havoc that Michael must negotiate every day: "I have this procedure and now not knowing what

this is [his continuing symptoms], it put a heavy stress on me…I be scared a whole lot…I might

be walking, never can tell when something might happen…And I'm up in here by myself."

Michael's symptoms reflect not just his current physical state but bring forth dilemmas about his future. His life is now uncertain and his symptoms are symbolic of the magnitude of his vulnerability:

> I say to myself, if I get a heart attack walking—all of that is on my mind. I used to be good and healthy when I was working. I'm walking out there enjoying myself. Now I don't do that that much, now I'm coming down with all of this…Now with the pain on me and I'm scared. I'm scared this is as far as this go…that's what I be worried about. If I walk out there, I might be running my mouth, shooting the breeze with my friends there. When I feel like that—that thing like that—[claps his hands twice loudly, rubs his chest with his fist, and contorts his face into a grimace]…I be saying I'm OK, but I'm scared. My age is getting up there. I want to see a lot more, especially to see my grandbaby finish her school. Last time I'm gonna say it. I'm worried here.

As this exemplar demonstrates, Michael's clinical symptoms are so much more than a layperson's tool to communicate disease or pathology. They are packed with symbolism about what they mean for Michael in terms of his own knowledge about his body, fears about the future, interpersonal relationships with others—his providers and friends, for instance—and perceptions of his own mortality. His symptoms have transformed his socially enjoyable and familiar activities into "scary" ones. Michael's statement, "Now with the pain on me…I'm scared this is as far as this go", refers to the new limits his illness has placed on his previously active life. Through his symptoms, Michael is trying to make sense of what his illness means to him and the impact his illness has on his life. In other words, the symbolic nature of symptoms transforms the physicality of symptoms into social realms beyond the body (Early, 1984). Thus

symptoms are complex and symbolic explanatory guides that give us added direction and insight into the personal and social burdens associated with the illness experience.

Origin Stories: "Being Normal" and "Not heeding the warnings"

Origin Stories is a complex category designed to capture participants' understandings of how their cultural history, preferences and practices influence their health behaviors. Exploring with an individual why s/he believes they have developed a particular illness exposes the disconnects between the biomedical understanding of disease etiology and lay views of causation (Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Liburd et al., 2004; J. K. Shim, 2005, 2010b).

Individuals' own causal accounts of disease also function as reflective links among micro, meso and macro social and cultural processes. Thus I found that the category of "origin stories" is comprised of two separate but related codes. "Being normal" reflects a participant's sense of independence to make autonomous health related decisions. "Not heeding the warnings" describes the collective attributes that influence health related behaviors that are structurally patterned and specific to the cultural, historical and racialized experiences of African Americans.

For example, in response to the question, "Why do you think you developed coronary heart disease", all of the participants to one degree or another cited poor eating habits as a principal reason they developed heart disease. However, most linked those dietary habits to their collective African American cultural experience. For instance, Dorothy is 73 years old and grew up on a farm in rural Mississippi where, she says:

> When you fat, you healthy. That's what they say, "Oh, she's so healthy, look how big
> she is. She's healthy. She's so healthy". You know, we was eating pig from right to

left—the feet, the tails—and my Daddy said, "Black Gal [Dorothy's nickname], you like the last thing that jumped the fence. And the last thing is the butt! 'Cause you like the tails, the oxtails [and] the turkey tails". You not supposed to eat all that, but we was raised up on this stuff, you know.

Darnell, a native San Franciscan, developed CHD in his early 40s and responded:

Well, I always looked at it when you had heart disease, what are YOU doing? What are YOU eating? For African Americans, that's a lot of the cause—the pork and the high cholesterol foods. I know that before I had heart disease, I was eating pork all the time! Ribs? You couldn't get me out of a rib place—bacon, pork chops, you know. And that could be bad for you…It's probably a primary cause. From what I understand of the history, we started off being slaves. We ate what we can and throughout time it just became a delicacy for us, making meals out of what we can. My parents are from New Orleans. It kind of [got] picked up from them what I thought was good food not realizing it was bad.

Both Dorothy and Darnell's origin stories are illustrative of their understanding of how cultural history, practices and preferences may influence ongoing dietary habits and subsequent health problems. But as Shim (2014, personal communication) notes, Darnell is also pointing to this history as a "shared history, a shared story of cause and in that sense the history is cultural as well". Beyond "practices and preferences being historically constructed and sustained…their construction of that history is also cultural and collective".

Although most of the participants could identify close relatives who developed heart disease and subsequently died from it, very few took any preventative steps to decrease their cardiovascular risk, and behavior changes were only made—by some and to a limited degree—

when they themselves were diagnosed. But rather than an example of a failure to engage in lifestyle change, from a sociological standpoint, origin stories of illness reveal how individuals, through their health behaviors, embrace their own "ideologies of normalcy" reflecting their sense of independence and autonomy (Becker, 1994, p. 195). Jackson's narrative illustrates this.

Jackson is 72 years old and was born and raised in Louisiana. Before being diagnosed, he reported, "Believe it or not, I had never been sick…never been in the hospital before". Like most participants in this study, the possibility of developing heart disease was not something on Jackson's radar. He could not recall anyone in his family who had heart disease. His father died at 76 from cancer—"he was a Camel smoker". His mother died at the age of 89 from unknown causes and his siblings, 2 sisters and a brother, all of whom are in their 90s, remain in relatively good health. When I asked Jackson why he thought he developed CHD, he said:

> To be truthful with you, it's kind of hard to explain because I was surprised when I had it. I thought I did everything normal. I guess my mother was right about the fat food…my mother use to tell me that I ate a lot of fat and a lot of greasy food and told me I had better watch it. I kept on doing it. She would see me, like on steaks, I would take—I used to just love the fat and the bacon fat and she'd say, "You know that ain't too good for you". "Yeah, yeah, I know". And I kept on going…She mentioned one thing, "it ain't good for the arteries and things".

Despite warnings from his mother that eating the fat off steak and bacon was inherently bad for him, Jackson persisted because for him what he was eating was "normal". There was no material evidence in his family history to demonstrate the link between diet and health: "I was surprised [to have developed heart disease] because I didn't remember anyone in the family having it".

Jackson admits that since being diagnosed with CHD he has made very few, if any, behavior changes that would modify his risk of future cardiac events or complications from heart disease with the exception of "taking my medicines and I always make my doctor's appointments". While he did quit smoking, he admits he did it mainly for economic reasons rather than health promoting ones.

But Jackson defines his behaviors, not according to their long-term effects on his health but in terms of "normalcy" and "being normal" and "doing normal things", ways of living and how he has come to grips living with CHD. After his diagnosis and subsequent 3 interventional cardiac procedures, Jackson thought about his future and considered the ways in which he was going to live with CHD. Jackson stated,

> I just had to accept it. It wasn't too difficult, it just came…I just tried to, not put it aside, but just try to be normal. I found out that it was better that way then…When I first found out I was trying to be careful and believe it or not, I was feeling badder. But as I got older and try to be regular, no problem…Just being your normal regular self, like you were at first…I do the same thing…I used to love bacon and eggs; I still eat bacon and eggs. I think I do more better doing them than if I worry I can't do them.

For Jackson, the life style changes encouraged by his physician and required to modify any further cardiovascular risk came with their own set of challenges, "worries" and "stress" that made living with CHD much more difficult. Those changes did not comport with his definition of what it means to live a normal life, and hence he considers but disregards these socially mediated and medically defined notions of normalcy: "I guess I just take everything for granted. I try not to let it bother me, 'cause I feel the more you let things bother you the more you have those times [symptom exacerbations]."

In choosing, as a reflective and agential agent, to live his life as he always has—his own version of normal—Jackson is asserting his autonomy and independence, reflected in his final comment to me, "I just go on my merry way and that's it. I just go on about it. The more I go carefree, the better I feel".

Marcus is another participant whose narrative demonstrates how alternative ideologies of normalcy and values are emplotted in ways that underlie health related behaviors. Emplotment is a process whereby the narrator assembles a series of historical and experiential events into a narrative with a plot, reshaping events and memories to draw on culturally, and in this case, racially salient images (Becker, 1994).

Marcus is 54 and was raised in a very large family in the East Bay. He has a strong family history of diabetes and heart disease; two of his sisters died in their early fifties and his grandmother died in her early sixties. Marcus was diagnosed with a heart murmur as a child but added:

> I really didn't have a problem. Growing up I had played basketball, sports, and never had a problem. No one else ever said anything else about it [his heart murmur] until I had the recent heart palpitation thing…As a kid you pretty much think you're invincible. You're going to last forever. So as long as you're going up the hill, you know, nothing really bothers you. Plus I was really active in sports. I was in real great shape.

To look at Marcus today, one would think his is still in great shape. He is well over 6 feet tall and is very muscular. Recently, however, Marcus was rushed to the hospital with his first cardiac event consisting of palpitations and severe chest pain. Marcus admits that some of his own behaviors impact how he feels on a day-to-day basis and they have had serious

consequences in terms of projecting his overall mortality. For instance, Marcus admits that he still eats "a lot of pork, a lot of fatty foods, a lot of fried foods":

> That's pretty much the norm…And I still smoke. I know there is going to be a time when I am going to have to make a true decision on that because I do feel how it affects me…I feel it. That's not my norm. So I know something's serious about it. [But], most of the people I know in the African American community, we don't heed the warnings well, okay? You know it has to be over the top or something dramatic [to change behaviors]. It's like running a light. We'll keep running that light even though we know it's wrong, until somebody hits the car. Then, "Okay, I get it now. I'll stop next time". That's how we pretty much live, you know? But most African Americans don't heed warnings well, like, "Hey, you need to stop smoking".

When I asked Marcus why he thought African Americans "don't heed warnings well", he replied, "We're just bucking the trend". As Marcus explained, growing up, "no matter what, you wanted to be different [from whites]". Marcus was heavily influenced by the turbulent times of the 1960s and 1970s. Being present during the student and civil rights protests and riots that engulfed the East Bay during that time and the violent nature in which those protests were put down left Marcus "with a pretty dim view of authority". His life took a turn toward crime, drugs and multiple arrests—a pattern he sees repeating in his son. For Marcus, "not heeding the warnings" is a collective attribute with structural roots specific to the collective experience of African Americans:

> We [African Americans] do things until it hurts. Until the consequences come. I can see it in my son. He's a good kid, but he's involved in like Richmond's gangs now. Not because he wanted to be, but because that's how everything over there is now. Like

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Oakland's the same way, you know? He's been arrested some times. He has had some

gun charges. I keep trying to explain to him, "These people aren't playing with you.

You have gun charges and it's going to be a long time before you see daylight again".

But just because I say it doesn't mean he's going to heed that warning until he's sitting

behind the bars, you know? We do that in a lot of major areas in our life. And we do it

as far as our health goes.

As this exemplar demonstrates, "not heeding the warnings" is a theme much more

complex than simple and individual choices about what to eat or whether or not to quit smoking.

Rather, through Marcus' narrative, his behaviors and those of his son appear as cultural symbols

of resistance to conformity with the social order.

If we look at the exemplars of Jackson along-side that of Marcus, we can see both micro-

agentic and macro-structural explanations for their continuing unhealthy behaviors. The "Social

Resistance Framework" (Factor, Kawachi, & Williams, 2011), is a model that suggests unhealthy

behaviors are neither a passive product of social structure nor are they the result of bad choices

or the lack of making good ones. Rather, power relations and pressures within society may

encourage members of a non-dominant group to actively engage, consciously or unconsciously,

in different everyday resistance behaviors.

For Jackson, these resistance behaviors might include his continuing unhealthy eating

habits despite pressures from his doctors to change them. In terms of Marcus' son, the social

resistance framework would suggest that his behaviors, particularly his gang affiliations, are

playing out in an "anonymous environment, i.e. a space where the dominant group has little

control" (Factor et al., 2011, p. 1294). Such a description could easily apply to certain areas of

Oakland and Richmond. These behaviors are reinforced through instant gratification and

immediate relief, and as Marcus notes, the negative consequences are neither realized nor are they perceived as relevant. Marcus' unhealthy behaviors such as smoking, drug use, poor eating habits, etc., are rooted in his early experiences related to racial discrimination and structural violence that even today, shape his everyday health behaviors.

As we have seen in all of the narratives in this section, the ways in which individuals think about their lives, health and the behaviors that facilitate or undermine health, are socially, historically, and culturally patterned and replicative of the social structure that produced them. Through these narratives we have seen some of the ways in which individuals make sense of and understand their illness as well as plot strategies for living with them.

CHD as a Racially Marked Disorder: "Living the Black is Hard"

Most of the participants in this study were well aware that, across all racial groups, African Americans bear the burden of the disease in terms of overall morbidity and mortality. The disproportionate burden of CHD within the African American community has made the disease a rather normative experience and one, which I have learned, is infused with powerful cultural, racial and historical significance. While in the section above the question was, "Why do you think you developed CHD?" here the framing question is, "Why do you think African Americans bear the brunt of CHD compared to other racial groups?" Many participant narrators linked that illness burden to life-course experiences of racial, cultural, social and economic disadvantage, as I demonstrate below.

William was only 50 when diagnosed with CHF related to CHD. He linked his current clinical condition and the disproportionate burden of CHD affecting African Americans to the historical conditions of slavery explaining,

Well, my understanding is that fluids builds up in it [the heart], and your heart's like a sponge, so it absorbed it all up and this is where I'm at now. And I think being an African American with the high blood pressure, we have sodium…Okay, so this is a theory that's been passed from generation to generation. When the slaves were brought over, they wouldn't give them much water. So they gave them salt. Then they let them drink something, and then the salt absorbs up into the body and the salt stays in their system longer. So, we've been salted down. We've been salted down to get here. So now that's been passed from generation to generation, the heart defect part. I think it's just that sodium thing has hindered our DNA. And I don't know if there's ever going to be a way to reverse it.

Here William is conveying a particular kind of racial history that he believes *genetically* explains the disproportionate burden of CHD among African Americans. That is to say, for William, CHD is a "black" disease. He is linking his current individual health state to a collective experience and membership within a particular racial group. The theory to which he refers is called the "Slavery Hypertension Hypothesis" and is most associated with the work of Wilson and Grim (Wilson & Grim, 1991). Briefly these authors hypothesize that during the capture and transport of enslaved individuals to the New World from Africa—where salt supplies were historically limited—an "abnormal" salt susceptibility resulted through the process of genetic selection. They argue that during the brutal voyage across the sea, massive salt wasting occurred through heat stress, vomiting, diarrhea, and salt and water deprivation. Those who survived the crossing were then abruptly exposed to a diet very high in salt. Being previously adapted to a low salt environment, their renal-adrenal receptors became overwhelmed in the salt rich New World. This resulted in an excess pressor response creating, over time,

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historically high blood pressure disparities amongst African Americans. This theory, though

extremely controversial and contested among geneticists, sociologists and racial inequalities

scholars, was and continues to be popularized in the media through an expose in the New York

Times and the Oprah Winfrey Show as late as 2007[2](J. S. Kaufman & Hall, 2003; Smedley,

Jeffries, Adelman, & Cheng, No Date).

Michael, whom we met earlier, also characterizes CHD as a "black" disease—a racially

marked disorder and one that is linked through everyday stressors to structural and racial

situations and personal histories. At first he ascribed his health issues to environmental

exposures. He described to me his time in the navy where he was assigned to a ship and "we had

to strip all that lead off the deck and we had to paint that whole thing". His work as a porter in a

large university hospital exposed him to "a whole lot of them chemicals—breathing in that

stripping and waxing floor fumes." But when I asked him why blacks seem to bear the burden of

heart disease he responded, "It's a whole lot of stress business out there. It mostly fall on us.

The stuff you got to put up with". He related his work experiences where he described a

constant barrage of interpersonal racism, what he referred to as others' "bad attitudes":

> I'm glad I retired young but that contribute a whole lot…Like sometime I just didn't,
>
> couldn't go to work and face people like the other crowd that was there. You know the
>
> attitude. They were different races come in there and there used to be a bad attitude there
>
> and you worry about you…I'm thinking about this [pointing to his chest]. I want to
>
> know why if it isn't diabetes, it the heart disease with the black. Diabetes and cancer.
>
> Why those three big sickness the blacks have mostly? Why it got to be us? Living the
>
> black is hard.

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[2] For more on the debate about this theory see: (J. S. Kaufman & Hall, 2003), (Blackburn, 2003), (Grim & Robinson, 2003).

For Michael, CHD, diabetes and cancer do not exist as de-contextualized diseases that some people get and others don't. Developing CHD is not the luck of the draw, nor is it totally related to exposures to environmental toxins. Michael's experiences demonstrate that for him, CHD is the result of a constellation of institutional and interpersonal racism that he and most blacks face on a day-to-day basis hence his illness cannot be separated from those racialized experiences.

Roy similarly describes how CHD as a normative experience is racially and culturally maintained and reproduced. Roy's medical history is lengthy and complicated. Besides CHD, he also suffers from diabetes, COPD, substance use and arthritis. He has had multiple hospitalizations for his multitude of illnesses including a cardiac arrest that left him in a coma for a prolonged period of time. Roy was born in the early 1950s in New Orleans but was raised in Baton Rouge. He describes himself as "a blessed child…a loved child". As Roy is a bit soft-spoken, during the interview I had to move my recorder closer to him. He commented that his being soft-spoken was something he had to learn at a very early age from his mother:

> When I was about 12 years old, she called to me one day: "Roy", [and I called back], "What, Mother?" She came in and banged me on the head and said, "As long as you a child or a grown man [there are] two things you don't do: raise your voice and say 'what' to me!" Yes, ma'am! And that was the end of speaking loud! That's where that comes from. Now, my mother loved me to death. I was her only child, but certain things she did not tolerate.

Along with the familial rules set down by Roy's mother, there were social ones as well. As a black person of any age during the 1950s and 1960s, there were certain places Roy could not go simply because he was black. Neighborhood boundaries were clearly delineated. Failure

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to comport to the social rules of the day could lead to dire circumstances. Roy recounted an experience he had when he was a boy of about 16 years of age:

Now everybody in America knows that you ain't got no business in 1968 walking across town at 10 o'clock at night through the white section or on the outskirts of the white section [of town]. They used to burn crosses there and one night I got caught. I got caught not paying attention to my senses, 'cause I smelled the wood burning. Well, I ignored it. When I realized what I was doing, [I was maybe] a half a block from a few hundred white folks with hoods on! Scared the shit of me! Them folks looked up and said, "By god, there's a nigger!" And the chase was on. I won, for I'm still here. That has been an experience, being looked at with disdain. It fucked me up, man. For a long time I felt like, "What have I done so wrong to get these people [to not] like me?" It played a part in my psyche and it definitely part on my nerves…I take medication now for that shit!

Social rules, boundaries and codes of conduct based on race and infused with racism permeated Roy's early life in the South and the penalty for "not paying attention" to them nearly cost Roy his life. Over 50 years later, these racialized experiences have lingered, and have manifested bodily by affecting his "nerves" that today require medication.

Roy is quite clear that a lifetime of disadvantage has been a major contributing factor to his ill health:

I went to segregated schools. I can remember colored and white restaurants, colored and white bathrooms. I can remember water fountains nice and white and pretty and clean for the white folk and ours over here were like, well, I'd just as soon wait 'til I get home before I drink some water, you know? That's the way it was. It was horrible. Second or

third-rate books…By the time I learned algebra…the white kids were learning

trigonometry and calculus. You know…that's the way they split the information.

In Roy's view the unequal distribution of materials, supplies and information, limited his

overall chances of opportunity. The systematic "splitting of information" advantaged whites

while ensuring that blacks could not and would not be able to compete. Anger, resentment and

the stress associated with being disadvantaged have subsequently taken a collective toll on his

health:

Well, for a long time I was real angry about that and that's had something to do with my

heart being fucked up, too. The stress of it all…that shit affected me, yes, to today as we

speak!

The racial dynamics to which Roy is pointing can be understood as a racial project, in

Omi and Winant's (1994) parlance. Racial projects are interpretations, representations or

explanations that link social structure and representation in an effort to reorganize and

redistribute resources along racial lines. Racial projects do the ideological work that connects

what race "means" to the ways in which both social structures and everyday experiences are

racially organized (1994, 2008). Thus historically situated racial projects, according to Omi and

Winant, determine the "social allocation of advantage and disadvantage, winners and losers, and

the origins and structure of discrimination" (Omi & Winant, 1994, p. 48).

Whether they are located at the macro-structural level (e.g. slavery, Jim Crow laws, anti-

miscegenation laws, exclusionary immigration policies, and affirmative action) or the micro-

social level (e.g. personal interactions, experiences and/or speech acts), racial projects

accumulate over time to shape both social structure in racialized ways and how we define and

interpret ourselves as racial subjects. These "racializing schemes" (Blumer, 1958, 1965;

Schwalbe, 2008) not only describe difference based on race, they result in particular ways people define and treat one another, as well as inscribing inequality into the social fabric. The unequal distribution of resources matter because it produces unequal distributions of experiences like health and illness (Schwalbe, 2008).

While Roy is "real clear" that "race", "economics" and "social structure"—all his own words—play a role in health inequalities, his narrative and experiences also paint a picture about how history and culture mark particular bodies through illness, making illness a normative expectation based on race:

Black folks—people that are under-privileged—we have very limited opportunity in this country. Very limited. African American males have even less opportunity than the female. That's just the way it is. So, the expectation for the African American is already looked at one way. Now, the poor white, going to the hospital, sick…Let's just say he has some of the same social problems that I've had: drug abuse, prison, traumatized as a kid, all of those things there, and on top of that, he likes to drink a little bit too much. Now after 4 or 5 times coming through there [the hospital emergency department], first of all, he's looked upon coming through the door [as] an embarrassment. He's an embarrassment to himself and to the race. That's the truth, because most whites have an opportunity to advance in this country.

Roy explained how he became aware of this dynamic as he watched the social and cultural transformation of the late 1960s and 1970s when he was living in Berkeley. He noted how after almost a decade of living as "hippies", the white kids:

Cut the beard, took a bath, put on their tie and went on to cover America. Now we have E-bay! You feel me? That's it there. That's the difference. So when a guy come in

there that's drunk, messy, smelly, crazy, and this is his fifth time in 6 weeks, his quality of care is gonna be worse than mine. See, the black man, at least he has a reason. He's black—because he's black. White folks won't admit it to most blacks, but they know, just like I know, the playing field is not even. So when they see me and I'm fucked up, they're gonna have a little bit more empathy for me than they gonna have for this other guy who has no right to be laying up there, 30 years old…in America, with an education, a damn drunk. White philosophy!

For Roy, his plight and his health status are normative expectations based on race. That whites perceive and expect blacks to have "social problems" that lead to illness re-inscribe particular notions about particular bodies based on race. The fact that Roy is in the ED with poor health is not at odds with his expectations or that of the ED staff—blacks in general have poor health. Not so much for the white individual with the same sort of social issues. According to Roy's view of white culture, the white man has no excuse for his circumstances being that he is the recipient of a historical legacy of privilege bestowed upon him simply because he is white. Falling short of his own dominant culture's social expectations results in material consequences for the "messy, smelly, crazy" drunk who happens to be white: if not poorer health care, then at least an observable difference in the way health care is delivered.

Through the narratives of William, Michael and Roy we have seen how CHD has become a normative experience and a racially marked disorder that carries with it a historical and culturally sustaining and replicative legacy. In the next section I explore the impact that CHD has on the day-to-day lived experiences of African Americans and the work it takes to maintain notions of selfhood.

The Illness Odyssey: "Being on the Slide"

The illness odyssey is a category designed to convey the illness trajectory from the time the participant was diagnosed with CHD. It is a brief sketch through which the participant relates changes in attitudes, routines, major life goals or relationships that have become reconsidered, or obstacles that have emerged as a result of the onset of CHD. As one participant described her life since being diagnosed with CHD, "It's been one thing after another". Below, I provide a more in-depth introduction to William, who we met briefly in the previous section, that paints a portrait of the self with whom William identifies and provides a context through which we can see the impact and footprint illness has left on William's life world. As I demonstrate, a diagnosis of CHD causes individuals to re-examine their past life and future plans, the practical logic of their day-to-day circumstances, their behaviors, as well as developing a new sense of self, of body, and bodily limitations that previously had been taken for granted or were "out of radar".

William is 57 years old and lives in the Bayview District of San Francisco. He is a native San Franciscan and has lived most of his life within a few blocks of where he lives now. William lives with his second wife, Alice and their little Chihuahua, Renfield, in a small but immaculately maintained home on a block known for drug activity, violence and gang warfare. William is a very large man and says, "All through my childhood I was always a chubby little boy". He characterizes himself as "jolly" and sports a frequent big wide grin; he has a very warm and pleasant demeanor. Despite that he is currently virtually incapacitated by congestive heart failure (CHF) related to CHD, he is very welcoming, down-to-earth and easy to talk to. He describes himself as an "every day" kind of man, who always approaches others with respect saying,

I try to treat people with respect and it always seems like I get it back. So, it's how you treat people. That's what it's all about...I was telling them at the hospital the other day, I had a nurse come up to me and put her arms around me, in tears, because she says, "You know William, today is—I don't know. Maybe it's my hormones or maybe it's just not my day. But you know, I've been hollered at and screamed at all day this morning. And here you come! Jolly William! You? It's like home".

As William reflected on his life prior to his illness onset, he described it as "hard work". William states,

I was an auto mechanic when I was working and I took responsibility of a person's car. My work speaks for what I do to someone's car...I give the utmost care...I want to be professional. I want to treat people as far as like how I want to be treated and then get the relationship and the friendship with the people whose cars I work on.

As we will see below, the onset of William's illness disordered what he knew, perceived, and experienced about himself, disrupting his understandings of his specific body parts and body systems, but also notions of his own body integrity as well (Becker, 1994). Like other participants in this study, William found his diagnosis to be a shocking one. He presented to the emergency room with what he thought was just a "bad cold" where he wasn't "moving no air":

I went to the hospital emergency. So one of the doctors—because I'm a jokester. I'm always cracking jokes, or you know, I try to be a jolly person that loves people...I learned from growing up that, you know, I can make people like me when I try to be loveable, and through loveable, I've become who I am. So in the hospital, we're laughing and talking. So he says, "You know, William, you got a big heart". I said, [grinning widely] "yeah, everybody tells me I got a big heart"...So, you know, I got

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home, went back to work, forgot all about it…So, two years go by and then I go through

the same scenario again…Okay, so the second time in emergency another doctor told me

the same thing. He says, "Yeah, so you know, you got a big heart". I says, "Yeah,

everybody tells me I got a big heart". He says, "No, no, no, no! Your heart is bigger

than the size it's supposed to be…your heart is getting worser and it's not moving. It's

not pumping like it's supposed to and we want you to follow up with a cardiology

doctor".

At this point in the interview, William's wide grin suddenly faded. Metaphorically,

"having a big heart" was a persona that William wanted, intended and thought he conveyed to

others—that of being a "big hearted", "respectful", "jolly" "jokester". At that moment of

diagnosis, the meaning of "having a big heart" took on a different dimension, disrupting his

notions of not only how others perceived him, but also his understanding of the orderly

functioning of his own body. His diagnosis also signaled the beginning of William's illness

odyssey:

So this is when I started going and visiting [specialists] and they was doing all kinds of

sonograms, and then they took me over there to a doctor over in Parnassus and they did a

MUGA[3] something…Before they did that, the chick run this thing down my throat…they

can see exactly what's going on with my heart and everything. So, you know, it really

had affected me I say maybe about the last five years. I had a stroke, and it's like I've

been on the slide. I'm constantly sliding farther and farther and farther down.

As we can see through William's odyssey thus far, experiencing chronic illness means

much more than physical distress, recognition of symptoms or the requiring and seeking of

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[3] William is referring to a multi-gated acquisition (MUGA) scan, which is a nuclear medicine
study that creates video images of the ventricles to evaluate function.

medical care. As Charmaz (2000) also noted in her work, illness challenges prior meanings of

body and self, ways of living and activities that have been previously taken for granted. In

William's case, prior to his illness onset he recalls:

> I was a good walker. I'd walk all over the place. Now I can just barely crawl from here
>
> to there and then, [demonstrates how he has to gasp for air and catch his breath]. The
>
> doctor told me last week, she's going to up my heart medicine. So, now she says,
>
> "You've got to be careful and not try to over exercise yourself". So now, I feel like I'm
>
> falling over. I'm just falling over.

In the span of a few short years, William has had to renegotiate even the most basic

activities of daily living. During our interview in his home, I noted that William was seated in an

oversized "lazy-boy" recliner positioned at a 90-degree angle. The chair was also carefully

camouflaged to conceal its auxiliary function as a commode. His very large and painfully

looking swollen legs were resting on a footstool in front of him. He required supplemental

oxygen provided by a portable condenser and a HEPA air filter quietly hummed in the

background. It was very evident that his illness had imposed a disorder upon his life and an

uncertainty about his physical limitations:

> It's like now it's tiring me down even more. I have a walker. So I'm pushing the walker
>
> around the hospital. Then I get tired, turn around and sit down on it…and then I scoot
>
> backwards on it…so I got to go through the back door to where they got the handicapped
>
> parking spots.

Still, William strives to maintain a semblance of order and control over his daily life by

being as independent as his condition permits saying, "You know, I want to get out. I want to do

things. I'm like—I'm stuck here". After falling several times with his walker, William's physician prescribed a wheelchair for him. But because of his weight:

> I'm sitting in it and like, I'm sinking in it…so I went and thought about something I could do. ***Something I could do***[4]. I know what to do. I went to Home Depot, measured it, went there and cut me a piece of wood, put it on the seat, and I been on it ever since.

As William's narrative demonstrates, his illness has left him virtually unable to care for many of his needs of daily living. Now he must rely on his wife for his physical care and on different types of medical equipment. He must reorder his physical environment at home and he must strategize new ways of negotiating his way around other physical places like the hospital. In the exemplar above, William is reaching back into his past experiences as someone with mechanical savvy, drawing upon his self of the past to care for his self of the present. This example of biographical work (Corbin & Strauss, 1985) is triggered through his illness, whereby William is re-discovering a part of his former self and using it to work out new ways of adapting to his current circumstances. It is a response to his altered bodily condition, disrupted routines, and forms of dependence that his illness has created. Sinking in his wheelchair, William is discovering himself in a newly conscious way. He is selectively and critically reflecting upon his illness and his current circumstances and in his determination to go to Home Depot and craft a solution to this problem *himself*, he is able to regain some semblance of autonomy and control.

As Charmaz (Charmaz, 1983, 2000) and others (Kleinman, 1988; Liburd et al., 2004) have noted, and as I found in this study as well, those who are chronically ill lose their previously taken-for-granted continuity of life. Becoming ill presents the individual with several challenges: 1) getting to know the symptoms through which they make sense of what the illness

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[4] Emphasis his.

means and represents in their life; 2) reordering their life in an effort to manage the illness and treatment regimens; and 3) maintaining a semblance of control over their life through the concrete activities of daily living that facilitate a regaining of continuity and a coherence of one's self and the new life-world they now occupy. As we saw through William's narrative, living with CHD required him to reexamine the practical logic of his day-to-day circumstances, his past life and future plans, as well as develop a new sense and meaning of his self and of his body and bodily limitations that he had previously taken for granted.

Personal and Interpersonal Significance of Illness: Sorting it out. Managing it. Creating New Pathways

In this section, I explore the social context of illness, revealing how individuals "sort out" the consequences that illness has had in an individual's personal and social life, how s/he re-negotiates traditional familial roles and how they see themselves reflected in the social world around them. Chronic illness changes the very foundation of an individual's life—a new platform from where we look to the future through new lenses and at different angles (Hyden, 1997), creating new and qualitatively different life conditions, perceptions and expectations.

While the personal and interpersonal "costs" associated with living with a chronic disease like CHD can be quite profound (Kleinman, 1988), living with chronic illness may also, ironically, create ways in which individuals forge new and positive life paths, behaviors, relationships and directions in order to reestablish continuity with themselves, as we will see below in the narratives of Darnell and Roy.

Darnell, who we briefly met earlier, grew up in the Western Addition of San Francisco. He was diagnosed with severe hypertension in his late 20s after seeking treatment for migraine headaches:

Migraines. That's a sign that the blood pressure is up really high. So when I went to the doctor, it was 237. Other than the migraines, I felt normal. Everyday normal. The heart disease started with the high blood pressure. And I didn't take my medication. And so not taking my medication started something else. Triggered the aorta. I have a tear in my aorta. So that triggered that. And they say if you don't take you medication, your organs and stuff get stretched with the high blood pressure. [When asked why he didn't take his medications, he responded], I grew up as an athlete. So being an athlete, you can take anything and do anything.

As a young man and throughout high school and college, Darnell was a track and football star. Playing sports was a primary focus of his early years. It kept him "motivated" to stay in school and "out of trouble". However, realizing the significance of his hypertension and the tear in his aorta required Darnell to temper his naturally competitive spirit:

It kind of set me back because you don't push yourself. You know if you push too hard, something may happen and so that is what I was really concerned about. You know, when there is too much pressure and too much stress. I didn't want to put myself through that so I didn't push myself as much as I should have.

As a result, Darnell settled into a series of unfulfilling and low paying jobs where he struggled to "keep it together, to do better". His illness also required Darnell to make other changes in terms of his personal and social life specifically, "less running around. You know,

I'm an outgoing person and I like to be out [with friends] especially on a nice day. So I had to stop being out so much".

Yet despite the physical, financial and social struggles that Darnell has suffered as a result of his illnesses—he also was recently diagnosed with type 2 diabetes—he considers his life now much less stressful and disrupted than it was before he was diagnosed. He has "settled down in like a family mode" and has become more "relaxed". To do so, Darnell stated that he had to "mentally get ready" to make much needed changes in his life:

> You kind of have to do it on your own. You have to mentally get ready knowing that you have to have your own support systems. Use your family and your friends…My family, my kids, are really concerned that I take my medications, make my appointments, don't stress and they are always worried about me. A lot of my family and friends are support. They make sure I don't eat the wrong thing…[The diabetes clinic], they taught me everything about diabetes, what I should eat, what I should do. They even showed me how to inject myself with insulin and take my blood tests. They were very helpful…Stay focused. Stay focused. Keep people around you who make you laugh [and] make you smile. Keep your head up. It's not the end of the world. You can live with it…Yeah, I feel better. I've lost weight [and] feel healthier than I've ever felt since high school. I feel good now…You just have to manage it. And that's what I've learned to do. I've learned to manage it.

As we can see through Darnell's narrative, the onset of CHD was a major disruptor to his biography and his sense of self. That said, "managing it" reflects his concrete and strategic actions of staying focused, being mentally prepared, and specific in terms of those he keeps close to him, all of which allow Darnell to reconstitute his sense of wholeness and regain continuity

and control over his own "game plan". His efforts to control and order his illness are also constitutive of a process of marshaling different types of resources—his own internal ones, those provided by the health care system, and those of his family and friends, and by rearranging his personal and social involvements in his attempts to "normalize in the face of disruption" (Becker, 1994; Bury, 1982, p. 177).

Roy, who we met before, acknowledges the role that living in a racialized society has had on his overall health, but he is quick to point out that isn't the whole story. He described his previous self as "destructive". He has a long history of serving multiple prison terms for drug related offenses, burglary, and armed robbery. Like Darnell, Roy developed not only a proactive attitude in terms of his illness management strategies; he takes full responsibility for his health and its every day management saying:

> You have to look at it from an African American perspective. And by that I mean getting rid of that shit that ain't good for our health. You know, I can't put it all on the system. I used to when I was an ignorant kid and didn't know better. But I know better now. System is fucked up, lord yeah! But I had some choices and that's what a person—black, white, male or female—has to understand when you are dealing with any disease, but especially heart disease. You have choices here. You have choices in how you eat. You have choices in what you eat. You have choices in how you see your imagery…What I'm doing now, I'm walking every day, working my way up…'cause I ain't gonna give up on me! When I leave this motherfucker, I'm leaving kicking and raising hell! I'm not kidding. That's how I'm going out. I'm not going out like no punk. I ain't never lived like one. I mean a coward, a copout artist. I ain't gonna live like that and I ain't gonna die like that…That's how I'm going to live it. I have a great amount of fear and respect

for this disease 'cause I know it will kill you. If I slip and not take care of Roy, don't

take my meds, start eating fatty foods, smoke too many cigarettes, go back to crack

cocaine period, I'll be dead in a matter of a little bit. I know that no matter what I do, I'm

only gonna get so much benefit out of it…I can't get 100% benefit out of exercising

anymore because physically I can't do 100% of what I used to do. I've done so much

damage to my heart and my lungs. I have to accept what I get.

Roy approaches his disease with a tenacious and fighting spirit is reminiscent of his "bad-

ass" persona and "hell-raising" days of the street where he was in total control of the choices he

made. While Roy accepts that he has no control over his disease per se, he can control its

progression to a certain extent by controlling his approach to illness management.

Beyond "learning to manage" his disease, Roy also reveals some of the positive changes

that living with CHD has brought into his life. As Roy took control of his illness through living

a healthier life, he was able to develop a new closeness in the relationship that he has with his

daughters, who provide him with a sense of comfort and support:

My heart disease has changed a lot of relationships with my children and I hate to say

this, but it's the truth. The worst thing that ever happened to me was getting sick. The

trials and tribulations of illness is the worst thing, but the best thing is now I've got a

bond with my girls. I've got a real bond with my daughters. They don't come over here

a lot…but I hear from one of them every day! Somebody gonna call me, one of them. I

don't even worry about it. Some days I call them. I got a bond with my kids. I didn't

have that when I was in the life. When I was being destructive, I didn't have that bond

with my children. I got a bond with my babies! If I leave [die] in the morning, I don't

give a fuck 'cause I got someone that cares about me! And that's my truth! That's got

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nothing to do with that medical shit…I got someone who cares about me and that's important to me…my babies' love and I love my babies! And that may not have happened had I not got sick.

As we have seen with both Darnell and Roy, each has had to engage in significant work to reconstruct their biographies of self. They had to "sort out" the consequences that CHD meant for their present in order to carve out a new path into the future. Beyond coming to value biomedical interventions through which they could appropriate the benefits of healthier living, both engaged and applied familiar aspects of their prior selves to their current circumstances—like Darnell's competitive "can do" spirit and Roy's "bad-ass" persona. In so doing, both Darnell and Roy built up a determination and resiliency in order to feel a sense of control and responsibility over their illness trajectory. In redefining their situations as more hopeful, both found in their illness experiences a fund of new knowledge and self-discovery through which they could imagine and create new opportunities for learning and thinking about their selves and their future.

Conclusion

In this chapter I have sought to present the narratives of African Americans living with CHD as an illness experience, peeling back its layers in order to expose its multidimensional nature. In so doing I have demonstrated that there is a broad range of micro, meso and macro-contextual factors that influenced their experiences.

First, we have seen that cardiac symptoms are much more complex than what they may or may not signal about a physiologic problem or circumstance. Symptoms may act as symbolic

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guides into the personal and social burdens associated with the illness experience. Symptoms also reflect an individual's local knowledge of his/her own body and their interpretations of how their body works, fears about the future, and may also be conceptualized as a lens though which individuals make sense of and evaluate the impact that illness has had on one's life.

Second, a diagnosis of CHD caused participants to reexamine their past lives, reconsidering and reconciling their current circumstances to the practical logic of their day-to-day activities, abilities and behaviors. To achieve continuity of the self required one to develop a new sense of self, of body and bodily limitations that had been previously taken for granted.

Third, for some participants, the illness experience was full of irony. Through illness, they were able to forge new and positive paths, behaviors and relationships by redefining their current situations as more hopeful.

Fourth, and I think most important, these findings demonstrate that for the African American participants in this study, the development of CHD and the behaviors that undermine or facilitate health cannot be separated from their social, cultural and racial moorings. That is to say, for them, CHD is a normative experience—a "black disease"—wherein certain bodies have become historically, racially and culturally marked, a conceptualization that is sustained and passed on by African Americans themselves. This should shift the medical community's view that CHD is a lifestyle disease where high-risk behaviors and lack of healthy choices prevail to one that must recognize the ongoing racial and social dynamics at play through which inequalities are created, sustained and replicated.

CHAPTER 3

Social Capital: Resources, Benefits and Costs

Over the last 10 years, researchers have examined how individuals' neighborhoods, social networks and the resources that stem from them, intersect to influence health. Thus, many have employed the concept of social capital as a theoretical framework through which health inequalities may be better understood. Social capital refers to the actual or potential resources inhered within social networks that may be used for individual or collective action (Carpiano, 2004, 2006, 2007).

Historically, health research on social capital has primarily relied on quantitative methods focusing predominantly on measurement of individual, community, and multi-level analyses of social capital (See for example: Kawachi, Kennedy, & Glass, 1999; Kawachi, Kennedy, Lochner, & Prothrow-Stith, 1997; Kawachi, Subramanian, & Kim, 2010; Sampson, Raudenbush, & Earls, 1997; Subramanian, Kim, & Kawachi, 2002; Subramanian, Lochner, & Kawachi, 2003). More recently, there has been an accumulation of a more robust literature on social capital using qualitative methods that are specific and limited to examining the relationship between neighborhoods and social capital to various aspects of health.

In what follows, I briefly review how the concept of social capital has been applied to health inequalities research. Second, I present my findings having organized them around 4 forms of social capital identified by Carpiano (Carpiano, 2006, 2007, 2008, 2010), exploring their influence on my participants' illness experiences. And finally, I discuss the implications and potential utility of the social capital concept to better understand the relationship between the lived environment and the illness of experiences of African Americans living with CHD.

Application of the Social Capital Concept in Health Research

Most health research on social capital today has heavily relied upon the theoretical framework proposed by political scientist Robert Putnam (1995, 2000) who conceptualizes social capital as "features of social organization, such as networks, norms, and trust that facilitate action and co-operation for mutual benefit" (Putnam, 1995, p. 67). In Putnam's conceptualization, social capital is collective asset related to the involvement and participatory behavior within a community, demonstrated, for example, in volunteerism and civic spirit. Theoretically grounding her research in Putnam's framework, Cattell (2001, 2004) uses a comparative approach of distinct yet similarly disadvantaged neighborhoods to explore the social dynamics involved between poverty and exclusion; neighborhood and health and well being by considering the role of social networks and social capital. In both studies she demonstrates how neighborhood characteristics, both structural and cultural, interact to influence network patterns and the forms of social capital created.

Eriksson and Emmelin (2013) also rely on Putnam to explore what constitutes a "health-enabling" neighborhood and concludes that neighborhood social capital can have both positive and negative influences on people's perceived health and that distinct forms of social capital differ for men and women. Boneham and Sixsmith (2006) draw upon the voices of older women living in a disadvantaged neighborhood whose findings counter assumptions that older women are merely dependent on and recipients of care by family, friends and neighbors. Indeed, their experiences of dealing with health related matters gave these women the confidence and autonomy as lay health experts enabling them to challenge professional medical advice. While many contributed to a community sense of wellbeing through their informal helping, it did not

occur without cost. Personal and community expectations could lead to stress and frustration pointing to the underside of social capital and its potential negative health consequences.

More recently, scholars have turned to Bourdieu's theory of social capital (1986) because of his focus on the potential or actual resources that can be drawn by an individual group member to pursue individual or collective goals. In other words, social capital refers to the resources that an individual possesses through their connection to others (Carpiano, 2010). Bourdieu's main interest was uncovering the processes through which social inequalities of all types are produced and reproduced. In applying a Bourdieusian framework, for example, Browne-Yung, Ziersch and Baum (2013) explored neighborhood effects on health and social capital creation through the experiences of low-income people living in higher resourced and affluent areas. They demonstrated that in differently resourced neighborhoods, being "low-income" was experienced differently and that living in an advantaged neighborhood did not guarantee access to or creation of health-enhancing social capital or networks. Williams, Hewison, Wagstaff and Randall (2012) explored African and African-Caribbean fathers' views about preventative primary care services. Their findings challenged current stereotypes of African and African-Caribbean men as "hyper-masculine" and "emotionally disconnected". Rather, they found that fathers reflexively understood the influence of social structures, linking fatherhood to family, community, history and material factors; they strove to create forms of social capital, shielding their children from the negative effects of the "hard" social world (p. 100).

While most of this literature above explores different facets of social capital, how it works and its influence on perceived health outcomes, the focus has been on the relationship between social capital and the neighborhood or community, be it advantaged or disadvantaged.

The concept of social capital therefore, is being used as a proxy for the social environment at large, missing important elements of the individual lived experience that may influence health amongst individual community members. In other words, neighborhoods are more than geographically and socioeconomically defined areas of human habitation. Within them exist contextually different lived environments—those "immediate areas" where we move, interact with one another, and live. Because the literature to date does not account for within neighborhood variations of access to various forms of social capital, how it is accumulated and its potential costs, we still do not have an in-depth understanding of the local conditions and contingent mechanisms through which social capital is generated (or not) in different contexts and its effect on health (Dolan, 2007).

Therefore, the purpose of this chapter is to explore various forms of social capital, how it is generated, accumulated and mobilized within contextually different lived environments and its influence on the illness experiences of African Americans living with CHD. To that end, this chapter seeks to address the following questions:

- To what extent does one's lived environment affect the forms and generation, accumulation and mobilization of social capital?

- What types of social networks are the most effective in creating particular forms of social capital within contextually different lived environments?

- To what extent does the cost of cultivating and sustaining social capital outweigh its potential health related benefits?

To address these questions, I draw upon the work of Carpiano (2004, 2006, 2007, 2008, 2010) who employs a Bourdieusian framework to conceptualize a theoretical model of social capital. His model considers social capital as conceptually distinct from: 1) what he terms its

"structural antecedents", that is, the inter and intra-community factors such as neighborhood socioeconomic status, racial and ethnic makeup, income inequality, and neighborhood stability that impact the living conditions of neighborhoods and the resources to which its residents have access; 2) social cohesion that encompasses the patterns of social interaction and values such as familiarity and mutual trust that lead to social capital; and 3) outcomes, goals and benefits that social capital can provide for individual members of a community or the neighborhood as a whole, taking account that not all outcomes of social capital are necessarily beneficial. Carpiano's model also attends to two critical elements of Bourdieu's social capital theory: viewing social capital as an interaction between the type and amount of resources a group or network has, and the ability of individuals within the group to access them.

While Bourdieu neither defined nor discussed different types of social capital, Carpiano considers four forms of social capital all of which have been previously identified in urban sociology research (See for example: Altschuler, Somkin, & Adler, 2004; Briggs, 1998; Dominguez & Watkins, 2003; Sampson, 2001; Thoits, 1995). None of these have been, as far as I can determine, explored in any great detail through qualitative methods. These forms of social capital include:

- Social support, which refers to a type of social capital that can be accessed in order for an individual to cope with daily problems and has been identified as a determinant of health through a multitude of pathways (Briggs, 1998; Dominguez & Watkins, 2003; Thoits, 1995);

- Social leverage, or a type of social capital that affords individuals the opportunity to minimize or avoid socioeconomic hardships that can negatively impact health

through accessing information relevant to employment, child care and health

(Cattell, 2001);

- Informal social control, which reflects individuals' abilities to collectively

  maintain social order (Sampson, 2001) through the monitoring and surveillance of

  the local area giving a perception (actual or potential) of neighborhood safety

  (Altschuler et al., 2004); and

- Neighborhood organization participation, referring to individuals' participation in

  formal organizations that address neighborhood issues specifically aimed at

  increasing residents' quality of life and fostering a sense of community and

  empowerment (Carpiano, 2004, 2006).

In what follows, I organize my findings around these four forms of social capital along

with the corresponding codes that emerged from my data. Regardless of the type of living space

a participant occupied, all of my participants to some degree could access a source of social

capital in order to cope with the daily challenges related to their illness. However, for different

lived environments, different forms of social capital prevailed. The forms of social capital and

the types of resources available varied depending upon the type of lived environment a

participant occupied. I use thick participant vignettes to highlight how each form of social capital

is generated, accumulated and mobilized within contextually different lived environments

existing within low-income neighborhoods, the material resources that inhere within them, how

they get exchanged and the influence it has had on my participants' illness experience.

Social Support: A Sword with a Double Edge

One type of social capital that I identified in this study was that accessed through what Bourdieu (Bourdieu, 1986, p. 250) calls "more or less institutionalized" types of networks such as family, extended relatives and neighborhood acquaintances. I found social support to be most prevalent and beneficial to those living in traditional types of lived environments like houses, apartments and condominiums. Regardless of the socioeconomic status of neighborhood, participants who lived in traditional types of housing were more likely to rely on this form of social capital.

However, as a form of social capital, social support was a sword with a double edge: On the one hand, social networks provided access to tangible types of resources or support, such as running errands, paying bills, grocery shopping and organization of medical information, medication management and other health-related activities. Yet on the other hand, there was a "pay to play" aspect to this form of social capital where those who provided it, rather than those who needed it, defined the actual resources and the scope of the support. Those providing the support imposed limits around the types of support that could be accessed, constraining the individual choice of the recipient. While social support was never completely withheld, its provision did come with certain expectations that were difficult at times for the recipient to meet, exposing social capital's potential negative aspects.

This double edge of social support is seen first in the exemplar of Alma, who is 63 years old and owns her own townhome in Visitacion Valley, in a complex referred to by the locals as the "Red Brick Homes". The Red Brick Homes are nestled in between two low-income housing developments and the largest and most dangerous housing project in the City. Her immediate neighborhood lacks many resources; there are no grocery stores (only "mom and pop" corner

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markets), banks, or post offices within walking distance. Her neighborhood is considered to be both high poverty and high crime, where 25% of the residents live below the poverty level and most of the serious violent crime in the City occurs. Although Alma relies on her 42-year-old son Ronald who provides daily help, she is also able to tap into a dense network of connections that provide additional support as the result of her longevity in the Red Brick Homes and the fact that many members of that network are extended relatives:

> [Rodney] was at the hospital every single day before going to work. When he got off work at night, he was there at 11:30 at night. He'd be sneaking in [to the hospital], "How you feel? What do I need to do"? He was [with me] at rehab every day…He lives in Oakley [about 50 miles outside of San Francisco]. But because I've been so sick, he's been here…He comes everyday—just went and did some banking for me, bought me some milk and stuff, make sure I have food in here, and takes me to the doctor appointments and picks me up. We make it on his off days, mostly so he can be there to ask questions…[My cousins] come down or walk over and bring the kids every other or so many days. We keep close…I have a girlfriend who lives across the street and checks on me at least twice a day…My day care [provider] is next door…She's out running errands. Her step dad is there [pointing next door]. I've known him since my son was like twelve. His son and my son kind of grew up together…My neighbor across the street, she brings me food to last for a couple of days because she knows I can't stand up that long. Next door, her mother, she might cook something or get fruits and give it to me. Betty, she goes to the food bank get me potatoes and onions and stuff so she saves me a lot of money from going to the grocery store…so there is always someone there for me.

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In this exemplar, Alma is drawing upon the resources available to her as a member of a kinship or family network. Her son Ronald provides her with needed help around her independent activities of daily living such as banking, errands, and providing support when she sees her health care providers. Despite the fact that her neighbors are poor and the neighborhood is under-resourced, Alma is able to acquire, through her membership in this network, tangible and material benefits like food, errands, and emotional support. These resources help her with her daily health care needs.

Michael is 63 years old and lives in a public housing project of relatively recent construction, nestled along "hotel row"—several blocks of low and moderately priced hotel chains that cater to tourists. He lives on a modest pension and receives a Section 8 housing subsidy. Michael's immediate neighborhood has a multitude of fast food restaurants, diner chains, pubs and storefronts geared to the tourist industry. About two blocks from Michael's complex is a Walgreen's Pharmacy, post office, and a Safeway grocery store.

Like Alma, Michael has a strong network of family—his daughters—all of whom are involved in his life on a daily basis despite the fact they all live across town. For example, Michael describes the social support he receives from his oldest daughter Maya as:

> She handle my business. Like sometime I can't go—most of the time I can't go, she do
> my grocery and pay my pills and that stuff. Sometime…like a day or two a week, she
> come here and if I don't feel like washing…she take care of that. Sometime she go with
> me to the doctor…she make sure I take my medicine.

Michael also has a close cadre of neighbors in his housing project from which he receives social support in the form of wellness checks. His upstairs neighbors, an elderly Chinese man and his wife, frequently check in on Michael and offer to bring him meals:

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Like Mama and Papa [how he refers to his neighbors], they go to the store seven days a

week. Sometime, two or three times, they go to Chinatown and she will bring me back

something [to eat]…If nobody don't see me, my doorbell will ring, "You okay?" and

something like that.

But as Bourdieu (Bourdieu, 1986, p. 250) points out these networks are neither a natural

nor a social given:

The network of relationships is the product of investment strategies, individual or

collective, consciously or unconsciously aimed at establishing or reproducing social

relationships that are directly usable in the short or long term, i.e. at transforming

contingent relations such as those of neighborhood, the workplace, or even kinship, into

relationships that are at once necessary and elective.

Both Alma's and Michael's examples reveal how their effort to establish, reproduce, and

otherwise invest in cultivating their social relationships result in tangible and material benefits

that positively impact their health. For Alma these investment strategies include her community

activism: "we always going to meetings and stuff" on behalf of the Red Brick Homes, "watching

the kids" of her neighbors when they are playing at the park, and keeping her neighbors informed

"about what's going on here" through her position as "corresponding secretary" on the board of

directors of her homeowner's association. For Michael, his investments include helping his

neighbors by keeping their front porches "free of the leaves". When his neighbors go out of

town, Michael tells them, "Don't worry about it. I will look after your yard. That's how we is".

Both Michael and Alma are pointing to the reciprocal nature of this type of social capital.

Michael also cultivates a type of informal social support through being sociable. Most of

his leisure time is spent walking through the residential section of his neighborhood. His walks

are routine and frequent.   Through his talkative and sociable nature he has become, what I call, a "neighborhood normal" where residents outside of his lived environment expect to see him at routine intervals. As a result, he has acquired social support of a different nature through different means:

> I get up in the early morning [about] six o'clock and over the hill before everybody come out. My walk over the hill, the people, they get to know you…you passing someone every morning taking your walk, they get to know you. People stop, [and say] "Good morning, good morning"…A lot of them are old people and if they don't see me like this morning, tomorrow morning they will say, "I don't see you [yesterday]".

> By stopping and interacting to "shoot the breeze" with them and "have a laugh or two",

Michael is cultivating an informal network of social support that has been extremely beneficial to his health. Through these brief interactions, information is passed and an informal and reciprocal type of caring is generated. For example, during one of his morning walks, Michael's cardiac symptoms became quite severe as he stopped to chat with one of his neighbors:

> I had to stop and say, "I'm short of breath" and she told me to sit down. And she gave me a thing of water. She say, "Do you want me to call an ambulance?" I say, "No. I will wait til I catch my breath". You know, that lady put me in her car and drove me right back here to the gate and brought me in. She stayed a little while until I tell her I'm going to go lay down. That's a good when you get to know people.

In this example, his neighbor who lives outside of his lived environment—outside of the housing project—takes an active interest in Michael's health and demonstrates to him an informal form of caring, driving him home and waiting with him until his symptoms passed. In addition to his strong formal network of family who attend to his activities of daily living and health related

matters, Michael can also rely on an informal network of connections who check on him at regular intervals and who provide, and are provided, interaction, sociability and help when needed.

For Alma, Michael and others I interviewed who resided in more traditional types of living spaces, social support was mostly accessed through close family and friendship networks that provided the recipient with tangible and material resources to assist with their daily health needs. The actual socioeconomic condition of the neighborhood itself had little, if any, effect on the amount of support provided or the types of resources they could avail themselves.

The Negative Aspects of Social Support: Boundaries, Limits and Expectations

Focusing on the types of resources as social capital also exposes its negative side. Accessing social support through family networks was neither open-ended nor limitless. There were many examples of strict limits set by the family member as to what type and how much social support a participant could draw as well as boundaries drawn around the types of resources that could be accessed by the recipient thereby constraining individual choice related to certain behaviors like dietary habits, smoking and drinking. In other words, those who provided support, rather than those who needed it, defined not only what resources were available but the nature and scope of those resources as well. For example, many participants related how their family members could be quite critical when asked to buy alcohol, cigarettes, or foods they felt were unhealthy. Michael said this of his daughters:

> They don't like to see me go downtown to my friend and the next thing I have a couple or
> too many beers. Like when they run and make my grocery, they used to buy me [beer]
> but now they don't do that. I got to do that on my own.

Another participant, Debra, lives with her older brother Donny in a mixed income apartment complex in the vibrant neighborhood of the Fillmore. I had the opportunity to also interview Donny, and he describes what it has been like for him living with his sister's multiple illnesses and watching her still engage in health-damaging behaviors like smoking:

It's hard because I understand health a little bit, so you know it's trying to get her to realize smoking and the heart runs hand-in-hand—one supports the other. So when she has problems, 85% of the time it's from the smoking. Despite the fact that the heart is still having that issue, she don't understand how her lungs are working hard, her heart's got work even harder, you know? It gets frustrating! You probably have brothers and sisters. Once they get a certain age, you can't tell them nothing anymore.

Donny, like other family members I interviewed, were a bit resigned that there was only so much they could do to change what they believed were health-harming behaviors. In all cases, however, they actively refused to enable such behaviors by providing or buying cigarettes or alcohol and did their best to try and temper the effects. Donny explains:

It's hard. But I try to tell her [his sister Debra], if she's going to smoke, at least go outside where she's not taking in the second hand smoke from sitting inside the bathroom [the only place in the residence where Debra smokes]. If you're going to smoke, you're going to smoke. At least go outside and smoke where when you exhale you don't have to breathe in the same stuff you're putting out.

In these examples as in others, it was demonstrated that social support not only had limits, but was also defined by the person providing it. While the limits placed on various types of support that would and could be provided constrained individual choices, Michael agrees that his daughter's refusal to buy his beer and cigars for him has had a positive influence on his

health-related behaviors: "[Before], I have no control over how much been I'm going to drink. But now, I drink 3 cans, you know? Sometimes less. [Before], I might pull a cigar, now I don't do that."

Similarly, Donny actively encourages Debra to quit smoking. As Donny said to Debra during our interview, "Our mother had the same problem. She was having the same kind of particular issues and she just stopped smoking…She just quit cold turkey". While he lives in the same apartment with her and doesn't forbid her to smoke, he insists that if Debra smokes in the house, she does so only in her bathroom. For Debra, these limits have been somewhat beneficial:

> I want to quit but when I get stressed out, I just smoke…I'm learning that if I light a cigarette and I have to go in the bathroom, I look at it and I say, "Okay, I don't need it". So, I'm learning a habit now. When I light it, I probably take two puffs and I'll look at the cigarette and say, "Okay, I don't need it".

Meeting expectations also played a large role when family members were the primary providers of social support. When the recipient failed to meet the expectations of the caregivers, the exchange of social support and the familial relationship became fraught with tension, as we see with Dorothy. Dorothy is 73 years old and has lived in the Sunnydale housing project for almost 40 years. Sunnydale is located in Visitacion Valley, the neighborhood where Alma lives. Dorothy has two sons and one daughter, all who live in the same project, albeit in different apartments. Dorothy was diagnosed with congestive heart failure and coronary heart disease 3 years ago. Last year, as her symptoms progressed, she required surgery and underwent a triple bypass. Her children are her primary source of social support and her daughter Monica is her primary care giver.

During our interview, Monica related to me that prior to her mother's illness, they enjoyed a very close relationship: "I don't mind chilling with my mom versus my friends because I want my mom's days here to be nice…enjoyable, you know"? But Monica admitted that once she understood the severity of her mother's condition, the treatment proposed and the expected outcomes, she envisioned a certain trajectory her mother's health would take post-operatively and planned her life and her mother's accordingly:

> When she came out from surgery, they said you'd be walking in 6 months. I trusted that!
> It was like, no excuses. So even though she wanted us to baby her and be like, "I can't
> walk", I would say, "the doctor said you supposed to be walking in 6 months…so that's
> how it was….I'm very strict on my mom and so now…see that tough love? Now she's
> walking!

That "tough love", however, did not come without a price. Monica's constant pushing and prodding of her mother to meet her expectations led to frequent arguing, and at one point the relationship became so tenuous that Adult Protective Services (APS) was called in to investigate Monica for potential elder abuse. Dorothy explained to Monica and me during our interview:

> That didn't come from me [the APS complaint]. When I'd go to the doctor and stuff,
> because of the way you treating me…then I guess they say, "Everywhere they go, they
> argue, they argue". But see, people watch how you treat people.

Monica explained that she was focused on providing the support she felt was necessary to move her mother along the continuum of care:

> I have to give her tough love because if I don't she's gonna be in the wheelchair. She's
> not gonna be helping herself. Sometimes she's trying to pull the wool over your

head…I'm not fixing to let her do it, you know? And so she gets mad at me, "Well, you know I can't do it". "Yes, you can do it!" And then we, you know, [argue and fight].

As these narratives have demonstrated, being able to access social support was a valuable form of social capital that was beneficial to the recipient's health status and trajectory. Social support was primarily accessed by those living in traditional lived environments such as single-family houses, apartments and condominiums and through traditional social networks like immediate and extended family members and/or close neighbors. However, while social support was never withheld entirely, the nature and scope of the support provided was defined and determined by those providing it. In many cases, the adult children and siblings were the main providers of such support, upsetting traditional power relationships where children and younger siblings became the caregivers with additional responsibilities and added burdens while the parent and older siblings became the receivers of care. As Carpiano (Carpiano, 2006) suggests, a Bourdieusian framework that focuses on types of resources as social capital exposes its negative side. That is, the limits and boundaries of support had the effect of constraining the personal choices of the recipient (e.g. dietary habits, smoking and drinking), and failing to meet the expectations of the support provider in exchange for the resource led to tensions and family discord.

Social Leverage: Cultural Capital Required

Participants who lived in traditional lived environments certainly had access to a plethora of information through their dense social networks in order to minimize socioeconomic and health hardships. However, those without formal or kinship-based social support that lived on the margins, in single resident occupancy hotels (SROs) and transitional housing, drew instead

upon social leverage, a type of social capital that affords individuals the ability to minimize socio-economic hardships that can negatively impact health, mainly through their reliance on government and city service agencies.

The resources provided by this form of social capital were access to food, housing and health care services. Drawing from this form of social capital was difficult and required proactivity upon the part of the participant to identify what resources would likely be helpful, develop the necessary social connections and deploy a number of cultural skills such as demonstrating initiative, a good work ethic, and conversational skills and so forth. The recipient then had to covert his/her stores of this cultural capital into social capital through which material, economic and tangible resources could be accessed, while complying with strict rules and surveillance to keep it. Many times, acquiring social leverage required a broker or advocate who was willing to help the participant navigate the system. Although many of the participants who lived in SROs or transitional housing had family, those traditional networks did not provide the resources needed to assist with their health care and activities of daily living needs.

While social leverage was seen as a helpful form of social capital to stabilize health status through access to community substance use treatment programs, housing and a reliable health care network, it only marginally allowed those who relied on it to get ahead. Most often, it allowed individuals to endure their social circumstances rather than overcome them in any substantive way.

One participant who demonstrates both the effort required to access social leverage and its limits is Roy, who is 58 years old and has lived in a Tenderloin hotel for most of the last 10 years after his release from prison. He has three daughters who live in the Bay Area, one in Novato and two in Oakland. While Roy acknowledges that he "has a bond with my babies" and

he talks to them frequently, they do not provide him with tangible or material resources that are helpful for him to live with his CHD. The severity of his clinical condition makes even local travel difficult for him, and the "rough" neighborhood in which he lives is a barrier to his family visiting. Roy explained:

> I can't go over there [to his daughter's house] like I want especially to see my grandson. I would love to be able to see him more than once or twice a month. It's difficult when I have to use that walker. I feel vulnerable with that…I don't know if you noticed where I live…it's pretty predatorial…so a lot of time won't go. I don't go to my grandson's much. I just wait for them to come to me. You know my daughter comes once every 2 month and see me for a few minutes. My kids across the bay, they'll be over about once every 3-4 months. My daughter, she calls a lot but she's not going to come over. So, I don't have any family [support]. I am my family.

Because Roy does not have access to social support resources, he must tap into a different network of connections that provide him a different type of social capital, social leverage—a myriad of city-provided services which, over time, Roy has become quite savvy at accessing and mobilizing. However, Roy must first deploy a repertoire of cultural skills, i.e. engaging in intelligible conversation, reading, evaluating options, asking relevant questions—all forms of cultural capital—and convert that capital into social leverage.

For example, Roy was placed in a halfway house following his release from prison where, "I saw it there, the first place that I really saw how these agencies were able to do things I couldn't…They were the first ones where I saw how the system could help you". After first observing how these agencies could help, Roy then had to "learn the system" to access economic

and material forms of capital like Social Security benefits, food stamps, and much needed

primary care. Roy explains:

> That's how I started learning how to use the system and work the system because there
>
> were a lot of young, fresh people there who would help and that I could engage in
>
> conversation about what I needed. We could sit down and look what they have versus
>
> what I need and all those things were great tools.

As a result, Roy was able to "start making decisions that were mature, healthy decisions," such

as ending his substance use and entering recovery.

Roy also recognized the importance his own tool kit of cultural capital had on his ability

to access the resources inhered within social leverage, using them in ways not only to stabilize

his health but improve it:

> I've always been fortunate enough to like to read, so I read a lot of medical stuff, so I had
>
> some idea about what I was up against…[What I] had was an idea because the
>
> information I had, I took it but it got me where I needed to go…I was able to start linking
>
> up with various doctors and agencies that could help me help myself if I was willing to
>
> do that. And that's what's been happening.

Roy is clear that neither the system nor one's own cultural skills in and of themselves are

enough to capture the resources necessary to provide a benefit to one's health. Rather he must

identify and cultivate relationships with a broker or intermediary willing to "advocate" and help

navigate the system in order to identify what resources are available and to determine how and

when to procure them:

The trick is you have to have some who is willing to advocate for you. If you don't have

an advocate, you in big trouble here…[The system] is great as long as you got someone

to advocate. It sucks when you ain't got nobody, you know?

For those like Roy, accessing social leverage required the recipients to be proactive and

do the "footwork". It also required them to be "on time" and "where and when they tell you"

and to "do what they tell you to do". The front-end costs of this type of social capital were

persistence, patience, and a willingness to "follow the rules". More importantly, however, in

order to the "leverage the leverage" so to speak, required the mobilization and deployment of

significant stores of cultural capital—resources previously accumulated like "reading up on

medical stuff", skills to evaluate different types of resources that might or might not be helpful,

the ability to engage in meaningful conversation in order to tap into the social networks of

"advocates" willing to help negotiate "the system". In other words cultural capital first had to be

converted into an advantage through which social leverage could then be accessed.

The experience of another participant, Marcus, provides unique insight into the

paramount importance of maintaining social network membership is to maintaining access and

benefits from social leverage. Marcus is 54 years old and currently resides in a residential

treatment facility. At the time of our interview, Marcus was in month 10 of a 13-month drug

treatment program. Prior to that, he was either homeless, living in SROs or incarcerated. It was

while he was in jail on crack cocaine charges that Marcus was diagnosed with CHD and

hypertension. It was also the time he decided to enter recovery:

I've been smoking crack for years and I can remember a couple of times actually being

arrested, and they were like—well, they had to call somebody to make sure I can go to

jail because my blood pressure was so high…For me, I just started to see the handwriting

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on the wall, you know? Like going out and doing the penitentiary and stuff all over

again, because it's an escalation. You don't just commit one crime and go to the

penitentiary. It's an escalation of things unless you kill somebody. So, I could see it

escalating so I decided—I said, "Well, you know what? I'm tired. I just can't do it

anymore.

Having explored his past life, current situation and made predictions about his future

life's landscape should he continue on his current trajectory, Marcus made the decision to "clean

up". That decision provided him entrée into a network of social connections with various

resources that would benefit him upon his release from custody:

I told them basically what I was trying to do [get clean and sober] and I had some [case

managers] in jail who said, "I got you. Don't worry about nothing". I knew from

experience that it's better to have too many people than not enough people. So I had an

agency get involved to where when the time came for me to leave [jail], they were able to

put me somewhere. If I had to go back [upon release] and get a room [on my own]—you

get the cheapest room, so it's the worst places. Then you got to hustle. So, I'm going to

get high in order not to feel bad. I'm a stay high. I don't want to think about it.

Marcus saw the lived environment of SROs as contributing to his reproducing patterns of

drug use. Recognizing the danger that "going it alone" posed to him and his planned recovery,

Marcus weighed his options and surrounded himself with the necessary social network

connections that would help him further his goal:

I had a choice. Either I can go outside and do something [on my own], or I could stay in

and wait. So I was able to stay in jail for a week until a spot opened up in the program.

And you know I'm still working with them [his case managers from jail].

Besides recognizing his own patterns of behavior, Marcus also had to be savvy enough to evaluate what resources were going to be the most valuable to him in the furtherance of his strategic goals. While the drug treatment program provided him with the concrete resources and skills to remain clean and sober, it was his fragile social circumstances that posed the greatest danger to his sobriety and his overall health. Therefore, Marcus maintains close contact with his case managers:

Where I'm at [referring to the residential treatment facility], they think they provide everything for you, but it's not true. There are some wants and needs that they just can't do…If it wasn't for [the jail case managers], I probably would still be on the street because they were able to put me somewhere [housing] when the program couldn't. Now, I'm in the transitional part of [the program]. If it wasn't for them [jail case managers], I'd be really, really nervous. I'd be really stressed out. When I talked to him [one of his case managers], he was like, "Don't worry about nothing. We're not going to let you fall through the cracks. We have housing [for you] and stuff like that. You just let me know when you're ready". So, that's a burden off my mind there. It may not be the best place in the world, but it's better than having to go back out there and doing the same thing over. I can really get on my feet.

By harnessing and maintaining these networks, Marcus has secured tangible and material resources like sobriety services, housing and access to primary care. These social connections also function for Marcus as a social scaffold that supports him and keeps him from "falling through the cracks" into a lived environment that, for Marcus, is a danger to him and the future he wants to create for himself.

Access to the material benefits of the sobriety program, however, requires a quid pro quo exchange of labor—working for free in a diner—and demonstrating certain valued cultural characteristics, namely a "good work ethic":

Here, [at the drug treatment facility] it's like you got 6 months of working in a diner for free. They tell you it's not free because it's [counted] as work experience. I mean I have a good work ethic. I can see how it does help some people, but some people don't make it through because of that. I also know that this place isn't really all about recovery. Their thing is, "we will help you, but we need you to do something". And the diner is the hub of the agency because…everybody sees this diner helping the homeless, feeding the hungry and they don't have a problem with donating for that. And the way they do it is, they have us working for free! You know they tell everybody, "Okay, we're also helping the drug addicts because they're coming here". But the truth is, it's not about that, because if you can't work, you can't be here.

According to Marcus, the diner (serving low income and the homeless) is funded primarily by philanthropic donations, however the diner saves money on overhead costs through the free labor of the substance use treatment clients. Under this model, not everyone gets an equal shake at sobriety, only those who can contribute physically and demonstrate the requisite cultural attributes as defined by the program. Marcus was therefore advantaged by demonstrating those physical skills and attributes while others, "who didn't have a problem working" [good work ethic] but for physical reasons could not work, "were put out" of the program. Therefore this resource is not "free" to all who seek such services, but only to those the program determines worthy and able.

Both Roy and Marcus acknowledge that having accessed these resources has been beneficial to them in terms of stabilizing their housing, securing economic benefits, providing access to health care. However, they describe how their respective life situations remain a bit tenuous. Roy admits, "I don't know how I'm going to make it", yet still he strives to capitalize on his experiences and knowledge of the system to help others in ways that he can: "I want to give something back to the medical field for helping me when I couldn't help myself. That's why I volunteer up at General on the 7th floor 'cause someone helped me when I couldn't help myself." For Marcus, he worries that his chances for any gainful employment are nil saying, "The only training I had was from experience". Still, he is trying to leverage that experience seeking work in case management and homeless shelters and various non-profits. Unfortunately for Marcus, his criminal justice history is the biggest impediment to him doing something he would like to do and would be, most probably, very successful at doing:

> It seems like it's not going to happen because I'm on probation. I believe in full disclosure…you got to let them know because they're going to find out eventually. I don't want to be working for 3 months and then they tell me I got to go. That seems to the biggest hindrance right now.

As these exemplars have demonstrated, acquiring social leverage necessitates a process through which stores of cultural capital are converted into an advantage that provides entrée into the types of social networks through which the resources inhered within social leverage could be accessed, such as government subsidies, housing, substance use treatment and work opportunities and experience. For Roy and Marcus, both first had to determine what goals they were trying to achieve and identify what resources would likely be helpful to achieve them. The had to be savvy enough to strategically deploy valued cultural resources like proactivity, ability

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to engage in conversations, demonstrate a "good work ethic" and an ability to "follow the rules". While social leverage did have some positive outcomes, its range was not limitless. For Roy and Marcus, and others like them, this form of social capital was highly circumscribed, access to it required a significant amount of cultural capital, and it certainly wasn't free—it had to be worked for and earned.

Informal Social Control: Individual Efforts Aimed at Personal Safety

The third form of social capital as conceptualized by Sampson (2001) and Altschuler, Somkin and Adler (2004) is called informal social control and is defined as individuals' abilities to collectively maintain social order through the monitoring and surveillance of the local area giving it at least the perception of safety. Concerns about both community and personal safety were common themes in my participants' narratives. However, rather than engaging collectively to maintain social order through active monitoring and surveillance to further neighborhood safety, most participants employed individual efforts and strategies to secure the safety of their immediate lived environments, rather than the neighborhood at large. That is to say, their social circumstances did not provide them with much access to informal social control as defined above.

For those living in public housing projects, beyond the learning and paying heed to the "codes" and "postures" required for everyday survival, protective social networks evolved out of their tenure as residents in a particular project, and through more tangible contributions of feeding and providing shelter to those in need regardless of the circumstances. While such actions did not make the neighborhood any more safe in a more general sense, they did afford some individuals an added sense of safety and security, as we will see below.

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Dorothy and her daughter Monica, whom we met earlier, have lived in the same housing project for almost 40 years. Sunnydale has the notorious reputation of being the most violent and crime-ridden project in the City. Both Monica and Dorothy admit that the projects are inherently dangerous and both have been caught in the crossfire of rival gangs. However, they are specifically not targeted for violence or crime because of Dorothy's long tenure as a resident in Sunnydale and her tangible contributions to her social network of never "turning nobody away". Over the years she has developed a certain social distinction through which an enduring social network has developed around her and her family that lends them a modicum of safety that others in the projects may not have. Monica explains:

> My mom is like the matriarch over here…My mom always fed everybody. She didn't turn nobody away. All my friends in here when we were little, making cakes with the flour everywhere, you know? And now, everybody, "Hi, Mom [referring to Dorothy]. How you doing? You all right, Mom?" Everybody, they still come here for food. You want to take a shower? She's not going to turn you away. All these guys and all these women [referring to the gang members in the project], they all know in the back of their mind, "If I ever need a place to stay, if I ever need a meal or if I ever need to take a shower, I can always go to [Dorothy's] house."

In fact, when Dorothy had the opportunity to move a safer neighborhood, she declined. She instead preferred the familiarity of the type of safety based in her membership and standing within her own social network, built through her sizable investment of providing food, shelter, and other amenities to individuals in the neighborhood who might otherwise pose a threat. Because of the scope and influence of Dorothy's individual social network, benefits

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subsequently accrue to her daughter and the rest of her family as well providing all of them with social standing and safety.

Similarly, for participants who lived in SROs, their primary concerns were less about the safety of the neighborhood and more about their particular living space within the hotel in which they resided. Most of my participants did not have access to social networking necessary for collective action and instead employed individual efforts rather than collective ones to keep their immediate lived environments safe.

For example, Marlie is 52 and lives in a privately owned Mission District hotel in the most congested part of the neighborhood, 16th Street and Mission. The building has no kitchen facilities or communal eating areas. There is no lobby where residents can gather and meet, rather the front door to the hotel opens immediately to a staircase that leads to individual hotel rooms located upstairs. The room Marlie occupies appears to measure about 160 square feet (about half the size of a standard commercial hotel room), and has hardwood floors covered with throw rugs. She has access to a shared bathroom down the hall from her room. There is a small window that overlooks a very busy and noisy alley.

Marlie has a small refrigerator in her room in which she keeps small containers of milk and juice. She is very food conscious; she shows me her stock of healthy snack bars, whole grain cereals and dried fruits that make up a large part of her diet. She "eats in colors" and when she prepares her plate, "it's got to be green, yellow, orange and red". Her room is meticulously neat and tidy. Nothing seems to be out of place. She has a few religious pictures on the wall and many tchotchkes abound that give the room a personal feel to it. As I enter, she asks me to remove my shoes so as "not to drag the outside, inside".

Lack of privacy, crowded conditions, excessive noise and personal safety are the biggest worries to Marlie. She does not feel safe living in the hotel and doesn't trust the hotel management. In fact, until recently Marlie was convinced that the hotel manager was entering her room unauthorized:

Every time I would leave, I would come home, someone's been in my room. And it's disgusting and gross, and it was scary. You know your home. As soon as you walk in, you could just feel that someone's been in here, you know? It's one thing if you're crazy, but I'm not crazy, not stupid, none of that. Someone was in my room each and every time. She wasn't stealing anything, but she was moving around and I know just how I got everything set in my room. Something's been moved. Something, like a drawer, won't be closed all the way…I started putting a string at the top of my door so when I leave—when I come back if that string's there, she hadn't come in here. If the string was gone, she was in here. And that's how I showed her one day. I go, "I had put the string here, and the string is not here. You went in my room. Okay, this has got to stop or, you know, something ugly is going to happen" because she's going to freak me out…I'm scared at this point and I'm about to lose it, you know?

In this example, because the hotel manager is not willing to abide by social norms and rules that designate Marlie's room as private, she deploys an individual type of control through which she is attempting to protect her personal space, her lived environment. I asked Marlie if she had told any of her neighbors what she was experiencing with the hotel manager and her suspicions that she was entering her room without permission; she responded:

I really don't socialize with my neighbors…It's best for me to stay to myself because the way people living in a hotel, I just don't want to talk to people in here. I stay in the hotel

and I stay to myself. Everybody's into drugs, the prostitution, and at times you have to

beat your way to your door…Nail your windows shut…When you come out of your

room—and you have to share a bathroom—what you see going to the bathroom, you

know, [it's] just a mess.

 In fact, none of the participants I interviewed who lived in SROs had any real social

interactions with their tenant neighbors at all. And many tenants of hotels made it clear that

social interaction was not welcomed and went so far as to fashion their doors with homemade

signs like the one I saw in a Tenderloin hotel:

"DON'T EVEN THINK OF KNOCKING CUZ I AIN'T GONNA GIVE YOU SHIT!"

None of the hotels I visited had any real designated spaces for social activities or

interactions. Those hotels that had front lobbies were not conducive for socializing as they

lacked sitting areas, were well trafficked, busy and noisy. The main forms of social interactions

for those living in SROs took place outside of the hotels "with people in the neighborhood" or

with visiting home health aides and caseworkers. Therefore, there were few opportunities for

tenants in SROs to engage in any collective form of informal social control as it has been

defined, rather most employed individual strategies to secure the safety of their immediate lived

environment.

Neighborhood Organization and Participation: A Valuable Rarity

Like informal social control, neighborhood organization and participation was not a very

common form of social capital that I saw being mobilized in the lives of my participants. It

seemed limited to those environments that had solid infrastructures and robust participation of

the network's members. When it was deployed, it proved to be a very powerful form of social

capital and elevated its members' sense of community spirit, pride and belonging. As we will

see with Alma's narrative below, neighborhood organization and participation was achieved by

tapping into strong social support networks that already existed.

As described earlier, Alma lives in a condominium complex in Visitacion Valley referred

to by the local as "The Red Brick Homes". Nestled in the center of the Red Brick Homes is a

park that is beautifully landscaped, clean and inviting. It boasts a gazebo, play equipment for

children and an open space for basketball and soccer. So beautiful is the park that people from

all different neighborhoods come to enjoy it. But as Alma explains, this park is a relatively new

addition to the neighborhood and wasn't always so peaceful:

Before, you or your kids couldn't go there. They were dealing dope in the park. They

were shooting and fighting. You couldn't even walk across the street. It was horrifying!

They found needles in the sand and they would hide drugs in it. It was terrible.

Strategically, purposefully and methodically, Alma organized her social support network

into a community effort with the common goal of increasing the residents' quality of life by

"cleaning up the park". First she had to get support of the homeowner's association to organize

her neighbors around this common goal. Second, she had to leverage the political assets and

connections one neighbor had with the San Francisco Board of Supervisors. And third, once the

park was renovated, the residents had to collectively maintain it through informal social control

by continual monitoring and surveillance of the activities in the park. Alma explains how what

was once a dangerous eyesore became a beautiful park:

It was me, two ladies across the street and [her next door neighbor] that fought to get that

park re-did…You know we just kept talking about it. He [her next door neighbor] used

to be on the city council. He was a supervisor. He kept saying his daughter had just had

a baby and he says, "Look, I can't take her to the park. Kids can't bring their kids to the park. We need this park clean"…We didn't have nobody come to clean it or empty the garbage half the time. We wrote what we wanted and we gave it to him. He kept going downtown and calling downtown. And we started calling and badgering downtown and finally this woman Megan [from Park and Recreation Department] came down here to see. Nobody even knew about this park. She said, "Well, what do you all want in this park"? We had a meeting and told her what we wanted and she went back and said there was a lot of money for this. "We have money for parks. We just never heard of your all's park!" She came out here with a whole crew of people…[Now], we see the guys outside in the rain playing soccer. And the boys, they have their basketball games. Seeing those kids laughing and hearing them play, it like, OK, it's worth living here. It's worth holding onto.

Here, neighborhood organization and participation was a valuable form of social capital that was achieved by tapping into strong social support networks that already existed. The value of this form of social capital was a result of individual network members sharing a common goal that the members of the network could collectively work toward. It required strategy, organization and collaboration in order to achieve the desired goal. It also required ongoing informal social control through which the activities in the park are monitored:

I see kids there trying to tear the sprinklers out the ground the other day while the water was going up. I'm like, "That doesn't belong to you! Leave it alone!". So, I hollered out the window, "Get your ass off from that park and leave them sprinklers alone before I come over there and beat the shit out of you! Get your ass to school!" He took off.

Beyond fostering a sense of community and empowerment, the park's rehabilitation has had a positive influence in terms of Alma's health. She notes that her stress level is down and she is more "mellow". She enjoys the fact that others from different neighborhoods come to enjoy the park saying:

> You can hear the Asians over there doing their exercises, and we all look out the window and watch them do their exercises…So, now I get up and walk over with my walker, and I walk down and I come back. I haven't made the whole circle yet, but I try to go out once a day and walk it. So it helps.

In coming together to achieve a collective goal that benefitted the whole social network of the Red Brick Homes, this type of social capital gave Alma and her neighbors a sense of empowerment, community pride and belonging, that despite the neighborhood violence that still surrounds them, their lived environment is "still worth holding onto".

Neighborhood organization and participations was the least common form of social capital among the participants in this study and was limited to those environments where solid infrastructures were in place as well as a robust participation of the network's members. It was principally achieved by tapping into strong social networks that already existed. Community engagement required organization and the coming together around a common goal of interest and necessitated the leveraging of political connections and assets.

Conclusion

The purpose of this chapter was to explore the extent to which one's lived environment affects the forms and generation, accumulation and mobilization of social capital; the types of networks most effective for accessing particular forms of social capital; and to what extent does

the cost of cultivating and sustaining various forms of social capital outweigh its potential benefits, using Carpiano's Bourdieusian based framework (Carpiano, 2004, 2006).

While it is not the only theoretical perspective on social capital or one that covers all of its many complexities and nuances, a Bourdieusian perspective has been particularly helpful in illuminating the relationship between individuals and their spatial contexts on health and illness. Bourdieu regarded social capital as a property of individuals and was the outcome of individual biography (Whitley, 2010). An individual's social connections and personal networks produce and reproduce useful relationships through which they may access material and tangible resources that may influence health and illness experiences.

This chapter contributes to the literature on social capital in a number of ways. First, it takes account of within neighborhood variations of social capital, adding a more nuanced and in-depth understanding of the local conditions and contingent mechanisms through which social capital is generated.

Second, a Bourdieusian focus on the types of resources inhered within various forms of social capital makes it possible to expose it negative aspects. As we saw in the example of social support, providers of various resources had the power to define the nature and scope of support offered as well as its limits and boundaries. This had the effect of constraining individual choice of the recipient and failing to meet the expectations of the provider could lead to family tensions.

Third, certain forms of social capital like social leverage required the conversion of valued cultural capital in order to successfully access the resources necessary to minimize the health-harming effects of socioeconomic hardships. Those who were able to deploy their stores of cultural assets successfully gained entrée into a wide array of social networks that provided material and economic resources such as government subsidies, housing, and substance abuse

treatment. However, this form of social capital was highly circumscribed and required constant vigilance and maintenance of the necessary social connections in order to retain the useful resources.

With the exception of neighborhood organization and participation, exploring the various forms of social capital reflect the Bourdieusian notion that social capital arises principally out of the scope and influence of one's individual social network, the benefit accruing to the individual as well as to their family. This is in contrast to Putnam's conceptualization that a communitarian approach facilitates action and cooperation for mutual benefit of an entire community (Whitley, 2010).

Exploring individual lives helps to uncover the actions and goals to which various forms of social capital are put to use and highlights the underlying contingent mechanisms at work that influence the genesis, access and utilization of various forms of social capital. In identifying the resources inhered within various forms of social capital and individuals' abilities to access them, the concept of social capital is a useful one to think about the different ways an individual's quality of life and overall health can be maintained, improved, or hindered within the lived environment s/he resides.

CHAPTER 4

The Multidimensional Nature of Habitus: Making Sense of Our Sense of Place

Stress and its role in the development and experience of coronary heart disease (CHD) was a central concept identified through interviews with primary participants and their family members. Almost all of the participants I interviewed readily conveyed that they had suffered or were currently suffering from stress and that stress was an active ingredient in the production of CHD. Participants attributed stress production to the lived environment in which they resided, which ultimately shaped their experiences living with CHD.

In this chapter I use concepts of habitus (Bourdieu, 1977) and collective habitus (Hillier & Rooksby, 2005) as analytical enhancements to explore the ways in which bodies and place are linked together and the effects that linkage has on stress perception, experience and production. Habitus is a set of non-natural, acquired dispositions, styles, attributes and characteristics that are the product of social conditions, and may be totally or partially common to people of the same or similar social conditions (Bourdieu, 2005a). In my study, participants cited and richly described how stress is produced through socio-spatial pressures experienced in everyday places and contexts. With the concept of habitus, I argue that there is a temporal dimension in which our bodies become habituated over time through our biographical experiences to particular states of equilibrium or our "sense of place". When there is a mismatch between our habitus, which we develop over time and within a specific set of social conditions, and the actual physical and social circumstances in which we find ourselves, our sense of place is disrupted, and stress becomes the bodily manifestation of that mismatch.

In what follows, I first explore existing scholarship on how the lived environment is conceptualized to influence health. Next, drawing upon the works of Bourdieu (1977, 1979,

1980, 1999, 2005b) and Casey (2001, 2009), I review in depth the concept of habitus, and in particular, its relationship to the body and the lived environment, using participant exemplars to elaborate on and illustrate various aspects of habitus. And finally, I present an extended narrative of an African American woman living with CHD to demonstrate the relationships between stress perception, experience and production on the one hand, and habitus and health on the other.

The Lived Environment and Health

The mechanisms that connect place to health, especially in terms of CHD, are neither straightforward nor well understood. Some scholars suggest that the physical environment is an important determinant in shaping the conditions that promote inequalities in health. The Alameda County Study, for example, was among the first to document the importance of physical "place" in relation to health outcomes by concluding that living in high poverty areas has negative effects on the life chances of those who live there (Haan, Kaplan, & Camacho, 1987). Several studies have demonstrated associations between living in a disadvantaged neighborhood and increased rates of death from cardiovascular disease (Diez Roux, Borrell, Haan, Jackson, & Schultz, 2004). Studies have also documented that neighborhood socioeconomic status is inversely related to the overall prevalence of subclinical cardiovascular disease (e.g. asymptomatic peripheral vascular disease, carotid atherosclerosis, and electrocardiogram and echocardiogram abnormalities) (Nordstrom, Diez Roux, Jackson, & Gardin, 2004). Other scholars note that neighborhood characteristics, residential environments and housing have been linked to inequalities in health because they possess *both* the physical and social attributes that could affect the health of individuals (Diez Roux & Mair, 2010; Frohlich,

Ross, & Richmond, 2006; Sampson, 2012; Warren-Findlow, 2006). A neighborhood's physical attributes may include its access to food, community services and quality housing; proximity to recreational resources and natural spaces; the degree of aesthetic quality it possesses; and its share of toxic environmental exposures. A neighborhood's social attributes include the degree and nature of social conditions, networks and cohesion, social norms and local institutions (Diez Roux & Mair, 2010).

But while a neighborhood's socioeconomic disadvantage is associated with poor health, the protective effects of high-income neighborhoods do not seem to benefit low-income adults who may also live in those neighborhoods (Yen, Michael, & Perdue, 2009). Although the reasons for this phenomenon are not well understood, one possibility is that the stress that accompanies individual- and household-level material deprivation and social exclusion might have a negative impact on cardiovascular health that is outweighed by the positive effects of the wider neighborhood in which one resides (Angus et al., 2007). Stress has well-documented direct effects on physiological processes that, over time, contribute to the development of CHD (Geronimus, 1992, 1996; Geronimus, Hicken, & Bound, 2006; McEwen & Gianaros, 2010; McEwen & Seeman, 1999; McEwen & Stellar, 1993). Significantly, all of these potential physiologic pathways to CHD involve a complex interplay between the individual body and the lived environment—the physical and social context—in which a body is situated; this interplay is often expressed as experiences of stress.

Several qualitative researchers have studied the lived environment, gender, and the experiences of African Americans living with CHD and found conceptualizations of stress to be an inevitable and ubiquitous part of everyday life (Angus et al., 2007; Pollock, 1988; Walters & Denton, 1997). For instance, Banks and Malone (2005) examined the meaning of delayed

treatment-seeking in African American women with unstable angina and acute MI and discovered that many of these women constantly "worried" about others and had become "accustomed to enduring" social deprivation related to SES, geographic factors, environmental dangers and racial discrimination. They concluded that cardiovascular disease risk is associated with social marginalization.

Warren-Findlow (Warren-Findlow, 2006) used the concept of "weathering" as a framework for African American women's descriptions of lifelong and recent incidents of stress that they perceived as contributing to their heart disease. The theory of weathering posits that cumulative stress across the life course results in accelerated aging. Geronimus (Geronimus, 1992, 1996) contends that from the time African American females are in utero until their deaths, their exposure to institutional racism, pollutants, family and kinship network obligations, as well as material and economic deprivation causes early onset of chronic diseases like CHD and increases the risk of early morbidity and mortality.

Ornelas and colleagues (2009) found that social stratification through racial discrimination, male gender socialization, and neighborhood characteristics were all important influences of African American men's health. Interpersonal racism was not only a daily stressor, but also created fear and mistrust of the health care system. They stated that male gender socialization included pressures to constantly display power, independence and stoicism while avoiding any emotion that could be construed as weakness, leading some to adopt unhealthy or risky behaviors. Living in racially segregated neighborhoods served as a chronic stressor and increased their consumption of unhealthy products and their exposure to dangerous physical environments and situations.

Finally, Woods-Giscombè (2010) investigated the phenomenon known as the "strong black woman/superwoman" role as a key influence on black women's experiences of stress. This phenomenon encompasses characteristics such as obligations to manifest strength and help others, while maintaining a resistance to vulnerability to and dependence on others. While the "superwoman" role had some tangible benefits like preserving the family, community or self, it was also associated with liabilities such as relationship strain and stress-related behaviors.

What all of this literature suggests is that the incidence and experience of stress as a contributory risk factor for CHD is closely linked to physical and social patterns of advantage and disadvantage. Yet, while these authors identify a wide range of mechanisms that lead to ill health—e.g. material and economic disadvantage, cultural stressors, structural and interpersonal racism, etc.—what remains less clear are the relationships among these mechanisms, physical and social environments, and the body. I argue that the concept of habitus can help us better understand the impacts of neighborhood disadvantage on health by explicating the ways in which bodies and places are connected, and how those connections impact stress perception, experience, and production.

Habitus and Health: Bodies in Place and Space

Bourdieu's (1977, 1980) concept of habitus was conceived as a way to explain human action, accounting for its regularity, coherence and order without ignoring its regulated, structured and structuring nature. Bourdieu posited that our actions or practice of everyday life cannot be understood simply as an expression, from within, of individual motivations or decision making, or as the result of social norms and social institutions directing our behaviors from

without. Instead, Bourdieu argued that our actions were shaped by what he termed habitus, which he defined as:

> systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them. Objectively "regulated" and "regular" without being in any way the product of obedience to rules, they can be collectively orchestrated without being the product of the organizing action of a conductor (Bourdieu, 1980, p. 53; emphasis in the original).

These dispositions serve as a tool kit of resources that guides our general sense of how to act in our daily lives. Hence, our practices and actions are the products of the relationship between our habitus on the one hand, and the given situation in which we find ourselves, on the other. We are not born with any particular habitus; it is a product of history, our social experiences and education. Such experiences, internalized over our life course from our earliest childhood experiences, become embodied systems of social norms, patterns of behaviors and understandings that predispose, but not necessarily determine, our actions. It is in this sense that habitus is both structured—in that it integrates and reflects one's social conditions and experience—and structuring, in that it shapes future practices, perceptions and ways of acting (Bourdieu, 1991; Bourdieu & Wacquant, 1992).

As Casey (Casey, 2009) points out, Bourdieu's concept of habitus importantly recognizes the body and place as media through which individuals act in accordance with their social influences and position:

These actions depend on *habitus*…a second nature that brings culture to bear in its very movements…Rather than being a passive recipient or mere vehicle of cultural enactments, the body is itself enactive of cultural practices by virtue of its considerable powers of incorporation, habituation, and expression. And as a creature of habitus, the same body necessarily *inhabits* places that are themselves culturally informed…Such a body is at once encultured and emplaced and enculturating and emplacing…(Casey, 2009, p. 336-337; emphasis in the original).

Thus, habitus is a useful concept because through it we can see how places, bodies, experiences, and actions are linked. Through habitus, our social location becomes internalized into different bodily dispositions and styles that orient, but not necessarily determine, our actions in particular physical and social settings. As Bourdieu (Bourdieu, 1999, p. 128) expressed it, "If the habitat shapes the habitus, the habitus also shapes the habitat, through the more or less adequate social usages that it tends to make of it" (see also Hillier & Rooksby, 2005). Habitus—because it arises out of specific social experiences that take place in specific physical settings, which we navigate and make sense of through our bodies—is both embodied and emplaced.[5]

In my study, participants' narratives about their experiences of stress and illness underscore the significance of habitus and its embodied and emplaced dimensions. For example, Barbara is 56 years old and lives in the Bayview district of San Francisco. I asked Barbara who

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[5] With the concept of habitus, Bourdieu was pointing to the practical but socially constituted sense we have as we engage in actions that seem natural and common-sensical to us when we interact in institutional settings or "fields of action". In each of these situated encounters, actors are endowed with socially structured and differentially distributed resources and competencies, or capital. This differential distribution of capital structures individuals' positions on the field and in relation to others. The findings of this study are not focused on how habitus begets capital, but rather how it mediates between bodies and place.

or what were some of the most important influences in her life. Barbara categorically stated, "being brought up the Southern way",

> We was brought up in the church, so there's some things you did and some things you didn't do [because] you didn't want no eyes on you. So, my mom didn't have a lot of restrictions because we knew what we were supposed to do and we did them and when we violated them our whole little world shut down. And we didn't want that to happen.

Barbara's church provided a system or structure of social norms and expectations that Barbara and her siblings embodied, predisposing them to act in certain ways rather than others. Deciding what to do or what not to do was not necessarily deliberative for Barbara, but rather an "intuitive practical reaction to a situation based on experience" (Calhoun, 2000, p. 712). In other words, Barbara had an embodied sense of what to do that led her to structured action. This exemplar is also illustrative of how habitus gives Barbara a sense of her (and others') places, expectations and roles in the world of her lived environment, as well as a cognitive sense of place of her "own little world".

In another example, Monica, who lives with her mother in the Sunnydale public housing project and is one of the family member participants in my study, describes the "survival skills" necessary to "make it in the projects":

> You know it's just a certain posture that you have to have. You can't just be walking around here like you own the whole Sunnydale and stuff. You can't have a big head and be boisterous…[But] if somebody come at you, you got to be able to come at them regardless. If they see any sign of weakness, you gonna get it.

While Monica can certainly reflect upon the types of dispositions, styles and attributes it takes to "survive" living in the projects when I asked her about it specifically, these are not

things she consciously deliberates about every day. Monica's practical sense of how to act and behave in the projects is not just comprised of having a certain state of mind, but also possessing and projecting a particular bodily state—an embodied sense of how to walk, talk, speak, stand, and "posture", in ways appropriate to her circumstances and her lived environment. This particular habitus is an embodied resource that arises out of her longtime socialization and inculcation in the particulars of her neighborhood, and that in turn allow her to survive and navigate that setting safely. Here, Monica points to (as does Bourdieu (1991)) the practical yet socially constituted sense we have of the practices and actions that seem common-sensical and natural to us when approaching a particular social situation and location. In short, our body's experiences in a particular place give rise to habitus, and that habitus in turn gives us a bodily sense of what actions, behaviors, styles, and responses are natural and sentient (Bourdieu, 1991) in that setting.

Connecting Health and Place: Collective Habitus

Both Barbara's and Monica's narratives also point to another aspect of habitus that has immediate relevance for my understandings of how CHD is shaped by race, class, and environment: the notion that habitus is *collectively* constructed, reproduced, and expressed. As habitus is a product of our social conditions, the set of acquired dispositions, styles, attributes and characteristics of which it is comprised may be similar to those who come from the same or similar social conditions. Therefore, people residing in the same places tend to share similar values, practices, and ways of knowing based on similar experiences living within that certain place. Actions, behaviors, and perceptions become second nature, natural and unquestioned, thereby reproducing these practices and becoming characteristic of the community (Richardson

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& Skott-Myhre, 2012). The result is a collective habitus (Hillier & Rooksby, 2005) where attitudes, behaviors and practices of those who live in a particular place seem to become naturalized and inherent characteristics of the places in which they occur, creating a social space where we feel at home and a sense of belonging, as well as where we "fit" within the social order. To illustrate this idea of collective habitus, and to demonstrate its utility in elaborating the connections between health and place, I re-introduce Alma, a participant whom we met in the previous chapter.

The Collective Habitus of the "Red Brick Homes"

Alma's narrative demonstrates a compelling picture of how the lived environment produces not only states of bodily equilibrium that for her are health-promoting, but also temporally unpredictable sources of stress that exacerbate her symptoms of CHD. As I explore her lived environment and the socio-spatial pressures she cites as the contributing factors leading to stress production and experience, I demonstrate how and under what circumstances Alma's sense of place is generated or disrupted and undermined by constraints, impingements, and intrusions to her lived environment through the material, physical and social contexts of everyday life. In what follows, Alma describes the elements of her lived environment that shape her sense of place, as well as the battles she must fight upon multiple fronts that are required to maintain it.

Alma is 63 years old and lives in Visitacion Valley, located in the extreme southeast quadrant of San Francisco. The neighborhood is bounded by Daly City to the south and Highway 101 to the east. Bayshore Boulevard is the main north-south artery that bisects Visitacion Valley to the west and Little Hollywood to the east. Sunnydale Avenue runs east to

west and is the main residential thoroughfare. Alma has lived in Visitacion Valley for most of her life and because of her longevity in the area, she possess a fund of historical and spatial knowledge about the neighborhood from which I draw upon next.

According to Alma, Visitacion Valley was developed during the 1940s as an expansion neighborhood to Bayview-Hunter's Point, during which the pre and post World War II years was home to one of the largest naval shipyards in California. To support the war effort, the Navy constructed additional housing barracks at the slope of McLaren Park to house predominantly black laborers who worked at the Hunter's Point Naval Shipyard. After the shipyard was decommissioned in the 1970s, these housing barracks became the Sunnydale-Velasco Housing project, the largest—and most dangerous—site of low-income and subsidized housing operated by the San Francisco Housing Authority.

Figure 4.1 – Sunnydale Housing Project (www.citydata.com)

Today, Visitacion Valley has a population of 38,904 of which 4,033 are African American, 34% of whom are living below the Federal Poverty Level (U.S. Census Bureau, 2011). Of all African Americans who reside in Visitacion Valley, 48% (1,933) live in the Sunnydale-Velasco Housing project (San Francisco Housing Authority, 2010). There is one elementary school to serve the entire area, but there are no churches, banks, post offices or

grocery stores within walking distance of Alma's home. A Boys and Girls Club advertises job

fairs and there is a health clinic operating in the center of the area. There are two main municipal

transit routes, one servicing Sunnydale Avenue and the other Bayshore Boulevard. There are

several mom-and-pop corner stores where the inventory is limited to "grab and go" food items,

sodas, alcohol and cigarettes. Cardiovascular disease is the leading cause of death in this

population living in Visitacion Valley (Harder & Company Community Research, 2012).

Alma lives in an owner-occupied townhome first purchased by her mother in the late

1960s. Her home is spotless, warm and inviting and she strives to make her guests feel welcome.

Her townhouse is part of a complex built in partnership with the City and County of San

Francisco in the hopes of enticing first-time homebuyers and young professionals to the area.

Alma's mother was among the first to buy into this complex named Geneva Terrace. The front

section of the development (where Alma lives) is situated in a horseshoe configuration and the

rest of the complex spans some 8-city streets comprised of identical square-shaped units with red

brick facades and arched windows. Most of the locals in the neighborhood simply refer to the

complex as "The Red Brick Homes". All of the units are equipped with steel safety gates on the

front door and security bars cover the street-level windows.

Figure 4.2 – Red
Brick Homes
(Photo
attributed to
Eichler Homes)

When Alma describes what she considers the spatial boundaries of her community to be, she limits its confines to that of the Red Brick Homes despite living in a geographic area defined by name, zip code and census tract. She considers her neighbors to be only those who live in the Red Brick Homes. Alma describes them collectively as "decent people" just trying to "get over" by working hard, "saving a little something", taking care of their children, their homes, and when necessary, each other.

In the center of the Red Brick Homes, is a beautiful park where Alma can sit on the bench, visit with her neighbors and watch the children play:

Now Monday to Friday there's a day care center on Leland [Avenue] at the church, there's another back here…across Sunnydale…and another one across the other side in Daly City. They bring them kids in different groups, different times. Every single day they bring them kids in that park. And they have such a ball. And it is such a joy to hear them playing! So, this Mexican guy, good-looking gentleman with his little daughter came riding through one day and he said, "Wow! When did they put that there? My god, it's beautiful!" He comes everyday with his daughter. People come from all over and bring their kids…So, when I get up on Saturday and Sunday mornings, and during the week I hear the kids out there, OK! It's gonna be a good day. A good day! So when you hear them out here now, see the parents coming from all over in their cars bringing more kids, it is really nice. It's content and quiet. So that has been keeping me mellow this year since I came home from the hospital.

Figure 4.3 – Park at the
Red Brick Homes
(Photo attributed to
Eichler Homes)

But as we learned in the previous chapter, this park was not always so peaceful. Alma described the state of the park just a few years earlier as a "killing zone" where "gangsters and drug dealers were shooting and fighting. You couldn't even walk across the street. It was horrifying!" Through neighborhood organization and participation, the residents of the Red Brick Homes were successful in having the City renovate the park. Alma feels comfortable here, "mellow" as she describes it, and welcomes particular types of others who come to enjoy this space with her.

For Alma, the park has become a symbolic representation of what community is all about. I argue that its symbolic importance is in part due to how it encapsulates and enforces a new collective habitus for the Red Brick Homes. By coming together around a common goal and interest, the residents of the Red Brick Homes have transformed the park from a physical place where no rules applied, into a socially structured space, where, through the interactions of those who use and control it, institutionalized rules now govern what behaviors and activities are permissible and appropriate. The residents continue to maintain the park through their constant

surveillance and monitoring of the activities in the park as well as collectively defining the behaviors and practices they deem appropriate. Those who are not welcome, for example, are "stupid grown people who have these mutts and bring these dogs and let them crap all in the grass. Come on! This is not a dog park. It's a kid's park. It's a people park". Therefore, to be welcomed into this space requires one to comport to the implicit, explicit and common sense "rules" of this space, by demonstrating the collective habitus that prevails here.

Critically, it is through this collective habitus that Alma's sense of place is created and sustained. Being "mellow", "calm" and "content" are the bodily manifestations of her sense of place produced through her lived environment as a result of the successful maintenance and enforcement, and subsequent experience, of this collective habitus. Although the park is located within a larger social environment that is continually described, experienced and understood to be unsafe, it symbolizes for Alma her sense of connection and belonging to the Red Brick Homes, and her and her neighbors' considerable investment in making their environment an oasis of safety, a "good place" where "decent" people come to enjoy time with their children and each other. Alma's home, her narrowly defined community within the Red Brick Homes, her neighbors and the park—all that comprise her lived environment—work together to produce for her a bodily equilibrium, a sense of place.

Figure 4.4 – Aerial View of the Park at the Red Brick Homes (Googlemaps.com)

Habitus Mismatch: The "Ghetto Critters"

In this section, I continue with Alma's narrative to demonstrate how even within the same geographically defined physical area, different types of lived environments exist producing different types of collective habitus. When social and spatial oppositions occur between individuals and groups, the different kinds of collective habitus they embody in turn clash. I argue that this habitus mismatch—when one collective habitus intrudes upon another—results in the creation of a palpable tension that is manifested bodily through stress production, perception and experience.

The Red Brick Homes are nestled within three blocks of the Sunnydale projects to the east, and straddling opposite sides of Sunnydale Avenue to the north are two low-income rental developments, Heritage Homes and Britton Courts. Under the management of a local non-profit working in partnership with the City and County of San Francisco, the latter two developments are relatively new additions to the neighborhood; construction was completed around 2002. They were built as a replacement for the two-tower, 18-story building that previously occupied the space. Built in 1968 and officially known as Geneva Towers, the building was referred to by

locals as "the high rise from hell". As notorious as Cabrini Green or the Robert Taylor Homes in

Chicago for violence, drugs, gang activity and substandard living conditions, Geneva Towers

was deemed a public housing disaster and imploded in 1998. The resulting physical layout of

this section of Visitacion Valley puts Alma and those who live in the Red Brick Homes in very

close proximity to three of the most high poverty and high crime developments in the City. Only

Garrison Avenue separates the Red Brick Homes from Heritage Homes; the back of the Red

Brick Homes complex abuts the entrance to the Sunnydale projects; and Sunnydale Avenue is

the dividing line between Heritage Homes and Britton Courts.
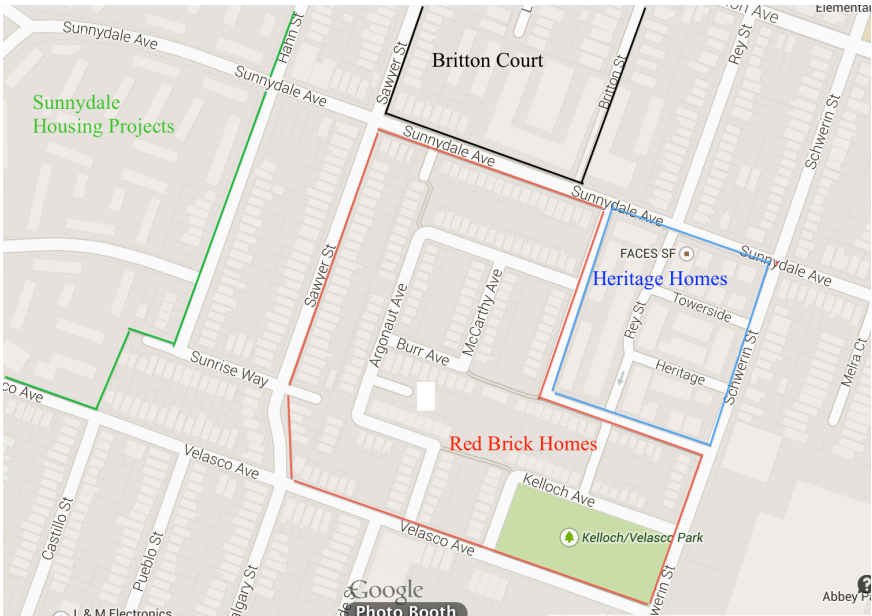
Figure 4.5 – Lived Environment in Perspective (Googlemaps.com)

While Alma classifies herself and her neighbors by saying "we're all poor", she

characterizes those who live in the low-income and public housing projects and those who

receive Section 8 housing subsidies as separate and distinct from herself and her neighbors,

blaming their actions and behaviors for having a devastating effect on the neighborhood and her

health. While Alma applauded the decision of the U.S. Department of Housing and Urban

Development to destroy the Geneva Towers, she laments that the City gave the previous

residents first choice to the new units once the new developments were completed. I asked her

what it was like to live in a neighborhood frequently associated with crime, violence and gang activity:

> You know, it's not the Red Brick Homes. It's the people across the street where the old Geneva Towers used to be and the Sunnydale project people. If we could ever get rid of them, this would be a good neighborhood…If we could get all the renters out that are on Section 8, this here would be good…[The City Supervisors] say, "We have to have some low income housing." Why? You keep giving these people [those on Section 8] places to live and they just screw up…You keep moving them out and you let them back in…They don't respect people's houses. As it is, they bring the bad element with them— you know these women with these JoJo-Tyrone, baby-daddies [referring to the unwed fathers of multiple children from different women]—who wants to live around that?

Another participant, Barry, who is 49 years old and grew up in and lived most of his life near the Sunnydale housing projects, also described the temporally unpredictable violence as a daily worry:

> Gunshots and getting robbed just walking to the bus stop or getting jumped on, you know? A lot of people there got beat with bats. Beat to death with bats. [Growing up] we had a lot of stuff to worry about. Just being safe getting in and out of there [the neighborhood], and going to school. But it's still the same people in the new places so nothing really changed. They just took it [Geneva Towers] down and put them in flat ground apartments. That's all. So now they fight with the people that live up in the projects. And even though they're both on the same street, it's like a war there.

Here, both Alma and Barry paint those who live in subsidized housing as strangers, "others," who bring chaos to the neighborhood and disrupt the social order as well as their sense

of place. Alma views those who live in the projects and Section 8 recipients as fundamentally

different from herself and her poor but hardworking neighbors. She related an experience of the

chaos that ensued when one of her Red Brick Home neighbors decided to rent his unit to "one of

them", a Section 8 recipient:

> People don't screen when they rent and that pisses me off! I be like, "Let me do it. Let
>
> me do it. Let me screen the people you sending here 'cause they go to live next door to
>
> me!" [My neighbor] didn't believe me. This girl moved here, to the third house. I think
>
> she was 39 and had 7 kids. Never raised any of them. They were all in foster care. And
>
> this is what I call real ghetto broads: They cut off her water and she was going over to
>
> the house back there getting jugs of water so they can flush the toilets over here. They
>
> ain't got no lights, so they was running a big orange extension cord across the parking lot.
>
> She's got electric but no water; they had water but no electric. Them is some real ghetto
>
> critters! And when they take the [electrical] boxes out of the concrete, you know you got
>
> a bad tenant. Why do some people not think? Don't they know that this is stressful? Get
>
> the bad elements out of here and this would be the greatest place on earth to live! Let
>
> folks live! Let people enjoy their homes!

Alma perceives these "bad elements" as being devoid of any sense of social or personal

responsibility to themselves or to their children. She blames them for the deterioration, fear, and

instability of the neighborhood as a result of the drug and gang activity. She cites the intrusion

of some of "them" into her lived environment, the Red Brick Homes, as a cause of her "stressful

living". She attributes their behaviors, actions and ways of being to "parenting…the way they

was raised…their mothers' on drugs and they are just not right!" In other words, she is

describing a collective habitus much different from that of her lived environment. Despite being

in close physical proximity, the social distance between Alma and "the bad elements" across the street is vast. By stigmatizing what she considers to be lesser or negative types of places and those who live there, Alma hierarchizes her position above theirs and socially distances herself from them by caustically referring to them as "ghetto critters".[6]

The intrusion of "them people across the street" into the Red Brick Homes disrupts Alma's lived environment of all that is familiar or makes her feel at home, safe, and "in place". Their very presence creates a social opposition or, what I call a habitus mismatch that upsets the social order of the Red Brick Homes creating tensions between her neighbors as well as affecting her in a bodily way through stress production. In other words, as Alma's physical and social circumstances begin to change and are no longer congruent with her actual and habitual experiences and expectations of and for her lived environment, fear, insecurity and stress become the bodily manifestations of this mismatch and the disruption of her sense of place.

"A Traumatized Little City"

Another mechanism through which Alma's sense of place becomes disrupted is through the behavior of her grandson, Lee, who lives part-time with his mother in Ohio and part-time with Alma and her son Rodney in the Red Brick Homes. Alma described Lee growing up as "sheltered", "sensitive" and "quiet". Lee had always been a good student and recently graduated high school. But over time, he has begun "crossing the street" and hanging out in the projects with his "boyz…his niggas…riding around smoking weed and drinking." Alma has a very

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[6] Interestingly, both Barry and Alma have adopted a "culture of poverty" explanation for the misadventures, misbehaviors and actions of those who "live across the street" eerily reminiscent of the 1965 Moynihan Report that argued poverty is perpetuated to a large degree by defective cultural practices and values and reliance on government subsidies. (See for example: (Acs, Braswell, Sorenson, & Turner, 2012)) Further research should explore how these explanations get reconstituted within these communities as well as being imposed on them from without.

difficult time trying to understand what draws Lee in a totally different direction from the one she and Rodney are trying to steer him:

> I'm like, "What's wrong with you? You got everything in the world. You got two worlds! You go home [to Ohio] in the summer to see your Momma. You come back here and live with us. Your daddy takes you on trips all over…what's the problem"? He just doesn't get it. Still doesn't get it.

While Lee was not available for an interview, one could consider the possibility that his sense of place is neither limited nor determined by the narrow confines of the Red Brick Homes that define Alma's. By developing relationships with "those across the street" and spending time in their environment, Lee must fulfill the conditions of that space in order for him to feel "in place" there. By "hanging with his boyz", Lee may be procuring some form of symbolic capital through what Bourdieu (1999) termed the "club effect", a process that excludes according to economic, social and cultural capital. Originally, this concept applied to select spaces such as chic neighborhoods, exclusive country clubs, and high-end boutiques that acquire symbolic capital based upon:

> the gathering together of people and things which are different from the vast majority and have in common the fact that they are not common, that is, the fact that they exclude everyone who does not present all the desired attributes or who presents (at least) one undesirable attribute (Bourdieu, 1999, p. 129).

In this case while Lee, his "boyz" and those who "live across the street" may not have access to conventional forms of capital, through their different lived environment, they seem to have created a different kind of collective habitus that reflects a very different social space where very different attitudes, behaviors, and practices "fit" and are appropriate.

But this has consequences for others who are not part of that club but are nonetheless caught in the conflict between two opposing types of habitus. As Bourdieu notes:

Bringing together on a single site a population homogeneous in its dispossession strengthens that dispossession, notably with respect to culture and cultural practices: the pressures exerted at the level of class or school or in public life by the most disadvantaged or those furthest from a "normal" existence pull everything down in a general leveling. They leave no escape other than flight toward other sites which lack of resources usually renders impossible (Bourdieu, 1999, p. 129).

In Alma's view, by simultaneously living with her while also "crossing the street" and hanging out and "riding around" with his "boyz," Lee brings the collective habitus of the projects into her own home. In her case, even the escape of flight is not available to her; instead she must confine herself to the ever-limited area of the Red Brick Homes, define her sense of place through it and battle to maintain it.

Alma sees a strong relationship between her bouts of poor health related to her sickle cell disease and her CHD and the tension caused by Lee's behavior and his adopting a lifestyle in total contradiction to the life path that she and Rodney are trying to provide. She refers to Visitacion Valley as a "traumatized little city" and as the violence of projects spills over into the Red Brick Homes, Alma's lived environment and her sense of place are disrupted. This disruption is manifested bodily through exacerbations of her sickle cell disease and her CHD:

[There was] a little boy who got killed coming to the [elementary school] graduation. [They] shot him out in front of the school. They shot him right out of his shoes. No! I can't have this around here 'cause they shooting anybody. They don't care. They shot a little retarded boy up the street who never, ever bothered anybody. How you shoot a

retarded child by mistake? You shoot him, you shoot anybody. And then they turned

him over and they were fixing to shoot him some more and they said, "Ah, brother, you

ain't even the right person"…That poor child…But it was like a domino effect. They had

been shooting and killing from Sunnydale down to Heritage. Then Heritage was against

Sunnydale and Britton Courts…I think 8 kids had got shot within a period of a year. I

couldn't see my grandson being here like that. I'd be petrified if he gonna get hurt, if he

gonna make it home. [She told Lee], "You stressing me. You keeping me sick. You see

these kids getting killed around here? I'm not fixing to have someone shooting up my

house when I'm already sickling [having a sickle cell crisis]. You are trying to kill me

for your stupidness…You got to stay away from here. I got to get better"…So, that was

keeping me a lot of stress. Maybe that did cause some of my heart trouble—stressing too

much and worrying. I was always worried about when he leave if he was gonna get

home safe.

Lee's behaviors, the socio-spatial oppositions and tensions between the Red Brick Homes

and Sunnydale, Heritage Homes, and Britton Courts, as well as the temporally unpredictable

episodes of violence, encapsulate the clash in the different kinds of collective habitus that

converge in Alma's lived environment. The resultant habitus mismatch disrupts her sense of

security and stability and her sense of belonging in her own community, which exacerbates her

sickle cell crises and her cardiac symptoms through stress production. For Alma, Lee's

behaviors are symbolic of these disrupting events and had her fearing they would soon breach

the boundaries of her own lived environment. As a result, Alma's health deteriorated to such a

degree that she required hospitalization to get her sickle cell disease and CHD back under

control. After Alma returned home from the hospital, one final conflict with Lee necessitated

her redrawing of both the physical and social boundaries of her relationship with her grandson—she threw him out:

> I got so mad one night. Oh god, my chest got to pounding. I got sharp pains. I was like, oh lord, putting nitro[glycerin] under my tongue. I mean it was scaring me. I told him, "I tell you what. You pack your suitcases. You got money saved…There's a hotel right there on Geneva. There's three more down the street. You take one of them and see who'll give you a room and you get the hell up out of my house. NOW! If you don't, I'm a start throwing shit outside. I want you out of my house. You are NOT going to kill me…you are my grandchild. I love you to death, but I'll kill YOU first." I'm on a new road, baby!

While Alma doesn't understand why Lee is changing from the "quiet", "sensitive" boy she helped to raise into the "gangster running with his boyz", she certainly recognizes that his "crossing the street" into the projects is habituating, socializing and naturalizing Lee to the attitudes and behaviors of those "bad elements" living in the projects. Lee's actions and behaviors threatened and disrupted all that was familiar and taken for granted by Alma—her sense of place in the Red Brick Homes. Lee was a crucially significant conduit through which her sense of place was breached and disrupted. Stress was the manifestation of this disruption that negatively and severely impacted her state of health. To regain her sense of place and her state of health required Alma to redraw both the physical and social boundaries between herself, her lived environment and her grandson.

Getting Some Peace

For Alma to maintain her sense of place requires of her an active engagement and vigilance to safeguard the collective habitus of the Red Brick Homes to the degree that she can. She finds that serving on the board of her homeowner's association and being politically active in the community mitigate some of her stress. She frequents neighborhood meetings with the police to discuss safety issues and advocate for additional patrols. She attends hearings at the Planning Commission and the San Francisco Housing Authority and offers public comments about future development plans:

> Me and the president [of the homeowner's association] go to the meetings…They gonna put 1500 houses up there [referring to the proposed future demolition and rebuilding of the Sunnydale projects]. These [referring to the red brick homes] are home owned, first time home-buyers and low income. We trying to see what kind of elements they trying to bring back in our neighborhoods and stuff. You bring these [Section 8 recipients] back but who want to have a first time home-buyer, a regular income persons and a project person next door to each other? When I'm doing it and I'm really involved and learning something, it gives me peace because I know we are trying to bring a better element [to the neighborhood].

Alma's community engagement on behalf of the Red Brick Homes is reflective of her struggles to appropriate space, or at the very least, the use of it. The goal of her struggle is to see that the proper "elements"—those who share her same or similar habitus—are the beneficiaries of these new housing units through which her sense of place, and hence her health, will be maintained. As Bourdieu himself noted, the mutual shaping of habitus with habitat:

throws doubt on the belief that bringing together in the same physical space agents who

are far apart in social space might, in itself, bring them closer socially: in fact, socially

distanced people find nothing more intolerable than physical proximity (Bourdieu, 1999,

p. 128).

Alma's narrative is certainly a case in point.

Conclusion

The purpose of this chapter was to offer the concepts of habitus and collective habitus as

analytic enhancements to more deeply explore the ways in which bodies and place are linked

together and the effects that linkage has on health. As a set of dispositions, styles and

characteristics that is the product of social conditions, habitus may be similar across those who

reside in similar or same social conditions and is the foundation through which we develop our

sense of place. In order to feel in place within our community, our collective sense of how

individuals ought to act, behave and comport ourselves must match the implicit and explicit rules

that prevail in the social spaces in which we live.

Alma's narrative provides a portrait of how the lived environment shapes her sense of

place and how health is produced or undermined through every day contexts, experiences and

burdens. The attitudes, behaviors and practices of those who live in the Red Brick Homes are

inherent and naturalized characteristics of a collective type of habitus that provides for Alma a

bodily sense of place manifested by feelings of calm, contentment and peace.

Alma's narrative also highlights the daily and collective struggles over space and the

kinds of social orders that characterize those spaces. The ability to establish and maintain a

socially structured space, as we saw in the example of the park at the Red Brick Homes, and in

the contrasting example of the projects "across the street," makes it possible to exclude those who do not belong, while at the same time bringing those who are desirable into the space allowing it to foster and thrive. In so doing, the collective habitus of the space is reproduced and the sense of place of those who live there is maintained.

However, we have also seen that even within distinct geographically defined neighborhoods, a number of different lived environments exist, producing different types of collective habitus where different attributes, values, expectations and ways of being predominate. Alma's narrative highlights the social and spatial oppositions between them—a habitus mismatch—that when one intrudes upon the other, social tensions are created manifesting itself bodily through stress production, perception and experience.

CHAPTER 5

Conclusion, Contributions and Implications for Health

Despite a rather precipitous drop in all cause mortality rates in the United States over the last 60 years, a significant racial gap still exists particularly in the realm of CHD where African Americans bear a disproportionate burden of death. As a result, vast literatures of both clinical and epidemiological approaches have emerged in order to identify the causal mechanisms of this disease and the etiology of its unequal distribution among African Americans. However, by better understanding the multiple social mechanisms and interactions through which such inequalities are produced, researchers and policy makers may glean insights into how social forces can mold a group's collective health status and lead efforts to the development of logical macro social interventions to improve population health. To that end, this dissertation has explored some of the processes through which race remains such a powerful determinant of health status in the United States and why it has been so disproportionately consequential for African Americans in particular. Below, I review the findings of this dissertation and discuss its contributions to the extant literature as well as implications for nursing theory, research and health policy.

Summary of Dissertation

This dissertation has provided a social and cultural analysis of the illness experiences of African American men and women living with CHD through which its multidimensional nature was explored. The illness experiences of my participants included the common-sense ways in which they categorized and explained the emotional and physiological distress caused by their disease processes, the disruptions to their previous lives, future plans, family relationships, and

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sense of self, as well as the reflexive and biographical work and adoption of different behaviors that had to be engaged in order for them to cope living with CHD.

In this study, I also demonstrated how individual accounts of disease functioned as reflexive links to micro, meso, and macro social and cultural processes through which CHD was constructed by African American participants as a normative experience—a "black disease"— wherein certain bodies have become historically, culturally and racially marked. This conceptualization is sustained and passed on by African Americans themselves. Therefore, for African Americans, the development of CHD and the behaviors that undermine or facilitate health cannot be separated from their social, cultural and racial moorings.

By taking account of within neighborhood variations of social capital, this dissertation provides a more nuanced and in-depth understanding of the local and contingent mechanisms though which social capital is generated in the first place. While all participants in this study could and did access some form of social capital that helped them live with CHD on a day-to-day basis, different forms of social capital prevailed in distinct lived environments. By exploring the various types of resources inhering within various forms of social capital, its negative effects were exposed that at times and under certain circumstances outweighed its potential benefits.

Finally, through the concepts of habitus and collective habitus, I demonstrated how the lived environment can shape our sense of place and how our health is produced or undermined through everyday contexts, experiences and burdens. In particular, I found that within the same geographically defined neighborhoods, multiple kinds of lived environments existed, producing different types of collective habitus that encompassed different values, expectations and ways of being. I demonstrated that bodily experiences of stress may actually be the result of a habitus

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mismatch arising out of social and spatial oppositions when one type of collective habitus intrudes upon another.

Contributions and Implications for Nursing and Health Policy Theory and Research

Methodological Contributions of Critical Interactionism

Grounding this study with the theoretical underpinnings of critical interactionism facilitated an in-depth exploration of a broad range of social factors, power relations and social structures that helped or hindered the health and illness experiences of the participants in this study. As several nursing scholars have pointed out, the use of symbolic interactionism within nursing research has been primarily focused at the individual or micro level in order to describe and understand the meanings and definitions among and between individuals, focusing on downstream experiences and outcomes of disease and illness (Kushner & Morrow, 2003; Martins & Burbank, 2011; Sundin & Fahy, 2008). Critical interactionism goes a step further by obligating researchers to expose the links between those local experiences, understandings, actions and behaviors to the extra-local pressures that heavily influence them. Specifically, through critical interactionism, I explored two key issues through the narrated experiences of my participants. First, as we saw in Chapter 2, particularly through the narratives of Roy, Michael, and Marcus, the actions of social institutions, entities and state treat people differently, shape policy decisions and distribute resources along racial lines. Second, best exemplified in the extended narrative of Alma in Chapter 4, we saw how at the individual or micro level, macro social and racial dynamics operate at the everyday (often pre-reflexive) level in ways that significantly impact health. In each of these exemplars, the various roles, actions, behaviors that were adopted at various stages during my participants' illness experiences were not merely

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described, they were explored through the historical, cultural and macro structural pressures that influenced those experiences.

While the history of symbolic interactionism is filled with work of a criticalist nature, (see for example, Blumer, 1939, 1958, 1965; Omi & Winant, 1994, 2008; J. K. Shim, 2005, 2010a), critical interactionism directly attends to issues and processes of power across a broad range of social arenas. This approach then offers additional theoretical leverage and opportunities for nursing and sociological research by requiring an examination of participant experiences and circumstances within their wider socio-structural influences and processes that impact the way health and illness are experienced.

Symbolic Nature of Symptoms

There is a growing nursing literature framed around the Symptom Management Theory (Humphreys et al., 2008). The three essential concepts of Symptom Management Theory (SMT) are symptom experience, symptom management strategies and symptom status outcomes. Within the symptom experience concept are three elements of perception, evaluation and response to change in an individual's usual feeling. Symptom management strategies are the efforts individuals use to minimize, delay or avert the symptom experience. Symptom status outcomes are the clear and measurable outcomes individuals use to assess the impact following the implementation of a strategy to relieve the symptom. SMT is conceptualized as a simultaneous interaction between all three concepts with each influencing the others. All three of these concepts are embedded within larger domains of person, environment and health/illness. An iterative process of perceiving symptom experience, experimenting with strategies, and assessing outcomes continues until the symptoms are relieved or resolved altogether.

Missing from the construct of SMT, however are the symbolic meanings that individuals attach to symptoms and how those meanings may influence strategies selected and the subsequent outcomes of those strategies. In this study I found through my participants' narratives that symptoms were more than clinical manifestations of disease or pathology; they had a symbolic nature and functioned as reminders of new limits to bodily abilities and of how participants' lives had changed. Symptoms were also symbolic guideposts pointing to the personal and social burdens associated with the illness experience. Through symptoms, as we saw in the narrative of Michael in Chapter 2, individuals make sense of what illness means and the impact it can and does have on one's life. Therefore, investigating the meanings that patients attach to their symptoms gives an added dimension into the symptom experience that can better elucidate the kinds of strategies individuals undertake and their assessments of symptom outcomes. These dynamics enhance our understanding of the influences of the social dimensions of particular interest to nursing science and in which these three concepts are embedded— person, environment, and health/illness.

Health Behaviors and Ideologies of Normalcy

Exploring why an individual believes s/he has developed a particular illness or disease exposes the disconnects between biomedical understandings of disease etiology and lay views of causation (Clarke et al., 2003; Liburd et al., 2004; J. K. Shim, 2005, 2010b). While most participants in this study could identify several cardiovascular risk factors, few took any preventative steps to decrease their risk, and behavior changes were made—and only to a limited degree—when the participants themselves were diagnosed with CHD. That said, participants like Jackson changed behaviors not because of their long-term health-harming effects, but rather

in terms of how those behaviors intersected with his notions of what "being normal" and living a normal life was all about. This finding adds to the literature by underscoring that lifestyle changes come with their own set of "worries", "stress" and aggravations that make living with CHD much more difficult.

Such a finding will hopefully help shift the medical community's view that CHD is a lifestyle disease that tends narrow ideas about prevention and treatment to a laundry list of behaviors to avoid or correct. Instead, my findings suggest that conceiving of CHD as culturally, racially and socially multidimensional and mediated could possibly account for individual "ideologies of normalcy" (Becker, 1994, p. 195). Reframing cardiovascular disease education in primary care and community outreach programs from an emphasis on avoiding high-risk behaviors and making healthy choices, to an acknowledgment of and attention to the burdens, stress and fears that lifestyle change entails, may have a more resonating effect for African Americans living with CHD or those most at risk.

Place

As noted earlier in this dissertation, "place" has upstream consequences for the pathways that contribute to health inequalities because it sets the context for *both* the physical and social characteristics in which people live (Diez Roux & Mair, 2010; Frohlich et al., 2006). One way that health researchers link health to place is through the concept of social capital. My findings suggest that the concept of social capital has some important implications for nursing theory and health policy research. From a theoretical perspective this dissertation adds to the literature by supporting Bourdieu's (1986) notion that social capital arises principally out of the scope and influence of one's personal social network, with benefits accruing to the individual as well as family. This contrasts with Putnam's conceptualization of a more communitarian approach to

social capital as a resource that facilitates cooperation for the benefit of the entire community (Whitley, 2010). While social capital in any of its various forms can provide for an individual's health and wellbeing, my findings illuminate the power dynamics that exist within the different forms of social capital that can both facilitate and constrain access to the types of health related resources inhered within them. For example as we saw in Chapter 3, individual choice with regard to dietary habits, smoking, and other health related behaviors were constrained by the power of those actually provided access to various resources to define the scope and nature of the support provided. In another example we saw how the conversion of cultural capital was imperative to gaining entrée into networks through which health related resources could be tapped. This gives nursing and other health professionals a new understanding of both the help and hindrances associated within various forms of social capital as well as the "work" required to maintain necessary and valuable social networks.

Exemplifying and building upon the work of Bourdieu (1977) and Hillier and Rooksby (2005), I also explored the notion of "place" and its multidimensional nature by using the concept of habitus. Habitus is not monolithic or immutable, nor are individuals confined to any single habitus. Rather, as we saw in Alma's extended narrative and her experiences with her grandson, Lee, individuals can move from one habitus to another and develop new adaptive behaviors consistent with the requirements of a particular lived environment. Thus, the concept of habitus may be a useful heuristic to explore other dimensions of place such as the nature of intra-neighborhood violence as well as serve to guide housing policy and the distribution of more economic resources to underserved communities. As noted in Chapter 4, another viable and important avenue for research should include an in-depth exploration of the interactional dynamics across and within different lived environments located within the same or similar

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geographically defined areas that may promote or hinder health-related behaviors and experiences.

As we learned from Alma's narrative, types of housing and housing policy were critical to her state of health and her illness experience, requiring her to maintain a constant vigilance over the distribution of "bad elements" to her neighborhood. The City's effort of replacing the high-rise Geneva Towers with blocks of predominantly low-income rental housing where the previous tenants had first right of return, ignored the needs and desires of the residents of Visitacion Valley and compounded the problem by not investing in the infrastructure to support the economic growth of area. Currently, there are plans to remedy that situation through the Choice Neighborhoods Initiative sponsored by the Obama administration. In 2012, San Francisco was chosen as one city where a limited number of public housing complexes like Sunnydale will be torn down. The program aims to redevelop the community through physical infrastructure and provision of resources for key institutions such as schools, a library, neighborhood-serving retail stores, community facilities, parks, health centers, open space areas and job opportunities for current, former and new residents. By creating a variety of housing types for a mix of incomes, these new units will be integrated into the surrounding community through interconnecting streets. Such changes may result in a neighborhood that improves the quality of residents' lives while providing new programs that enable youth and families to thrive and succeed. This approach represents a significant shift away from a long-standing pattern of housing policy where poor (and mostly African American) individuals are concentrated within large public housing projects, and towards more integrated and heterogeneous neighborhoods where residents have access to the resources necessary for them to thrive, rather than the alternative imperative to merely survive. (Office of the Mayor, 2012; Sharkey, 2013).

* * * * * * *

The landscape of everyday life, the practices of people and the ways in which they define and interpret their situations and circumstances, what they know and how they know it, as well as their interactions with others are all shaped, though not necessarily determined by the social contexts in which they find themselves. In this dissertation, I have explored the illness experiences of African Americans living with CHD and by peeling back its layers, exposed its multidimensional nature. It is my sincere hope that this work goes some of the way toward cleaving a better understanding of the social processes that create, sustain, and reproduce racial inequalities in health.

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Appendix A: Interview Guide

Questions	Probes
1. Tell me about yourself: Where did you grow up? What was that like?	Childhood? Schools? Expectations? Who are/were the friends and family members most important to you?
2. Tell me the story of when and how you were diagnosed with heart disease.	What experiences of heart disease or other illnesses did you have with any members of your family?
3. What were your thoughts and feelings when you learned you had heart disease?	Were you surprised to learn you had CHD? Why or why not?
4. Think back to the time before you were diagnosed with CHD. What were your views about heart disease?	Was your diagnosis a surprise to you? Did you think you were at risk for CHD? Why/why not.
5. In what ways have your views changed?	
6. Can you describe some of your experiences in seeking medical help?	Did you ever feel that you were being treated better or worse than others? Can you tell me about that time? Why do you think that was? Was there any particular time when you were getting care that you felt being black American influenced how you were treated? In what ways? (Follow-up question for women/men: In what ways do you feel being a woman/man influenced how you were being treated?) Was there any time that you can remember when you felt that your income status influenced the way you were treated or the treatments you were offered? How so?
7. Describe for me what a typical day is like for you. How has having CHD altered what a typical day is	Frequency of medical follow-up; medication regimen, etc. Describe the changes you have made in your life as a

like?	result of CHD.
8. In what ways has having CHD affected your family?	How has it affected other relationships you have, for instance, at work or personal friendships
9. What helps you in your day to day living with CHD?	Neighbors? Family? Health care providers? Church? Social services?
10. What doesn't help you?	Lack of services? Difficulty accessing services? Costs?
11. Tell me about where you live now?	What is it like to live here? Describe the boundaries of what you consider your neighborhood to be? Probe for neighborhood conveniences: Schools, parks, grocery stores/pharmacies, community centers/churches, banks, police/fire, hospitals, transit, etc.
12. What particular advice would you give to a black American who has just been told they have CHD? 13. Is there anything else you would like to share with me about your experiences? 14. Is there anything you would like to ask me?	

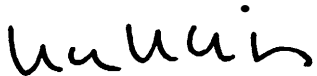**Table 1. Primary Participant and Family Member Demographics and Characteristics**

Primary Participants	N=22
Male	12 (54.5%)
Female	10 (45.5%)
Age	
40-50	5 (22%)
51-60	10 (45%)
61-70	4 (18%)
>70	3 (13%)
Education	
<High School	6 (27%)
Some High School	6 (27%)
High School Graduate	8 (36%)
College Graduate	2 (9%)
Number of Comorbidities	
	1 (4.5%)
1	6 (27%)
2	8 (36%)
3	7 (32%)
Housing	
SRO	5 (22%)
Board and Care	1 (4.5%)
Public Housing Project	8 (36%)
Substance Treatment Program	1 (4.5%)
Owner Occupied	2 (9%)
Low-Income Housing	5 (22%)
Family Member Participants	N=10
Sibling	3
Adult Children	2
Spouse/Partner	4
Parent	1

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