Title

Illness Narratives of African Americans Living With Coronary Heart Disease

Permalink

https://escholarship.org/uc/item/71c9082b

Journal

Qualitative Health Research, 27(4)

ISSN

1049-7323

Authors

Dubbin, Leslie
McLemore, Monica
Shim, Janet K

Publication Date

2017-03-01

DOI

10.1177/1049732316645319

Peer reviewed

Illness Narratives of African Americans Living With Coronary Heart Disease: A Critical Interactionist Analysis

Leslie Dubbin[1], Monica McLemore[1], and Janet K. Shim[1]

Abstract
How African American men and women respond to and manage living with coronary heart disease (CHD) is not well understood despite the well-documented disproportionate burden of CHD and its complications among African Americans in the United States. Through a critical interactionist perspective, we explore illness experiences of African Americans living with CHD and describe a broad range of micro-, meso-, and macro-contextual factors that influence their illness experiences. For participants in this study, CHD has become a "Black disease" wherein certain bodies have become historically and racially marked; a conceptualization maintained and passed on by African Americans themselves. Such findings highlight that CHD is more than a "lifestyle disease" where high-risk behaviors and lack of healthy choices are ultimate culprits. Rather, CHD is perceived by African Americans who have it as yet another product of ongoing racial and socio-structural dynamics through which their health burdens are created, sustained, and reproduced.

Accruing over the last 30 years, a large and collective body of illness narratives now provides 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). Through this corpus of work, illness narratives have been an innovative way to examine individuals' assumptions about health and illness (Becker, 1994; Kleinman, 1988), disruption and continuity (Bury, 1982; Charmaz, 1983; G. Williams, 1984), and defining illness and illness management strategies (Corbin & Strauss, 1985a, 1985b, 1987, 1988). In addition, 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, Namageyo-Funa, Jack, & Gregg, 2004; Marmot, 2005; Marmot & Wilkinson, 2006; Zola, 1966).

However, 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 et al., 2004; Samuel-Hodge et al., 2000). Such explorations are important as they provide opportunities 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).

Acknowledging that CHD is a major killer across all racial groups, a large literature suggests that racism, in all of its varied forms—interpersonal, institutional, and structural—disproportionately undermines the health of African Americans in the United States (Lukacho, Hatzenbuehler, & Keyes, 2014). Multiple scholars argue that racism becomes "embodied" over the life course negatively affecting the health of African Americans through multiple pathways like disproportionate exposure to environmental toxins as well as economic and social deprivation (Jones, 2000; Krieger, 2012; Lukacho

[1]University of California, San Francisco, California, USA

Corresponding Author:
Leslie Dubbin, Department of Social and Behavioral Sciences, University of California, 3333 California Street, Suite 455, San Francisco, CA 94143, USA.
Email: Leslie.dubbin@ucsf.edu

et al., 2014; D. R. Williams & Mohammed, 2009). Thus conceptualized, racism is an element of social structure through which dominant social groups maintain power, privilege, and control over differing types and the distribution of health-enhancing resources such as wealth, knowledge, and housing (Feagin, 2000; Feagin & Bennefield, 2014; Link & Phelan, 1995).

Other scholars have explored how particular diseases have become "racialized" through what Pollock (2012) calls "durable preoccupations" with race as they intersect with social politics and the fields of science, medicine, and the pharmaceutical industry. For example, Wailoo (2001) traces the history and transformation of sickle cell disease "from early-twentieth century invisibility to intense late-twentieth century politicization" (p. 3). His work explores the processes through which a once "invisible" disorder acquired a racial identity as well as political and symbolic significance. Metzl (2009) investigates how schizophrenia became a diagnosis overwhelmingly applied to African Americans during the tumultuous protest years of the 1960s and 1970s. He unveils the inner workings of how structural violence and institutional racism act as silent processes engaged to maintain the status quo "through established and respected institutions" that ultimately were "destructive to human life" (p. 202).

Turning specifically to heart disease, Pollock (2012) explores how racial discourse shaped the earliest years of cardiology as a specialty of medicine. Through a detailed examination of the construction of and the relationship between the Framingham Heart Study of 1948 and the Jackson Heart Study of 2000, Pollock documents the processes through which "African American" became a risk factor for hypertension, African American hypertension became a distinct disease category, and how BiDil—the first race based drug approved by the Federal Drug Administration (FDA)—became an intervention specifically targeted to "self-identified Black patients."

Shim (2014) attends to what she calls the "science-lay" divide, wherein the routinized and ritualized inclusion of the "usual suspects" of race, class, and gender in epidemiological studies to explain disparities in cardiovascular disease distribution have been inscribed with particular meanings and definitions at odds with the lived experiences of minority groups living with heart disease. Exploring the sociology and politics of knowledge production, Shim points out how this "usual suspects" approach devolves and "flattens" complex social processes into individual characteristics, missing altogether the "complex and nuanced understandings of the intersecting relationships between group status, relations of power, and well-being" (p. 15). For those living with heart disease, the effects of race, class, and gender on health are predominantly mediated through social processes, not biological ones. Rather race, class, and gender are structuring agents in which their everyday experiences and life chances affect their risk of disease.

In this article, we offer a critical interactionist analysis of illness experiences of African American men and women living with CHD. First, we conceptualize and describe this approach as a theory/methods package (Clarke, 2005) that includes a set of ontological and epistemological assumptions. Next, we offer our theoretically informed collection of methodological procedures based on grounded theory (GT) approaches. We argue that such an approach affords a better view and richer understanding of the broad range of micro-, meso-, and macro-contextual factors that inform the multidimensionality of these experiences. Our study and methodological approach complements and adds to previous literature in that we not only describe the ways in which people think about their health and the actions and behaviors that facilitate or hinder it but also demonstrate how these experiences are socially, historically, and racially patterned, reflective of the social structures that produce them. Our findings demonstrate that for African Americans in this study, CHD is understood to be a "Black disease": a racially marked disorder, where the development of this particular chronic disease is seen by those who develop it as a normative experience and expectation.

Critical Interactionism: A Fusion of Critical Theory and Symbolic Interactionism

This article is anchored 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 a genre of inquiry premised on the ontological view 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). In other words, critical research is explicitly and empirically grounded in prior evidence that the structure and content of social life disproportionately burdens some groups over others as a result of their social position, which provides the "jumping-off" point for further research (Thomas, 1993). Using 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).

Symbolic interactionism is a theoretical perspective that produces a dynamic understanding of actions and events because it views people as active beings engaged in practical activities of daily life and is interested in the processes and actions through which those activities are accomplished (Charmaz, 2014). Its distinctive approach to the study of human group life and conduct primarily rests on three underlying assumptions, according to Blumer (1969b). 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 each other. And third, we engage with, handle, and modify those meanings through an interpretive process as we encounter and interact with things and other people. Foundational to the symbolic interactionist tradition is that whatever meanings we assign to things arise from the ways other people act in relation to those things and our responses in social interactions. How we act, therefore, is in response to how others act and how we view or interpret the situations in which we find ourselves.

We are certainly not the first authors to use the term *critical interactionism* or to call for a more explicitly critical turn to symbolic interactionism. Previous scholars (see, for example, Lather, 1986a; Martins & Burbank, 2011; Sandstrom & Fine, 2003; Sandstrom, Martin, & Fine, 2001; Sundin & Fahy, 2008) have established and extended this approach to refer to a focused inquiry that is openly ideological, with the expressed purpose of probing the lived realities of individuals and the social conditions that inform their construction, as well as the possible transformation of those realities. Thus, scholars working from a critical interactionist approach take seriously the symbolic interactionist tenets that symbols and meanings are socially constructed but also combine this with explicit attention to relations of power that shape this construction. As several scholars have pointed out, the use of symbolic interactionism within social science research (particularly nursing) has been primarily focused at the individual or micro level 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.

Merging these two perspectives then, provides a solid theoretical grounding for this study and allows us to use the narrated experiences of our participants to explore two key issues: (a) the influences of social institutions, entities, and the state where people are treated differently by race, shaping policy decisions and distributing resources accordingly (Omi & Winant, 1994), and (b) the presence of human agency, emergent processes, problem solving practices, actions, and the subjective meanings our participants attach to their material and symbolic worlds (Charmaz, 2014). Using this approach, we were able to specifically examine how our participants understood the power relations that structured how their everyday lives were lived; highlight the effects of institutional structures such as racism, housing, and neighborhoods on their experiences living with CHD; and explore the practical activities, behaviors, and actions they adopted and adapted to live with it. Critical interactionism allows a more penetrating exploration of the relationship between macro-structural conditions and the concrete realities that people live (Lather, 1986a, 1986b; Sandstrom & Fine, 2003; Sandstrom et al., 2001).

Our work also builds off of the intersections of Critical Race Theory (CRT) and public health models that elucidate racial phenomena by highlighting the social dynamics that perpetuate racial inequalities in health. CRT draws upon transdisciplinary methodologies, theory, and experiential knowledge to illuminate the causes of structural racism. By shifting the discourse away from the dominant social voice to the perspectives of marginalized groups, their lived experience becomes the vehicle through which new knowledge is not only created but also made relevant to the communities of concern (Ford & Airhihenbuwa, 2008).

Method

Critical and symbolic interactionist research may use a variety of data, however, in-depth interviewing is a hallmark component of both perspectives as it provides researchers with "insider knowledge" about the domain of interest (Charmaz, 2014; Madison, 2005; Rubin & Rubin, 1995). In this study, because we were interested in the intersection between the personal experiences of African Americans living with CHD and the social context in which those experiences were realized, we used in-depth interviews as our primary data collection method.

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 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 cardiologist or clinic nurse identified potential participants during each clinic session. Although we considered posting a flyer to allow potential participants to self-identify as having CHD, we believe that the integrity of the study demanded a documented diagnosis of CHD in the medical record. As we did not have permission to access those records ourselves, we relied on the cardiologist or clinic nurse to be the gatekeepers in identifying potential participants with a documented diagnosis of CHD during each clinic session. As critical researchers, we acknowledge the power that inheres in such gatekeeping and how it may have shaped our participant pool in particular ways, for example, by providers perhaps selecting potential participants who were better known to them. That said the role of the clinic staff was only to identify those patients who met our eligibility criteria, regardless of those patients' histories with the providers and the clinic. The first author approached the patients independently to explain the study, answer questions about the study, and consent the patients to participate.

Eligibility criteria included (a) participant self-identified as Black, Black American, or African American; (b) participant had been living with a diagnosis of CHD for at least 6 months; and (c) participant was above the age of 18 years. The first author 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 participants' 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 US$50 gift card at the end of each interview. The University of California, San Francisco, Committee on Human Research approved this study (institutional review board [IRB] number 10-01126).

Data Collection: In-Depth Interviews

Our research team was comprised three women: one White, one Asian American, and one African American. All of the participant interviews (with the exception of one) were conducted at the participants' home by the first author, a White woman. Therefore, the cross-racial nature of the interviews must be emphasized and may have influenced the interviews in particular ways, such as the type of questions that were or were not probed further; failure to recognize culturally specific opportunities for further exploration; and/or misinterpreting/ misunderstanding verbal colloquialisms, and so on.

However, consistent with a critical interactionist approach to interviewing, the interview guide was constructed to be as open-ended as possible, and the follow-up questions, the directions each interview took, the content, and the pace of the interview were guided as much as possible by the participants themselves.

Our commitment to the application of critical interactionism determined both how we constructed our interview guide and our probing questions. Our semi-structured interview guide was designed to elicit 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. During the interviews, we asked open-ended questions to seek 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.

Our role as interviewers was to attempt to identify the subjective meanings participants attributed to those experiences. We asked participants to describe their neighborhoods and the influence their lived environment had on the experience of living with CHD; the availability, distribution, or lack of social resources in their neighborhoods; their understandings and explanations for the development of CHD; and their thoughts and feelings upon learning they had CHD. Through in-depth probing, we explored the meanings they attached to CHD and/or its symptoms, their experiences and meanings of stress, experiences seeking medical help, and the impacts having CHD had on their family, work and social life, and relationships.

A total of 22 primary participants and 10 family members participated in this study (see online Table 1, for primary participant and family member demographic characteristics). 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. Primary interviews lasted from 45 minutes to more than 2 hours. Eight of the 22 primary participants agreed to participate in a follow-up interview, each lasting approximately 1 hour. The purpose of these second interviews was to share with the participants the preliminary themes and concepts that emerged in the data to get their sense if those themes resonated. All interviews were digitally recorded and transcribed verbatim.

Data Analysis

GT encompasses systematic yet flexible guidelines and procedures for collecting and analyzing qualitative data that theory may be generated from the data (Charmaz,

2014). Symbolic interactionism is the major theoretical perspective that forms the epistemological foundation of GT (Blumer, 1969b; Charmaz, 2014; Strauss & Corbin, 1994). As discussed above, critical interactionism takes symbolic interactionist commitments to the significance of the meanings of things and of human agency, and combines them with attention to the social shaping of local experiences and actions, and the influence of power relations on everyday life. As such, many critical researchers rely on GT's systematic procedures for data collection and analysis (Charmaz, 2014; Clarke, 2005; Madison, 2005; Thomas, 1993) as a means to reveal the relationships between structural and institutional forces and individual and group experiences.

Data analysis followed the methods of a post-modern constructivist approach to GT (Charmaz, 2005, 2007). As both Clarke (2005) and Charmaz (2006, 2007, 2014) contend, data are not collected nor analyzed "tabula rasa," and theories are not discovered; instead they are constructed in and through what participants and researchers bring to the research project and what they (and us) do within the research environment. Thus, constructivist GT research procedures provided the flexibility for us to include—as researchers—our critical perspective, our past experiences, and our prior research practices.

Specifically, our procedures included conducting our data collection and analysis simultaneously in an iterative fashion, while constantly comparing data across and within our participants' narratives. First, the entire transcripts of each interview were read and re-read to identify emergent themes and concepts. Listening to the audio recordings at the same time as reading the transcripts allowed us to note and record nuances in linguistic syntax as well as spoken emphases that may not have been clear solely from a transcribed text.

We began our data analysis using a traditional GT approach—line-by-line coding through which we developed a cadre of codes that could be used to theorize across different participant experiences. We coded descriptions and different facets of the illness experience including participants' understanding of CHD, its development and causation; descriptions of family and family history of illness; experiences, meanings, and definitions of stress; strategies and behaviors for coping; disease and symptom management; experiences seeking medical care; disease impact on social, familial, and work relationships; decision making; as well as participants' fears and anxieties around being diagnosed with a serious chronic illness. Our codes also included participants' descriptions of their neighborhoods; types of resources needed and relied upon; experiences of interpersonal and institutional racism; personal goals and dreams—realized or not—and influences of social

structures like education and housing on the illness experience. We continuously explored the data noting variation among the participants and relationships between various codes. We developed our codes and categories through extensive memoing, and then selected individual narratives for presentation that best demonstrated how particular categories were operationalized.

"Thick biographies" of each participant were also written, a narrative of each participant's life history as it was relayed by the participant including important historical and current events (Rehm, 2010). These thick descriptions (Geertz, 1973) of participants' social and cultural contexts, emotions, and their thoughts and perceptions gave us 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 us to see experiences across participants where they were similar and where they were not. Writing these extensive biographical memos allowed us to think through the codes and categories derived from GT coding procedures in a more narrative fashion. It was through the combination of memos on codes and categories jointly with the biographical memos that we were able to highlight the impact and intersections of biography, biology, and racialized experiences that influenced our participants' understandings of CHD. Finally, field notes were written and a reflexive journal kept about the research experience.

Following where our data led us, we used theoretical sampling to explore different perspectives of the illness experience—namely that of family members and the impact chronic disease had on social and familial relationships. We also used theoretical sampling to pursue a wide range of ages in our participant sample. This was motivated by our recognition that first, African Americans bear the burden of CHD at earlier ages than other racial groups and we wished to grasp how their understandings of CHD changed over time and how their experiences of it varied by when they were most affected by it. Second, given our emergent finding that participants experienced CHD as a racialized disease, different cohorts' experiences of race relations and racism could be distinct and therefore would be important to explore. We concluded participant recruitment when we were confident that we had explored all of the properties of the patterns we identified that constituted our coding and categorical scheme.

We 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. As a result of this systematic process, we were able to generate our theoretical premise that the experiences of African Americans in this study represent

the racialization of a disease into a culturally normative experience.

Following a wide range of scholars from a broad spectrum of qualitative traditions (see, for example, Becker, 1994; Charmaz, 1983; S. R. Kaufman, 1988; Kleinman, 1988), we present our findings using an illness narrative style. It should be noted that we did not interpret data exemplars as a whole or use a "case-centered" approach as narrative analysis dictates (Riessman, 2008). Rather, following the tenets of a critical approach, we have left the exemplars of participants as intact as possible. A key component to critical research is the rendering of oral histories and stories as they are told, which have the power to expose, break open, and revise unjust structural systems (Madison, 2005). As Becker (1994) notes, when individuals narrate their illness experiences, they tend to do so in a linear fashion with a beginning, middle, and an end. Each participant assembles a series of historical and experiential events into a narrative of reshaped events and memories that draw upon culturally salient images, all coming together around a common plot—a process called emplotment.

In what follows, we present a collective plot from several of our participants that comprise one of our major coding categories. In "Origin Stories," we reveal two processes through which CHD has become a racially marked disorder and a normative experience for our participants. The first process, identified through the in vivo code "living the Black is hard," links participants' current health experiences to the cumulative effects of interpersonal and institutional racism and disadvantage over their life course. The second process, "we've been salted down," reflects the historical and intergenerational burden of disease that African Americans bear as an ongoing legacy of slavery. Through these narratives, we see some of the ways in which individuals make sense of and understand their illness exposing the multidimensionality of the illness experience. In this article, we only include quoted data from men. Although the women in our study acknowledged that historicized racial dynamics have influences that negatively affected their health, their conceptualizations of CHD as a "Black disease" were neither central to their experiences of living with CHD nor were they expressed as part of their origin stories for how they, as women, developed CHD. That said, through member checking, none of our female participants refuted, disputed, or contradicted the narratives of the men in our study, rather they supported those narratives as representative of experiences they witnessed men in their lives as having or have had. We believe that the African American women's experiences require an in-depth analysis of their own and will be the subject of a subsequent paper. We also draw upon supplementary data from other participants when necessary to expand on emerging themes. All participant names are pseudonyms.

Origin Stories

When we asked participants their understanding of how they developed CHD, all of them to one degree or another cited poor eating habits as a principal reason. However, most linked those dietary habits to their collective African American cultural experience. Their origin stories are illustrative of their understanding of how cultural history, practices, and preferences influence their subsequent health problems. Yet, most of the participants in this study were also well aware that, across all racial groups, African Americans bear the burden of the disease in terms of overall morbidity and mortality. Through the following exemplars, we describe the ways in which the disproportionate burden of CHD within the African American community is seen to be a rather normative experience—a Black disease—and one that is infused with powerful cultural, racial, and historical significance. As we illustrate below, this view is borne out of the legacy of slavery, produced and sustained by interpersonal and institutional racism, and reproduced through structural inequalities based on race.

"Living the Black Is Hard"

Michael is 68 years old and characterizes CHD as a "Black" disease and one that is linked through everyday interpersonal and institutional racism. At first, he ascribed his health issues to environmental exposures. He described 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 Michael 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 . . . Livin' the black is hard." 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 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's the heart disease with the black. Diabetes and cancer. Why those three big sicknesses the blacks have mostly? Why it got to be us?

For Michael, CHD, diabetes, and cancer do not exist as de-contextualized diseases that some people get and others do not. 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 becomes a normative experience, maintained and reproduced through systematic structural inequalities based on race. Roy's medical history is lengthy and complicated. Besides CHD, he also suffers from diabetes, lung disease, 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 described the social "rules" he was expected, as an African American, to rigidly follow. For example, 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 that separated Whites from Blacks were clearly delineated. Failure 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 [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 [out] 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!

These normalized 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. More than 50 years later, the effects of these racialized experiences have lingered, and have manifested bodily by affecting his "nerves" that today require medication. Roy's experiences reflect that not only is the presence of CHD a normalized occurrence but that the causation of CHD among Blacks has also been normalized by and through normalized racialized social rules, expectations, and codes of conduct.

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 systematic and unequal distribution of materials, supplies, and information limited his overall chances of opportunity. The "splitting of information" advantaged Whites while ensuring that Blacks could not and would not be able to compete socially or economically within the larger social arena. 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!

Although 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 . . . See, the black man, at least he has a reason [to be ill] . . . because he's black.

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 EBay! You feel me? That's it there. That's the difference . . . White folks won't admit it to most blacks, but they know, just like I know, the playing field is not even.

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 emergency department (ED) with CHD is neither at odds with his expectations nor that of the ED staff—it is normal for Blacks in general have poor health.

"We've Been Salted Down"

In this next section, we illustrate how individuals' origin stories function as reflective links among micro, meso, and macro social and cultural processes. These stories reflect their understandings of how their cultural history, practices, and preferences may influence ongoing health behaviors. In the following exemplars, participants point 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, construction of that history is also cultural and collective.

Darnell, a native San Franciscan who developed CHD in his early 40s, described this succinctly:

> 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.

William was only 50 years old when diagnosed with congestive heart failure (CHF) related to CHD. He also linked his current clinical condition and the disproportionate burden of CHD affecting African Americans to the historical conditions of slavery:

> 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.

The theory to which William refers is called the "Slavery Hypertension Hypothesis" and is most associated with the work of Wilson and 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. At its most basic, this hypothesis states that those who managed to survive the crossing were those who were presumably genetically disposed to retain salt. According to Wilson and Grimm, the resulting kidney dysfunction, over time, created historically high blood pressure disparities among African Americans and, hence, has led to a myriad of cardiac conditions. 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 recently as 2007[1] (J. S. Kaufman & Hall, 2003; Smedley, Jeffries, Adelman, & Cheng, n.d.).

By invoking this explanation, William is conveying a particular origin story that he believes *genetically* and *scientifically* explains the disproportionate burden of CHD among African Americans. That is to say, for William, CHD is a "Black" disease because "science" says so, by directly linking disproportionately high rates of disease among African Americans to the violent history of enslavement. William is also linking and locating his current *individual* health state to a *collective* membership within a particular racial group whose experiences included the forcible dislocation and enslavement (and murder) of millions. For William, these experiences are not ancient history. That history has current relevance because it demonstrates how its consequences have traveled through the centuries to affect his health and life chances today.

The extended narratives of Michael, Roy, Darnell, and William demonstrate how they see and perceive at the individual or micro level, the ways in which macro social and racial dynamics operate everyday in ways that significantly affect health. In each of these exemplars, their illness experiences were not merely described, they were explored through the historical, cultural, and macrostructural pressures that influenced them. Seeking the relationship between the macro-social fabric and the concrete realities that our participants share and live, use of a critical interactionist approach also exposed the paradoxical dynamics of how CHD has become a normative experience when there is nothing normal at all about a disease that disproportionately burdens African Americans over all other populations. Through its racialization, CHD has become normalized and its normalization reflects the successful racialization of a disease into a normative expectation. For African Americans, their experiential understanding of living with CHD links their present illness burden to their past experiences of limited opportunities based on racial, cultural, social, and economic disadvantage that accumulate over their life course, as well as to a more distant history of stratification and violence inflicted on the generations who preceded them.

Conclusion

In this article, we have presented narratives of African Americans living with CHD as illness experiences, peeling back their layers to expose their multidimensional natures. Our efforts in this study were to unpack what Shim (2014) calls the "black box" of social processes—present yet hidden—that contribute to the rise not only of the differential distribution of disease and the taken-for-granted medical explanations for them but also the differential distribution of experiences of health and illness. By foregrounding our participants' narratives within the context of their own lived experiences, we complement and add to the work of other inequalities scholars like Pollock (2012), Metzl (2009), Wailoo (2001), and Shim (2002, 2005, 2014) in two significant ways. First, we have demonstrated that there is a broad range of micro-, meso-, and macro-contextual factors that influenced our participants' experiences of living with CHD. Second, our findings demonstrate that for the 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, culturally, and racially marked, a conceptualization that is sustained and passed on by African Americans themselves.

However, this normalizing is anything but random. The widespread and routine presence of a disproportionate share of ill health in African American bodies and communities occurs through the long-standing history of racism and the intergenerational accumulation of disadvantage, and the myriad institutional and historical ways in which that stratification is sustained and reproduced. Our findings highlight that CHD is much more than a "lifestyle" disease where high-risk behaviors and lack of healthy choices are the ultimate culprits. Rather, CHD is perceived by African Americans who have it as yet another product of ongoing racial and socio-structural dynamics, through which their health burdens are created, sustained, and reproduced.

Critical research grew out of growing dissatisfaction with accounts of social structures like class, patriarchy, and racism in which no human actors appeared, and cultural accounts of human actors in which structural constraints of class, patriarchy, and racism were not examined. For symbolic interactionism, power is a process played out in the course of interaction. The exercise of power is dependent upon whose definition of the situation prevails. Although many have criticized symbolic interactionism for its focus on micro-level interactions with no regard for macro-structural influences and power relations on human experience, Blumer (1939, 1958, 1965, 1969a) himself wrote many works on race prejudice, segregation, industrialization, and labor management relations. In fusing a critical perspective with symbolic interactionism, the framework of critical interactionism *explicitly* bridges social structure and individual experience and allows the researcher to move between them.

In this study, attending to 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. 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 sociological and nursing research by requiring an examination of participant experiences and circumstances within wider socio-structural influences and processes that affect the way health and illness are experienced.

Declaration of Conflicting Interests

Funding

Note

1. For more on the debate about this theory, see Pollock (2012), J. S. Kaufman and Hall (2003), Blackburn (2003), Grim and Robinson (2003), and Blumer (1939, 1958, 1965).

References

Becker, G. (1994). *Disrupted lives: How people create meaning in a chaotic world*. Berkeley: University of California Press.

Becker, G., Gates, R. J., & Newsom, E. (2004). Self-care among chronically ill African Americans: Culture, health disparities, and health insurance status. *American Journal of Public Health*, *94*, 2066–2073.

Becker, G., & Newsom, E. (2005). Resilience in the face of serious illness among chronically ill African Americans in later life. *Journal of Gerontology: Social Sciences*, *60B*, S214–S223.

Blackburn, H. (2003). The slavery hypothesis of hypertension among African-Americans. *Epidemiology*, *14*, 118–119.

Blumer, H. (1939). The nature of race prejudice. In S. M. Lyman & A. J. Vidich (Eds.), *Selected works of Herbert Blumer: A public philosophy for mass society* (pp. 183–195). Chicago: University of Illinois Press.

Blumer, H. (1958). Race prejudice as sense of group position. *Pacific Sociological Review*, *1*, 3–8.

Blumer, H. (1965). The future of the color line. In S. M. Lyman & A. J. Vidich (Eds.), *Selected works of Herbert Blumer: A public philosophy for mass society* (pp. 208–222). Chicago: University of Illinois.

Blumer, H. (1969a). Society as symbolic interaction. In H. Blumer (Ed.), *Symbolic interactionism: Perspective & method* (pp. 78-89). Berkeley: University of California Press.

Blumer, H. (1969b). *Symbolic Interactionism: Perspective & method*. Berkeley: University of California Press.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, *4*, 167–182.

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, *5*, 168–195.

Charmaz, K. (2000). Experiencing chronic illness. In G. L. Albrecht, R. Fitzpatrick, & S. C. Scrimshaw (Eds.), *The handbook of social studies in health & medicine* (pp. 278–292). London: Sage.

Charmaz, K. (2005). Grounded theory in the 21st century. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 507–546). Thousand Oaks, CA: Sage.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Los Angeles: Sage.

Charmaz, K. (2007). Shifting the grounds: Constructivist grounded theory methods. In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. E. Clarke (Eds.), *Developing grounded theory: The second generation* (pp. 127-154). Walnut Creek, CA: Left Coast Press.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Los Angeles: Sage.

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. London: Sage.

Conrad, P. (1990). Qualitative research on chronic illness: A commentary on method & conceptual development. *Social Science and Medicine*, *30*, 1257–1263.

Corbin, J., & Strauss, A. (1985a). Issues concerning regimen management in the home. *Aging and Society*, *5*, 249–265.

Corbin, J., & Strauss, A. (1985b). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, *8*, 224–247.

Corbin, J., & Strauss, A. (1987). Accompaniments of chronic illness: Changes in body, self, biography and biographical time. In J. A. Roth & P. Conrad (Eds.), *Research in the sociology of health care* (pp. 249-281). Greenwich, UK: JAI Press.

Corbin, J., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.

Feagin, J. R. (2000). *Racist America: Roots, current realities, & future reparations*. New York: Routledge.

Feagin, J. R., & Bennefield, Z. (2014). Systemic racism. *Social Science & Medicine*, *103*, 7–14.

Ford, C. L., & Airhihenbuwa, C. O. (2008). Critical race theory, race equity, and public health: Toward antiracism praxis. *American Journal of Public Health*, *27*, 693–698.

Geertz, C. (1973). *The interpretation of cultures*. New York: Basic Books.

Grim, C. E., & Robinson, M. (2003). Salt, slavery and survival: Hypertension in the African Diaspora. *Epidemiology*, *14*, 120–122.

Holloway, I., & Wheeler, S. (2002). *Qualitative research in nursing*. Oxford, UK: Blackwell.

Jones, C. P. (2000). Levels of racism: A theoretic framework and a gardener's tale. *American Journal of Public Health*, *90*, 1212–1215.

Kaufman, J. S., & Hall, S. A. (2003). The slavery hypertension hypothesis: Dissemination and appeal of a modern race theory. *Epidemiology*, *14*, 111–118.

Kaufman, S. R. (1988). Illness, biography, and the interpretation of self following a stroke. *Journal of Aging Studies*, *2*, 217–227.

Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.

Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine, 88*, 251–258.

Krieger, N. (2012). Methods for the scientific study of discrimination and health: An ecosocial approach. *American Journal of Public Health, 102*, 936–944.

Kushner, K. E., & Morrow, R. (2003). Grounded theory, feminist theory, critical theory: Toward theoretical triangulation. *Advances in Nursing Science, 26*, 30–43.

Lather, P. (1986a). Issues of validity in openly ideological research: Between a rock and a soft place. *Interchange, 17*(4), 63–84.

Lather, P. (1986b). Research as praxis. *Harvard Educational Review, 56*, 257–277.

Lawton, J. (2003). Lay experiences of health and illness: Past research and future agendas. *Sociology of Health and Illness, 25*, 23–40.

Liburd, L. C., Namageyo-Funa, A., Jack, L., & Gregg, E. (2004). Views from within and beyond: Illness narratives of African-American men with type 2 diabetes. *Diabetes Spectrum, 17*, 219–224.

Link, B. G., & Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior, 35*, 80–94.

Lukacho, A., Hatzenbuehler, M. L., & Keyes, K. M. (2014). Structural racism and myocardial infarction in the United States. *Social Science & Medicine, 103*, 42–50.

Madison, D. S. (2005). *Critical ethnography: Method, ethics, and performance.* Thousand Oaks, CA: Sage.

Marmot, M. (2005). *The status syndrome: How social standing affects our health & longevity.* New York: Owl Books.

Marmot, M., & Wilkinson, R. G. (Eds.). (2006). *Social determinants of health.* Oxford, UK: Oxford University Press.

Martins, D. C., & Burbank, P. M. (2011). Critical interactionism: An upstream-downstream approach to health care reform. *Advances in Nursing Science, 34*, 315–329.

Metzl, J. M. (2009). *The protest psychosis.* Boston: Beacon.

Omi, M., & Winant, H. (1994). *Racial formation in the United States: From the 1960s to the 1990s.* New York: Routledge.

Pollock, A. (2012). *Medicating race: Heart disease and durable preoccupations with difference.* London: Duke University Press.

Rehm, R. (2010). Interpretive data management & analysis. In W. Holzemer (Ed.), *Improving health through nursing research* (pp.142-156). New York: Wiley-Blackwell.

Riessman, C. K. (2008). *Narrative methods for the human sciences.* Thousand Oaks, CA: Sage.

Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing data.* Thousand Oaks, CA: Sage.

Samuel-Hodge, C. D., Skelly, S. W., Ingram, A. F., Keyserling, T. C., Jackson, E. J., Ammerman, A., . . . Elasy, T.A. (2000). Influences on day-to-day self management of type 2 diabetes among African American women. *Diabetes Care, 23*, 928–933.

Sandstrom, K. L., & Fine, G. A. (2003). Triumphs, emerging voices, and the future. In L. T. Reynolds & N. J. Herman-Kinney (Eds.), *Handbook of symbolic interactionism* (pp. 1041-1058). New York: AltaMira Press.

Sandstrom, K. L., Martin, D. D., & Fine, G. A. (2001). Symbolic interactionism at the end of the century. In G. Ritzer & B. Smart (Eds.), *Handbook of social theory* (pp. 217-231). Los Angeles: Sage.

Shim, J. K. (2002). *Race, class and gender across the science-lay divide: Expertise, experience and "difference" in cardiovascular disease* (PhD thesis). University of California, San Francisco, CA.

Shim, J. K. (2005). Constructing "race" across the science-lay divide: Racial formation in the epidemiology and experience of cardiovascular disease. *Social Studies of Science, 35*, 405-436.

Shim, J. K. (2014). *Heart-sick.* New York: New York University Press.

Simon, R., & Dippo, D. (1986). On critical ethnographic work. *Anthropology & Education Quarterly, 17*, 195–202.

Smedley, B., Jeffries, M., Adelman, L., & Cheng, J. (n.d.). *Race, racial inequality and health inequities: Separating myth from fact.* The Opportunity Agenda. http://www.emfp.org/MainMenuCategory/Library/ResearchResourceLinks/RaceRacialInequalityandHealthInequitiespdf.aspx

Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273–285). Thousand Oaks, CA: Sage.

Sundin, D., & Fahy, K. (2008). Critical, post-structural, interpretive interactionism: An update on Denzin's methodology. *Nurse Researcher, 16*(1), 7–23.

Thomas, J. (1993). *Doing critical ethnography.* Los Angeles: Sage.

Wailoo, K. (2001). *Dying in the city of the blues: Sickle cell anemia and the politics of race and health.* London: University of North Carolina Press.

Williams, D. R., & Mohammed, S. A. (2009). Discrimination and racial disparities in health: Evidence and needed research. *Journal of Behavioral Medicine, 32*, 20–47.

Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness, 6*, 175–200.

Wilson, T. W., & Grim, C. E. (1991). Biohistory of slavery and blood pressure difference in blacks today: A hypothesis. *Hypertension, 17*, 1122–1129.

Zola, I. K. (1966). Culture & symptoms: An analysis of patient's presenting complaints. *American Sociological Review, 31*, 615–630.

Author Biographies

Leslie Dubbin, PhD, MS, RN is assistant adjunct professor in Nursing for the Department of Social and Behavioral Sciences at the University of California, San Francisco. Her research explores the mechanisms of the reproduction of racial inequalities in health, the influences of the lived environment on individuals' experiences living with chronic

illness, patient-provider interactions, and the relationship of life-course stress experiences of Black women and their risk for pre-term birth.

Monica McLemore, PhD, MPH, RN is assistant professor in the Family Health Care Nursing Department and an affiliated research scientist with the Advancing New Standards in Reproductive Health program of the Bixby Center for Global Reproductive Health in the Department of Obstetrics, Gynecology, and Reproductive Sciences at the University of California, San Francisco.

Janet K. Shim is associate professor of sociology in the Department of Social and Behavioral Sciences, University of California, San Francisco. Her current research focuses on analyzing the science of health disparities and the production of health care inequalities. She is the author of *Heart-Sick: The Politics of Risk, Inequality, and Heart Disease* (2014, NYU Press).