

UC Berkeley

ISSI Fellows Working Papers

Title

Pediatric Cancer, Racial Formation, and the Existential Weight of Anti-Blackness

Permalink

<https://escholarship.org/uc/item/86w5k7th>

Author

Wright, Anthony

Publication Date

2018-08-08

Data Availability

The data associated with this publication are available upon request.

ISSI GRADUATE FELLOWS WORKING PAPER SERIES 2017-2018.84

**Pediatric Cancer, Racial Formation, and the Existential
Weight of Anti-Blackness**

by Anthony Wright

Medical Anthropology

University of California, Berkeley, and University of California, San Francisco

August 8, 2018



Institute for the
Study of
Societal Issues

**Pediatric Cancer, Racial Formation,
and the Existential Weight of Anti-Blackness**

Anthony Wright
Medical Anthropology
**University of California, Berkeley, and University of California, San
Francisco**

agwright@berkeley.edu

This paper is based on an ethnographic case study drawn from 16 months of fieldwork with families and young people going through cancer diagnosis and treatment in Oakland, California. The paper explores the intersection of cancer patienthood and racial formation, emphasizing the entanglement of biogenetic and sociogenetic processes. The paper shows how, as cancer-inflicted bodies move through the world, they are subjected to sociohistorically produced racial classifications that can be deployed in destructive, humiliating, and stress-inducing ways. Yet racialization can also occur in a more affirming, supportive, and resistant register—for example, through participation in community-based cancer advocacy efforts. The paper emphasizes three points of intersection between cancer patienthood and racial formation: 1) the racialization of oncologically transformed bodies; 2) the racialization of attempts to raise cancer awareness; and 3) the racialization of the expression of negative emotions in healthcare interactions. In doing so, the paper shows that racialization is a fundamental sociogenetic process that is entangled with the biogenetic processes that cancer scientists describe as “oncogenesis.” Entangled biogenetic and sociogenetic processes constitute the existential trajectories that cancer patients and their families inhabit.

The Institute for the Study of Societal Issues (ISSI) is an Organized Research Unit of the University of California, Berkeley. The views expressed in working papers are those of the author(s) and do not necessarily represent those of ISSI or the Regents of the University of California.

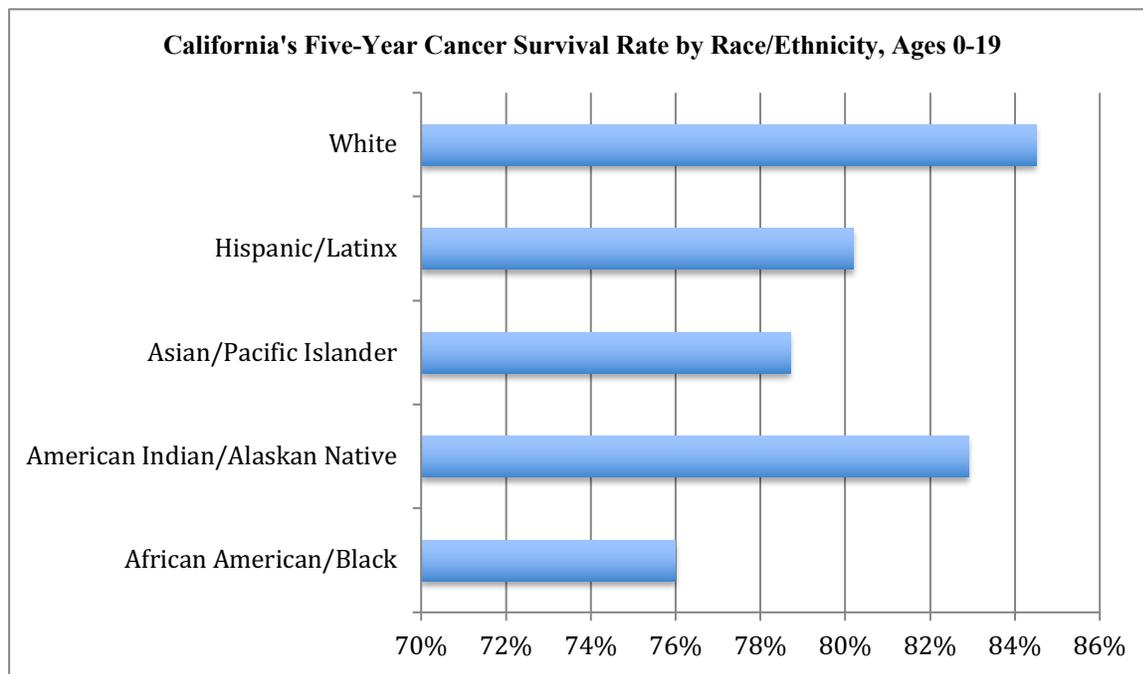
Introduction

Although there is no universal experience of cancer treatment, certain kinds of experiences are, as Julie Livingston points out, “fundamental to cancer everywhere in the world” (2012, 23). For example, most patients and their loved ones will experience cancer treatment as shocking and traumatic in some way for some duration of time. While I do not take psychiatric categories for granted, clinically oriented studies suggest a significant number of cancer patients and their family members in the United States meet criteria for post-traumatic stress disorder (Cordova, Riba, and Spiegel, 2017; Erickson and Steiner, 2000).¹

The contentiousness of psychiatric categories aside, it is safe to say that cancer diagnosis and treatment involve intense emotional experiences for all patients and members of their intimate networks. This may be particularly true when diagnosis occurs at a young age. Yet to say that such experiences are fundamental to cancer is not to say that they are all identical in content. Rather, like all experiences, those that arise in the context of cancer are shaped by the existential conditions inhabited by particular people in particular times and places. Any anthropological account of cancer experience must therefore take into account how specific people interact with, navigate, and interpret the constitutive conditions of their individual and collective existence. The physiological processes of cancer can be described as one such condition, but the existential condition of cancer emerges in relation to other existential conditions that enable and constrain experience and health outcomes.

¹ For a critical analysis of post-traumatic stress disorder as a diagnostic category see Young’s *The Harmony of Illusions: Inventing Post-Traumatic Stress Disorder* (1995).

Sociogenetic processes not only shape the experience of illness; they have an actual impact on the physiological functioning of human bodies, as is demonstrated by the vast literature on racial and ethnic health disparities (Kuzawa and Gravlee 2016; Rouse 2009). As with many other illnesses, such disparities are found among pediatric cancer patients. For example, the following graph shows racial and ethnic disparities in five-year cancer survival rates among cancer patients of age 0-19 in California from 2003-2013, with African American children and teenagers having the lowest survival rate of any ethnoracial group:



This pattern is not a simple reflection of biogenetic differences among populations. To repeat Carolyn Rouse's assertion, the use of racial and ethnic categories as facile proxies for genetic endowment "is equal parts retrograde and offensive" (Rouse 2009, 161). While it is true that sociogenetic processes of racial formation have a regulatory effect on human sexual activity and thus must to some extent guide the transmission of biogenetic material, it is not the case that this has produced stable, biogenetically homogenous populations that can each

unproblematically be matched with one discrete racial or ethnic category. After all, there has been a great deal of what biological scientists often blithely refer to as “genetic admixture” across racialized populations. Although interracial sexual activity can be consensual and voluntary, it also occurs through the sexual violence of patriarchy and white supremacy. This is a fact that is obscured by the notion of genetically homogeneous ethnic and racial populations. As Kuzawa and Gravlee (2016, 91) note, “Only a small part of the variability in human genes is explained by knowing what continent someone is from, or in what group they reside within a continent. Instead, the vast majority of genetic variation is found within human groups.” Given what is known about biogenetic variability within and across populations, the disparities above are arguably due less to biogenetic differences than to the sociogenetic processes through which people are racially categorized and economically positioned in relation to sources of capital accumulation.

In what follows, I discuss the relationship between racial formation and cancer in the United States through an ethnographic case study of an African American family I met at UCSF Benioff Children’s Hospital (BCHO) in Oakland, California, where I conducted fieldwork for 16 months in 2017 and 2018. The case study focuses on Rashad², a 12-year old boy diagnosed with acute myeloid leukemia (AML)³ and his parents, Malachi and Tanya. In describing Rashad’s case, I show how he and his family have been negatively affected by experiences of stigmatization, discrimination, and inequality. I emphasize the relationship between these experiences and inherited processes of racial formation that can be traced back to the settler colonization of North America and the institution of race-based slavery that was essential to the

² All names of patients and family members are pseudonyms.

³ AML is a cancer of the white blood cells. According to the National Cancer Institute (SEER 2018), there will be an estimated 19,250 new cases of AML diagnosed in 2018, and 4.9% of those were patients younger than 20. Since 1975, the five-year survival rate has gone from 20% to 68% for children younger than 15 years (NCI 2017).

development of United States, and which set the stage for legal segregation and “hyperincarceration” (Wacquant 2010).

Cancer Patienthood, Racial Formation, and Biosocial Entanglement

According to the now dominant epidemiological account, *oncogenesis*, or the biological development of cancer, is related to processes of genetic inheritance. Genes inherited from biological parents sometimes contain oncogenic mutations, and sometimes at-risk genes acquire such mutations through interactions between the body and carcinogenic environmental conditions (Mukherjee 2010; Fujimura 1996). Some anthropologists may read these claims with hesitation, as they come from scientific fields that have been accused of biological reductionism and determinism. For example, Margaret Lock suggests that even emergent epigenetic discourses, which are generally credited with showing how factors external to the body can produce heritable alterations in gene expression, may fail to challenge longstanding patterns of “somatic reductionism”:

Although the contribution of environments, social and physical, to human development, health, and illness, are now well recognized, there is a distinct danger that the molecular endpoints that these variables bring about, and very little else, will receive due attention. Epigeneticists have thrown down the gauntlet to genetic reductionists but, even so, the full significance of social, economic, and political aspects of health inequalities remain distinctly shadowy (Lock 2013, 292).

Although this paper is not a challenge to contemporary theories of oncogenesis, I do want to point out that biogenetic inheritance is not the only mode of inheritance significant to the development of cancer as an existential condition, or an embodied series of interactions with the facts of one’s world. I reiterate Troy Duster’s (2003) observation that biogenetically inherited risks and conditions, including cancer, are always generated, diagnosed, treated, and lived within

inherited social orders. Here I will focus on the intersection of cancer patienthood and racial formation.

As Omi and Winant observe, in the contemporary world, racial discourses provide “master categories” (2015, 106) that empower racializing modes of social recognition and identification. In other words, they provide globally pervasive tools for differentiating human bodies and persons. Over the past half millennium, since the European colonization of the Americas, what Omi and Winant refer to as “racial projects” have shaped contemporary social structures. Within the lived, phenomenological space of racialized social structures, interactive processes of racialization produce embodied, experiential effects (Omi and Winant 2015, 137). As I will discuss below, historically conditioned processes of racial formation—which can be affirmative and constructive, or derogatory and destructive—can have a profound effect on the way cancer patients, their family members, and biomedical professionals interact with themselves and each other. To put it differently, cancer patienthood and racial formation are intertwined existential conditions.

In speaking of cancer patienthood as an existential condition, I follow many other scholars in emphasizing connections across previously purified domains—for example, the biological, the psychological, the economic, and the social. Yet as Scheper-Hughes and Lock observe, the attempt to reintegrate what has been analytically separated can lead to conceptual fragmentation and, perhaps, confusion:

As we struggle to explore the illness experience from an integrated critical perspective—one that entails an appreciation of humans as simultaneously physical, social, economic, and symbolic beings—we find ourselves entrapped in our own Cartesian epistemological legacy. We are without a language with which to address mind-body-society interactions, and so are left hanging in mid-air, suspended in hyphens that testify to the radical disconnectedness of our thoughts. We resort to such fragmented concepts as the bio-social, the psycho-somatic, the psycho-social, the somata-social as a feeble way of expressing the complex and myriad ways that our minds speak to us through our bodies, and the ways in which society is inscribed on the expectant canvas for our flesh and bones, blood and guts (Scheper-Hughes and Lock 1986, 137).

Of course, since the time Scheper-Hughes and Lock wrote the preceding passage, a great deal of critical discussion has focused on dismantling dualisms by emphasizing connections across previously purified domains. It is now widely held by medical anthropologists that certain commonly held dualisms—most notably, mind/body and nature/culture—are not best thought of as separately existing entities or processes. The theoretical terms that scholars have constructed to describe certain domains and processes of existence have historically enacted what Latour (1993) refers to as “purifications” that shape the way people think about and engage with themselves and the world around them. In response to the work of purification, many social theorists, particularly those working in the area of Science and Technology Studies (STS), have called for an emphasis on hybridity and entanglement. As Scheper-Hughes and Lock noticed quite early on, such attention to hybridity and connection can lead to the proliferation of conjoined terms and neologisms, such as Donna Haraway’s “naturecultures” (2003). While this practice of linguistic mash-up may indeed cause confusion or even annoyance, especially where practitioners from multiple disciplines meet, it has nevertheless led to a profound recognition of the inextricable entanglement of existential conditions that are created by human thought and practice (for example, racial categories and carcinogenic production processes) and those which are not (for example, blood and environmentally dependent bodies). Of course, to use blood as an example of something not made by humans might be misleading insofar as scientists have developed synthetic blood (Sarkar 2008), but my point is that blood existed well before the invention of synthetic blood, and even well before humans invented the term “blood” or its ancient equivalents. Racial categories and carcinogenic production processes, however, have not. Yet they have had a profound effect on the blood-filled bodies that depend upon the planet’s environments in order to go on living. It thus seems that an understanding of sociogenetic and

biogenetic processes as thoroughly entangled is necessary in order to make sense of racial and ethnic health disparities.

As cancer is forming in the body, and as patients undergo treatment and learn how to inhabit the role of cancer patient, they are simultaneously moving through socio-historically produced, institutionalized worlds. As the physiology and appearance of the body change in response to disease progression and the iatrogenic effects of treatment, these changes have an effect not only on how young patients feel, but also on how they are treated as they move through various spaces. In addition to experiencing intense side effects, patients may develop concerns about stigmas related to racial positionality and body image, and these concerns are often associated with real changes in the ways they are evaluated and treated by others.

In the case study that follows, I explore how African American positionality has a constitutive effect on cancer-related experiences both inside and outside of biomedical facilities. While my focus is on an African American family in this paper, my intention is not to produce an exhaustive account of “African American cancer experience.” Such an analysis would only perpetuate stereotypes and misrepresent the issue at hand. My point in analyzing the intersection of racial formation and cancer experience is not to reify or homogenize any particular individual or group’s experience of cancer, but rather to show how socio-historically produced modes of racialization affect the experience of illness in specific situations. The process of becoming and being a cancer patient always occurs in relation to pre-existing biographies, histories, social relationships, and living conditions, all of which—at least within the social order of the contemporary United States—are shaped by histories of racial formation that continue to exert constitutive effects on the present. As Omi and Winant remind us, “We cannot step outside of race and racism, since our society and our identities are constituted by them; we live in racial

history” (2015, 137). This is as true for cancer patients and their families as it is for any of us, and the intersection of cancer and racial formation can lead to a variety of emotionally charged experiences.

Meeting Rashad, Malachi, and Tanya: A Note on Positionality and Method

The material on which this paper is based was collected during 16 months of ethnographic fieldwork with patients, families, and professionals at UCSF Benioff Children’s Hospital Oakland (BCHO).⁴ I use the term “ethnography” in a manner similar to Cerwonka and Malkki (2007, 164), who describe it as “situated, long-term, empirical field research...simultaneously a critical theoretical practice, a quotidian ethical practice, and an improvisational practice.” Ethnography involves entering a setting as a participant, forming relationships, and empirically documenting interactions, impressions, and narratives along the way.

But having said that, I want to emphasize that “empirical documentation” is far from a straightforward process. A reflexive ethnographic approach entails attention to the effects of the researcher’s positionality upon processes of empirical construction, selection, and analysis. For me, as a white male with an affiliation to an elite university, this has involved paying careful attention to the ways in which race, class, and gender shape my interactions with participants and my interpretations of data. In the interest of producing accounts that faithfully represent the experiences of the patients and families with whom I have worked, I have regularly shared my descriptions and analyses with them. This has enabled a process of dialogue through which they have been able to offer feedback and question any theoretical or empirical details.

⁴ I report on other findings from the project in my dissertation.

In the context of this particular paper, which focuses on the experiences of an African American family, the process of dialogue and relationship formation struck me as an important way to address the racist dynamic that philosopher George Yancy criticizes, wherein “Blacks only offer *experiences* while whites provide the necessary *theoretical* framing of those experiences” (2017, 52). While it was ultimately me who wrote this paper, as I got to know Rashad and his family, I have attempted to draw on their interpretations and explanatory framings, which I have placed in conversation with conventional academic theoretical framings. Although the term *theory* tends to be associated with scientists and intellectuals, academic discourse is not the only source of explanations about why the world is the way it is. All people articulate explanations that can be explored through fieldwork and used to challenge, corroborate, or complicate formal academic theories. As bell hooks reminds us, “one may practice theorizing without ever knowing/possessing the term just as we can live and act in feminist resistance without ever using the word ‘feminism’” (1991, 3).

During the months I spent doing fieldwork at BCHO, I served as a volunteer with the hospital’s team of “Child Life Specialists,” who organize therapeutic and entertaining activities for patients while they are in the hospital. This involved helping professional therapists facilitate art and music therapy groups; helping with Thursday night BINGO in the hospital’s Teen Lounge; helping with special events, such as when the Oakland Raiders came to visit the hospital; hanging out and playing games or doing art with patients at their bedsides; and other similar activities. In addition to volunteering, I also shadowed oncologists in the clinic and the hospital, and I conducted interviews with patients, parents, and a variety of professionals. Interviews focused on life histories and themes related to the social, psychological, and physical effects of cancer diagnosis and treatment. It was in this context that I met Malachi, Tanya, and

their son Rashad, who, at the time of this writing, is being treated for AML. They were one of the first families with whom I developed an ongoing relationship, and I eventually came to know Malachi very well through our regular musical collaboration.

Tanya and Malachi are no longer in a relationship, and their only child together is Rashad, although they each have two other children with other partners. Well after she and Malachi split up, Tanya and Rashad moved to Berkeley, California, when she was admitted as an undergraduate to the University of California, Berkeley to study public health. Tanya described her situation to me one afternoon:

I'm moving us to a different level of life. You talk about socioeconomic status. Mine and [Rashad's] dad's socioeconomic status is uneducated, low income, y'know, from the zip codes that have the most health disparities within San Diego. Basically from "the hood" you could say... And I'm trying to break chains. I'm trying to break cycles. I'm trying to break these socioeconomic conditions that have been with us from generation to generation.

As Rayna Rapp (1978, 182) points out, "'class' isn't a static place which individuals inhabit. It is a process determined by the relationships set up in capital accumulation." While it is true that class is not static, "the relationships set up in capital accumulation" are, in many cases, historically durable from generation to generation. In the quote above, Tanya describes her plan for class mobility in the context of longstanding cycles of dispossession; she hopes to transcend her inherited class position by getting a college education. In referring to "the hood," Tanya also emphasizes the intersection of race and class, and, in doing so, she responded to a term I had used minutes before in describing my research questions to her: *socioeconomic conditions*. In commenting on this term, Tanya offered a generational theory of her socioeconomic position in the world. It is no coincidence that she metaphorically spoke of herself as "breaking chains." As I got to know Tanya, it became apparent that she had a critical, historically informed understanding of race in the United States. For Tanya, the socioeconomic conditions she and her children have inherited are not primarily the product of any unique pathology or moral failing on

the part of herself or previous generations of her family. Rather, Tanya suggests that her family's condition is a product of American history—a history in which her ancestors were enslaved and, after the abolition of slavery, systematically prevented from accumulating capital.

I point all of this out in order to offer a sense of Rashad and his family's positionality, but also to suggest, drawing on Tanya's point, that positionality is always constituted in part by inherited relationships within racial formation, which intersects with processes of capital accumulation. The Southern California neighborhood into which Rashad was born exists as a result of the United States' history of racial discrimination and residential segregation,⁵ and the educational system within which Tanya is fighting for socioeconomic mobility is marked in various ways by attempts to delegitimize African American knowledge and intelligence.⁶

In the following sections, I will provide a series of ethnographic descriptions and interview excerpts that demonstrate Rashad and his family's positionality in relation to various aspects of racial formation. In doing so, I will emphasize the intersection of racialization and cancer treatment, showing how racial stigma and discriminatory treatment enter into the experience of illness. At the same time, as I will show below, racialization can occur in a more affirmative and therapeutic register, serving as a resource for the production of solidarity in contexts of collective struggle that have emerged out of the United States' history of racism.

⁵ According to Loïc Wacquant (2002), the African American ghetto is one among an ensemble of institutional technologies—also including slavery, Jim Crow laws, and mass incarceration—that the United States has used to contain and control the social unrest produced by the history of racism. In a later article, Wacquant (2010) suggests replacing the term “mass incarceration” with “hyperincarceration” to reflect the fact that incarceration is not a phenomenon that affects everyone uniformly. Instead, the carceral apparatus is hyper-deployed in certain racialized, gendered, and classed segments of the population, leaving poor, black men most likely to be targeted.

⁶ While Tanya is now able to leverage the university as a resource for attempting to transcend the inheritance of racist dispossession, American universities, particularly elite universities like UC Berkeley, were originally designed for wealthy men of Anglo-European heritage (Horowitz 1987). Although a great deal has changed between the time universities like UC Berkeley were founded and now, their originally exclusionary designs arguably continue to exert an effect on their contemporary functioning.

As Troy Duster (2009, 99) describes it, “for the first two-thirds of its history, American higher education had a decidedly apartheid-like character.” As historians point out, American universities have since adopted various strategies aimed at promoting campus diversity, but such strategies have not necessarily led to equitable representation or learning conditions for all groups. For example, according to UC Berkeley's Division of Equity and Inclusion, African American students represent only three percent of the student body, while African Americans represent seven percent of the state population (UC Regents, 2018).

Black Skin, Prophylactic Masks

Since cancer treatment often involves extended periods of time in which patients' immune systems are severely compromised, many patients are instructed to wear a prophylactic mask when they are out in public. Most young people I met were not excited to have to wear these masks, and for some it caused a great deal of anxiety. In attempts to make this a slightly less unpleasant experience, the hospital offers facemasks made out of durable, washable cloth, as opposed to the disposable masks that healthcare professionals wear. Some of these facemasks have colorful designs, while others are more low profile solid colors. One day, Rashad was with his father at Walgreen's to pick up his medication, and he was wearing a hoodie and a facemask. A store employee approached him suspiciously and asked him why he was wearing a mask. "I have cancer..." he responded. "Oh, sorry," the employee said awkwardly and walked away.

After the interaction, Rashad was confused. He described the situation to Malachi, asking why the man approached him so aggressively and why he drew attention to his mask. Malachi explained to him that the man probably thought he was going to rob the store, and this made Rashad angry and upset. Malachi tried to console him by saying that maybe the man had had a previous experience with someone wearing a mask trying to rob the store, but Malachi also expressed frustration that perhaps the man had racially profiled his son. "I mean, I like to give people the benefit of the doubt," he vented. "But if that woulda been a little white kid wearin' a mask you think he woulda said that shit? Doubt it."

Tanya also expressed concern about people racially profiling Rashad as dangerous or criminal because of his mask. She described how the stress of wearing the mask went away for a while when there were wildfires blazing nearby in Napa Valley:

When we had the fires, people stopped staring at him with the mask because everyone was walking around with a mask. He was in heaven. He loved it. He was like “Everyone has on masks, nobody’s staring at me ‘cause they think it’s from the fires!” But then the fires cleared up, and he’s the only one walking around with this mask, and people were staring at him. I noticed it a couple times with some store clerks, but I’d just give ‘em that mom stare like “Don’t even think it. You’re gonna have to deal with mama bear.”

In addition to being racially profiled and stared at in stores and other public spaces, Rashad also felt stigmatized and shunned by some of the other children who lived at The Summit, a university-operated apartment complex for families.

A couple of times he’s come in from outside crying, because before people didn’t used to see him as the black kid at The Summit. We have a lot of international students, a lot of Chinese kids. And before, it was just like kids playing outside. But once he had the bald head, and the mask on his face, *and* he was black, then it was just too much. And the thing about it is, what they don’t realize is that they would say things in Mandarin, but Rashad understands some Mandarin, and he heard someone say, “Get away from that black boy!”

As Tanya describes, the mask and the effects of treatment on Rashad’s appearance seemed to make his race more salient to the other children at The Summit. Tanya also expressed worry that Rashad was more likely to be seen in a negative light as he gets older and grows physically larger and more mature.

I swear he’s grown about a foot in the past year... I heard a lady somewhere on a show talking about it, and the lady was like “Before when my son was young he was a cute little black boy and everybody from every race would be like, ‘Oh he’s such a cute little black boy!’ But now that he’s a teenager, nobody thinks he’s cute anymore.” So it’s that type of situation.

As all of these examples demonstrate, Rashad and his family have inherited existential conditions in which black bodies—particularly those also marked as male and adolescent or adult—are often recognized as relatively prone to danger and criminality. As Rashad, Malachi, and Tanya move through the world, they must negotiate interactions and situations that are imbued with this heritage. It is always possible that their bodies and selves will be evaluated negatively on the basis of anti-blackness, and at certain moments these evaluations may give rise to more consequential outcomes than others.

In *Black Skin, White Masks*, Frantz Fanon, who died at 36 of leukemia, discusses the “fact of blackness” (2008, 82). For Fanon, blackness is a fact, but it has nothing to do with so-

called “natural” properties of bodies. Rather, it is an unavoidable existential condition that has been thrust upon black people by the white world. In order to demonstrate the experience of confronting blackness, he offers a story in which he boards a train in France, and a white child addresses him with racial epithets and amusement, which then melted into fear. The boy expressed concern to his mother that Fanon was going to eat him. The boy’s mother apologizes to Fanon: “Take no notice, sir, he does not know that you are as civilized as we...” Reflecting on the situation Fanon describes his experience: “On that day, completely dislocated, unable to be abroad with the other, the white man, who unmercifully imprisoned me, I took myself far off from my own presence, far indeed, and made myself an object. What else could it be for me but an amputation, an excision, a hemorrhage that splattered my whole body with black blood?” (2008, 85).

In his analysis of this scene, philosopher George Yancy suggests that, although the young white boy presumably did not know that his words and actions would affect Fanon the way they did, he nevertheless voiced a common white perception of blackness as savagery. In doing so, he became a representative of white society, which had molded his very existence. In many ways, Fanon’s experience of racialization on the train is analogous to Rashad’s experiences at the store, as well as with the other children at his apartment community. In being treated with fear and suspicion, Rashad was forced to confront stigmatized images of himself that he had no hand in creating. At the same time, it was also not the children at his apartment complex or the security guard at the store who *created* these images of blackness as danger and criminality. Rather, stigmatized images of blackness can be traced back to the “bipolar black-white racial opposition” (Ong 2003) that served as a founding condition of the United States, and which continues to resonate today. Such images remain available for citation in both thought and speech, and, as

Yancy (2017) points out above, they can condition affect in ways that shape perception and social interaction.

Although the security guard presumably did not know that he was going to scare and hurt the feelings of a child with cancer, he nevertheless insinuated—or at least was easily read as insinuating—a perception of blackness as criminality. Unlike the boy who Fanon encountered on the train, or the children at Rashad’s apartment complex, the security guard did not verbally racialize Rashad, and he did not overtly accuse Rashad of theft. But his aggression and suspicion were palpable, and Malachi could not help but feel that Rashad’s race had something to do with this. This was no doubt related to Malachi’s and his son’s previous experiences of racial profiling and criminalization, which I will discuss in the following section.

Black Masculinity and the Specter of Young Death

Here is what I would like for you to know: In America it is traditional to destroy the black body—it is *heritage*.

-Ta-Nehisi Coates, addressing his son in *Between the World and Me* (2015, 103)

One day at the hospital, after talking about our mutual love of music, Malachi suggested that we start a “hospital band.” At first I thought he was joking, but I later learned that he was seriously interested in making music for artistic and therapeutic reasons, so we started meeting every Friday morning to write and record songs. Afterwards, we would usually eat lunch and talk about whatever was on our minds at the moment. Most the time, these conversations were spontaneous and would cover a huge range of topics. Other times, I would go into anthropologist mode and ask more targeted questions.

One day while we were playing music, I was thinking about Lochlann Jain’s book *Malignant*. Jain, who is a cancer survivor, suggests that one reason cancer diagnosis is so

shocking to most people who endure it is that it disrupts commonly held “ideologies of life span.” Jain emphasizes the relationship between individuals and the inherited institutional orders that shape the form and content of life trajectories, arguing that the shock of cancer diagnosis is exacerbated by “a collision in modes of time” (2013, 101). On the one hand, there is the timeline of the individual life span, which is typically imagined as a series of normative biographical events: for example, birth, naming, starting school, high school graduation, marriage, parenthood, retirement, etc. On the other hand, there is what Jain refers to as the “immortal time” of various systems, such as states, schools, and employers. As individual, embodied persons flicker in and out of existence, these systems hum along in seeming perpetuity, promoting future-oriented forms of investment and accumulation. For those affected by cancer, the perpetual pulsations of institutional time can serve as a reminder that one may be forced out of one’s particular position in the dramas of social life before one is ready to leave.

Although I certainly saw Jain’s argument play out among families at BCHO, it also became obvious that not all families embodied the kinds of optimistic “ideologies of life span” Jain describes. Young mortality, whether it is caused by violence or disease, does not occur with the same frequency across the racialized, classed, and gendered populations that inhabit the United States. With this fact in mind, I asked Malachi if he had known anyone who had died young. In response, he described the blatant presence of young mortality in the Southern California neighborhood where he grew up. He described the experience of having close friends die young, and of his family worrying about him getting caught up in a situation of police brutality or gang violence. I asked him how often he worried about his own sons dying young or facing violence. He responded:

Oh everyday. So Malachi Jr., he just turned 23. With him it’s the hothead rebel attitude. So I worry that, even though he might be doing something justified to defend himself, he doesn’t know how to be too diplomatic... It might be the police, or it could be somebody else. But just his defensive nature... I worry

about him thinkin' he's gotta prove himself. Like he's gotta prove he's not soft because of how he looks. He's biracial, so they automatically assume, "Oh, here comes white boy. He's soft. He's a chump. We could just walk all over him." But he's just so against that stereotype. He's just all ARRGGGH!

He grit his teeth and made fists, imitating Malachi Jr. in a fit of rage at the idea of being emasculated by other young men. "And then there's the police..." He proceeded to tell a story in which he and Malachi Jr. were racially profiled by the police, but he got them out of it by going into what he called "diplomatic dad mode" and deploying his personal connections with a particular police sergeant.

As I listened to Malachi describe his worries, I was struck by the extent to which his concern focused on his oldest son, Malachi Jr. I assumed that his lack of focus on his youngest son, Prince, was due to the fact that Prince is still a baby and not yet likely to be the target of violence, but I asked him if he worried about Rashad, who is almost a teenager, confronting similar issues. He replied:

Oh, of course he still is gonna have to worry about it. [But right now] it's like, what if he doesn't make it to be Malachi Jr.'s age? Those fears are irrelevant. Because, right now, his biggest fight is the leukemia, and then once we get rid of it, [we have to make sure it] doesn't come back. Because that's something he's gonna have to get checked for for a loooong time. And that fear's gonna always be there in the back of our heads, because any form of cancer could come back. But then on top of it, to have to have that conversation with him of... you might not make it. Because I had never had that conversation with him, like ever, ever. Like with Malachi Jr., I've had to be real like "Homie, you keep actin' like you're actin', and somebody's gonna take your ass out." But with Rashad, you can't even put that possibility out there. I mean, he came to me with it: "Dad, I'm scared I'm gonna die." I had to just be like, "Ain't gonna happen. God didn't bring us this far to leave us." That's when that faith kinda makes you just kinda... [deep sigh]. Ok, let me just give it to God.

As this quote shows, it is not only fear of death by cancer that affects patients and families, although this fear is always just beneath the surface and may surge forth at any moment. For many people, living with cancer, whether in one's own body or in the body of a loved one, indeed comes with constant reminders of the possibility of early death, but it also generates thoughts of an altered future. After all, many young cancer patients end up cured of their initial malignancies and live for decades after treatment. But as Malachi's words reflect, life post-malignancy is profoundly altered. In many ways, the experience of cancer treatment leaves

indelible traces in the bodies and subjectivities of patients and their loved ones. In both positive and negative ways, the effects of oncological medicine can totally rework a person's visions and plans for the future.

As Malachi's words demonstrate, the temporal collision to which Jain refers does not only occur in relation to institutions that are typically framed as beneficial to the subject—e.g., families, schools, and employers. What Malachi describes above is also a collision in modes of time with the carceral state and the prison industrial complex, which constitute a predatory and violent inheritance for black families in the United States today (see Wacquant 2010, 2009, 2002; Alexander 2010). Malachi suggests that, for him, cancer diagnosis has enacted a temporary reduction of anxiety about Rashad's potential exploitation by the prison-industrial complex. Right now, that is not the first thing on his mind. Instead, his primary concern for Rashad is that he makes it through treatment.

Blackness, Cancer, and the Expression of Negative Emotions

Cancer diagnosis may have made Malachi slightly less anxious about the possibility of Rashad being affected by the violence of police and gangs, and the spatial isolation imposed by cancer treatment may actually act as a mechanism through which the chances of subjection to these forms of violence may be reduced. But there are nevertheless ways in which the intertwined logics of racialization and criminalization find their way into even the most isolated treatment environments, such as the hospital's immunocompromised unit, where patients and family members live during the most intensive phases of treatment, and during acute moments of illness, such as when patients acquire infections.

One day, a few weeks after his stem cell transplant, Rashad was hanging out in the 5 South playroom with his dad and a nurse. Rashad was not particularly fond of this nurse, as she had previously hurt his feelings by jokingly calling him a “bed bum” one day when he slept until noon. Although according to Malachi the nurse meant well, she had overstepped the boundaries of her relationship with Rashad, attempting to joke in a moment when he didn’t feel like joking, especially at his own expense. On this day, the nurse was talking to Malachi and Rashad about another patient who they all knew, another African American boy named Devon, who had a reputation on the unit as being tough and untalkative. The nurse, a white woman, jokingly referred to Devon as a “little street thug.” In using the term “thug,” the nurse cited a complex history of criminalization and resistance, and this triggered intense emotions in Rashad and Malachi, who both identified with Devon on an ontological level. After the fact, Rashad reflected on the situation, suggesting that the nurse had racialized Devon’s intensely negative reaction to cancer diagnosis and treatment.

[Devon] was sad, disappointed, and enraged with his situation. So I think it’s uncalled for for a nurse to go to another patient and be like “Oh my goodness there’s this patient...” She said he was a “thug” or “ghetto” or something like that, and that’s upsetting because it’s an emotional experience and everybody deals with it differently, so I don’t think it’s right for her to judge him like that, when this might just be his reaction to having a life-threatening disease... I mean, there’s other kids who respond that way, and she doesn’t call them thugs.

Malachi was also taken aback by the nurse’s choice of words. He reflected on the situation to me: “How are you gonna call a kid with cancer ‘a little street thug,’ especially right to the faces of two black males?!” He asked indignantly. “I mean, the kid is hard, but I would have chosen different words. Something like, ‘Oh, yeah, that Devon, he’s pretty stoic.’” Despite Malachi’s frustration, he decided to let the interaction slide, and he said nothing to the nurse. “I think she’s just got a fucked-up sense of humor,” he said. “She’s good people though.” But then, afterward, Rashad expressed anger at Malachi. “Dad, why didn’t you say something to her?” he

asked. “What if it was me she was calling a street thug?” Malachi later decided to report the nurse to her superior.

In many ways, Rashad’s diagnosis of the situation echoes the work of historian Keith Wailoo (2011), who shows how ideas about who is affected by cancer and how have changed dramatically over time in the United States. In the early twentieth century, many scientists and medical professionals viewed cancer as a disease of modernity that primarily affected wealthy, white women. African Americans, on the other hand, were viewed as immune to the disease due to a supposedly primitive biological constitution. Cancer awareness campaigns reflected this racialized, gendered, and classed view, often focusing on the experiences, worries, and concerns of wealthy, white women. By the 1950’s, ideas changed, and cancer became seen as a democratic disease that affected all races, classes, and genders. Yet it would be two more decades until the rhythm and blues singer Minnie Riperton became one of the first widely recognized African American cancer awareness advocates and a broad public was exposed to the cancer narrative of an African American person for the first time. As Wailoo points out, even as cancer awareness discourses began to recognize the fact of African American cancer, they nevertheless portrayed African Americans as “the colored multitudes,” lacking in the kind of individual psychological depth and complex inner experiences that were often attributed to white people (Wailoo 2011, 179).

This is precisely what Rashad felt the nurse had done to Devon by racializing his negative emotions and reducing him to a “thug” with a bad attitude, as opposed to a terrified young person with a life-threatening disease. Of course, as Malachi generously observed, the nurse may have been joking. There may have been no malicious intent behind her comment. The point here is not to condemn the nurse, but to recognize the impact of her words on Rashad and

Malachi, and to show how such statements, joking or not, resonate with the historical intersection of racial formation and cancer awareness described by Wailoo (2011). The delegitimization of African American emotional experience is not a new cultural pattern, and it continues to shape institutions, social interactions, and subjectivities in both overt and covert ways.

In the following section, I will describe an event at which Malachi and Rashad attempted to raise cancer awareness in the African American community by sharing their story and urging attendees to donate bone marrow. In doing so, Rashad and Malachi also attempted to challenge negative stereotypes of black men—the same kinds of stereotypes the nurse had applied to Devon.

Cancer Awareness and Resistance to Anti-Black Stereotypes

One weekend I went to a historic black-owned bookstore in Oakland to hear Malachi and Rashad speak. Earlier in the week, Malachi had given me a flier for the event. The main part of the event would be a presentation by a professor from a local community college. Malachi and Rashad were scheduled to open the event with a short testimony about Rashad's diagnosis and the importance of bone marrow donation in the African American community. As I walked up to the entrance, I saw Malachi talking to another African American man. Malachi looked over toward me and nodded his head in a greeting. "Hey, Professor, I wanna introduce you to another professor," Malachi said to the man. I laughed and told them that I wasn't a professor—just a lowly graduate student. The man laughed and introduced himself as Dr. Khalid Akil White, a professor from a local university. I introduced myself and asked him about the topic of his research. He responded that he was a professor of ethnic studies, and he had just published a

book on the struggles and joys of black fatherhood (White 2016). He would be presenting some stories from the book later in the evening after Malachi and Rashad spoke.

After chatting for a while, we all entered the bookstore. There were about 10-15 people inside sitting in several rows of chairs that were set up for the event, I saw Rashad in the front row playing a handheld videogame. I went and sat beside him. “Hey Rashad,” I said as I sat down. “Hey,” he replied, barely taking his eyes off of the screen. He played for five to ten more seconds, then pressed pause. I asked him if he was ready to speak, and he responded unenthusiastically: “Yeah, I guess.” Earlier in the week Rashad had commented that Malachi was “making” him speak at the bookstore. When I later mentioned Rashad’s comment to Malachi, he laughed in an understanding way and said, “Ah, I knew he didn’t really wanna do it, but it was good for the little homie. He’s gotta learn how to give his testimony.” As I learned, Malachi views the ability to eloquently communicate and give one’s testimony as an essential skill for black men navigating a racist world. This is also reflected in the quote in the section above, where Malachi stresses the importance of diplomacy with the police as a method of avoiding violence. As a father, he saw it as his duty to pass these communicative skills on to his sons. From Malachi’s perspective, this was not simply an attempt to transmit “good manners,” but rather a survival strategy, in both a social and physical sense.

After a few minutes, the older woman who ran the bookstore announced that the event was starting. She thanked the crowd for attending and introduced Malachi and Rashad. There was a round of applause, and Rashad stood nervously next to his father, who placed his arm around him in a firm embrace. In a quiet but steady voice, Rashad introduced himself, telling the crowd about his recent diagnosis and the stem cell transplant he would soon undergo. Malachi then introduced himself, telling the crowd that he was a proud father of three boys, including

Rashad. He explained that they were lucky because one of Rashad's brothers was "a match" and could serve as a stem cell donor for the transplant. "But a lot of people aren't so lucky," he continued, explaining to the crowd that people of color are underrepresented in bone marrow banks. "So if y'all ever get a chance to donate marrow, please do it. It's extremely important for this disease and a lot of other diseases," Malachi urged the crowd. He and Rashad then thanked the bookstore and the crowd, and Malachi introduced Professor White.

Malachi and Rashad took their seats as Professor White greeted the crowd. He opened by noting the 2014 murder of 18-year-old Michael Brown by police officer Darren Wilson in Ferguson, Missouri. He described how upsetting it was for him to see young black men like Brown getting assaulted and killed by police—a problem which he knew was as old as the United States. "I felt it personally," he said. "That could have been me or one of my students." He felt he had to try to do something to change the situation. He explained that part of the problem is that mainstream media and entertainment outlets bombard people with stereotypical representations of black men: "There are all these mainstream narratives about black boys and men being criminals and black fathers being absent deadbeats. But think about the people you know. I personally know many black men who love and support their children."

Professor White proceeded to describe some of the stories told in his book. He emphasized the difficulties faced by black men as they enter fatherhood, and each story featured an inspiring example of a black man rising to the task. At the same time, the stories were not sanitized. They did not shy away from addressing the trials and moral conundrums faced by each man as he went through the difficult process of leaving behind adolescent fantasies of stardom and material and sexual conquest—fantasies that act as engines of consumerist capitalism and are of course not unique to young black men. Professor White insisted that telling these kinds of

stories was necessary in order to reframe the national conversation about black masculinity and fatherhood and to de-stigmatize black boys and men as a group.

After Professor White finished his talk, he opened the floor up for questions and comments. A number of audience members, primarily other black men, expressed their gratitude to Professor White, thanking him for discussing such an important issue. They were all intimately familiar with the stigmatized existential condition of black masculinity, and they were all concerned to disprove racist stereotypes by rising above the negative expectations they see reflected in hegemonic constructions of black men. In a sense, this is what Malachi and Rashad were doing by giving their testimony at the event. By standing in front of a crowd as a father-son unit and urging those present to donate bone marrow, Malachi and Rashad were simultaneously publicly affirming the value of African American masculinity and kin relations, as well as implicitly rejecting racist narratives of morally bankrupt black fathers who fail their children.

Conclusion: Cancer, Racial Formation, and the Sociogenetic Body

Reacting against the constitutionalist tendency of the late nineteenth century, Freud insisted that the individual factor be taken into account through psychoanalysis. He substituted for a phylogenetic theory the ontogenetic perspective. It will be seen that the black [person's] alienation is not an individual question. Beside phylogeny and ontogeny stands sociogeny.

-Frantz Fanon 2008, 4

In this paper, I have emphasized the intersection of racial formation and cancer treatment by exploring the case of Rashad and his parents as they navigate experiences of racialization in the context of cancer diagnosis and treatment. Processes of racial formation can be constructive and affirmative—for example, the longstanding heritage of black resistance that served as a source of inspiration at the bookstore event. But constructive forms of resistance always exist in relation to violence, exploitation, and stigmatization. Malachi's worries about his sons being

subjected to violence, Rashad's experiences of stigmatization and criminalization, and Tanya's concerns about the social effects of physical maturation are all related to the antagonistic history of anti-blackness in the United States.

All of these examples also demonstrate the entanglement of inherited biogenetic and sociogenetic processes. While the genes that Rashad inherited from Malachi and Tanya no doubt played a role in producing the cancer that led him to seek medical care, it is also plainly the case that the inheritance of an African American, male positionality shaped his experience of the illness and treatment process in a profound way. As his body changed in response to treatment, Rashad became increasingly sensitized to the dangers and liabilities of moving through the world as a young black man. In many ways, the stigma of cancer compounded racial stigma and vice-versa. This led to a series of stressful and frustrating situations that Rashad and his family had to navigate at the same time as they were navigating cancer treatment.

In emphasizing the entanglement of inherited biogenetic and the sociogenetic processes in cancer diagnosis and treatment, I also want to point out that there is more at stake than a patient and family's experience of illness, which biomedicine cordons off in the domain of the "psychosocial." As noted earlier, African American children and teens have the lowest rates of surviving cancer of any ethnoracial group. Human bodies and the diseases and illness experiences to which they are susceptible are as much a product of what Frantz Fanon called *sociogeny* as they are of what biologists refer to as *ontogeny*. While ontogeny stresses the biological development of individual bodies, sociogeny stresses the development of bodies and subjectivities within socio-historically formed institutional fields and relations of wealth and power. As Scheper-Hughes and Lock note, the body is "simultaneously a physical and symbolic artifact...securely anchored in a particular historical moment" (1987, 7). Biogenetic and

sociogenetic processes converge in the constitution of cancer treatment, outcomes and illness experiences.

Works Cited

- Alexander, Michelle. 2010. *The New Jim Crow: Mass Incarceration in the Age of Colorblindness*. New York: New Press.
- Cerwonka, Allaine, and Liisa Malkki. 2007. *Improvising Theory: Process and Temporality in Ethnographic Fieldwork*. Chicago: University of Chicago Press.
- Coates, Ta-Nehisi. 2015. *Between the World and Me*. New York: Spiegel & Grau, Random House.
- Cordova, Matthew J., Michelle B. Riba, and David Spiegel. 2017. "Post-Traumatic Stress Disorder and Cancer." *The Lancet Psychiatry* 4: 330–38.
- Du Bois, W. E. B. 2007[1940]. *Dusk of Dawn: An Essay Toward an Autobiography of a Race Concept*. Oxford W.E.B. Du Bois. Oxford ; New York: Oxford University Press.
- Duster, Troy. 2003. *Backdoor to Eugenics*. 2nd ed. New York: Routledge.
- _____. 2009. "The Long Path to Higher Education for African Americans." *The NEA Higher Education Journal*, no. Fall: 99–110.
- Erickson, Sarah J., and Hans Steiner. 2000. "Trauma Spectrum Adaptation: Somatic Symptoms in Long-Term Pediatric Cancer Survivors." *Psychosomatics* 41 (4): 339–46.
- Fanon, Frantz. 2008. *Black Skin, White Masks*. Translated by Charles Lam Markmann. London: Pluto Press.
- Fujimura, Joan H. 1996. *Crafting Science: A Sociohistory of the Quest for the Genetics of Cancer*. Cambridge, Mass: Harvard University Press.

- Haraway, Donna. 2003. *The Companion Species Manifesto: Dogs, People, and Significant Otherness*. Vol. 1. Chicago: Prickly Paradigm Press.
- hooks, bell. 1991. "Theory as Liberatory Practice." *Yale Journal of Law & Feminism* 4 (1): 1–12.
- Horowitz, Helen Lefkowitz. 1987. *Campus Life: Undergraduate Culture from the End of the Eighteenth Century to the Present*. New York: Knopf Doubleday.
- Jain, S. Lochlann. 2013. *Malignant: How Cancer Becomes Us*. Berkeley, CA: University of California Press.
- Kuzawa, Christopher W., and Clarence C. Gravlee. 2016. "Beyond Genetic Race: Biocultural Insights into the Causes of Racial Health Disparities." In *New Directions in Biocultural Anthropology*, 89–106. Hoboken, NJ: Wiley Blackwell.
- Latour, Bruno. 1993. *We Have Never Been Modern*. Translated by Catherine Porter. Cambridge, MA: Harvard University Press.
- Livingston, Julie. 2012. *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic*. Durham, NC: Duke University Press.
- Lock, Margaret. 2013. "The Epigenome and Nature/Nurture Reunification: A Challenge for Anthropology." *Medical Anthropology* 32 (4): 291–308.
- Lucile Packard Foundation for Children's Health. 2018. "Childhood Cancer Diagnoses, by Race/Ethnicity and Age." Kidsdata.org. 2018. <http://kidsdata.org/topic/247/cancer-race/bar>.
- Mukherjee, Siddhartha. 2010. *The Emperor of All Maladies: A Biography of Cancer*. New York: Scribner.

- National Cancer Institute. 2017. "Childhood Acute Myeloid Leukemia/Other Myeloid Malignancies Treatment (PDQ®)–Health Professional Version." National Cancer Institute. 2017. <https://www.cancer.gov/types/leukemia/hp/child-aml-treatment-pdq>.
- Omi, Michael, and Howard Winant. 2015. *Racial Formation in the United States*. Third edition. New York: Routledge/Taylor & Francis Group.
- Ong, Aihwa. 2003. *Buddha Is Hiding: Refugees, Citizenship, the New America*. Berkeley, CA: University of California Press.
- Rapp, Rayna. 1978. "Family and Class in Contemporary America: Notes toward an Understanding of Ideology." *Science & Society*, 278–300.
- Rouse, Carolyn Moxley. 2009. *Uncertain Suffering: Racial Health Care Disparities and Sickle Cell Disease*. Berkeley: University of California Press.
- Sarkar, Suman. 2008. "Artificial Blood." *Indian Journal of Critical Medical Care*. 12 (3): 140-144.
- Scheper-Hughes, Nancy, and Margaret M. Lock. 1986. "Speaking 'Truth' to Illness: Metaphors, Reification, and a Pedagogy for Patients." *Medical Anthropology Quarterly* 17 (5): 137–40.
- _____. 1987. "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology." *Medical Anthropology Quarterly* 1 (1): 6–41.
- Surveillance, Epidemiology, and End Results Program. 2018. "Acute Myeloid Leukemia - Cancer Stat Facts." National Cancer Institute. 2018. <https://seer.cancer.gov/statfacts/html/amyl.html>.

UC Regents. 2018. "Diversity Data Dashboard." UC Berkeley Division of Equity and Inclusion.

<https://diversity.berkeley.edu/reports-data/diversity-data-dashboard>.

Wacquant, Loïc. 2002. "From Slavery to Mass Incarceration: Rethinking the 'Race Question' in the US." *New Left Review* 13: 41–60.

_____. 2009. *Punishing the Poor: The Neoliberal Government of Social Insecurity*. English. Durham, NC: Duke University Press.

_____. 2010. "Class, race & hyperincarceration in revanchist America." *Daedalus* 139 (3): 74-90.

Wailoo, Keith. 2011. *How Cancer Crossed the Color Line*. Oxford: Oxford University Press.

White, Khalid Akil. 2016. *Black Fatherhood: Trials & Tribulations, Testimony & Triumph*. Oakland, CA: BLKMPWR LLC.

Yancy, George. 2017. *Black Bodies, White Gazes: The Continuing Significance of Race in America*. Second Edition. Lanham: Rowman & Littlefield.

Young, Allan. 1995. *The Harmony of Illusions: Inventing Post-Traumatic Stress Disorder*. Princeton, N.J: Princeton University Press.



Institute for the
Study of
Societal Issues

2420 Bowditch St. # 5670
Berkeley , CA 94720-5670

tel: 510-642-0813

fax: 510-642-8674

email: issi@berkeley.edu

web: <http://issi.berkeley.edu>