

ARTICLE

Bioethical Matriarchy: Race, Gender, and the Gift in Genomic Research

James Doucet-Battle
University of California, Santa Cruz
jbattle@ucsc.edu

Abstract

The 2013 sequencing of the epigenome and genome from Henrietta Lacks's HeLa cell line illuminates the bioethical intersections of genomics, race, and gender. Subsequent announcements by Francis Collins and reports in the scientific media referring to Henrietta Lacks as a *matriarch*, expose the missing political and resource allocations alluded to by the quasi-viral matriarchal designation, an assemblage I term *bioethical matriarchy*. Drawing from field, media, biomedical archival research, I am concerned with the ways African-descent and matriarchal status reproduce the social order, reflecting racialized and gendered histories of kinship, desire, and status inequality. I address these concerns through an anthropological engagement with African American/Diaspora studies and Feminist technoscientific scholarship in both the social sciences and humanities. I build on Richard Hyland (2014), by arguing that unequal and gendered forms of exchange (re)produce wealth and obligations to give, but not necessarily to reciprocate. I discuss why the bioethical, intellectual property, and legal implications of these asymmetrical relationships necessarily take our discussion beyond issues of consent and inclusion to engaging larger questions of reparative and restorative justice.

Doucet-Battle, J. (2016). Bioethical matriarchy: Race, gender, and the gift in genomic research. *Catalyst: Feminism, Theory, Technoscience*, 2(2), 1-28

<http://www.catalystjournal.org> | ISSN: 2380-3312

© James Doucet-Battle, 2016 | Licensed to the Catalyst Project under a Creative Commons Attribution Non-Commercial No Derivatives license

Introduction

(Now) the director of the US National Institutes of Health (NIH), Francis Collins, is trying to make up for decades of slights. Over the past four months, he has met Lacks family members to answer questions and to discuss what should be done with genome data from their *matriarch's* cell line.

(Callaway, 2013, p. 132, emphasis added)

Narratives—socializing stories—that are attached to all women and blacks of both genders have an inordinate control over the potential for private personhood. The public controls of race and gender are so robust that private individuation is rarely an opportunity for those whose identities fall within these two social constructs.

(Holloway, 2011, p. 7)

Is that where the manhood lay? In the *naming* done by a white man who was supposed to know? Who gave them the privilege not of working but of deciding *how* to?

(Morrison, 1998, p. 147, emphasis added)

In a letter to the journal *Nature* on August 8, 2013, a research team led by Andrew Adey, Joshua Burton, and Jacob Kitzman from the Department of Genome Sciences at the University of Washington, Seattle announced the successful mapping of the genome and epigenome of the HeLa cell line.¹ This development occurred less than seven months after a German research group directed by Lars Steinmetz published data in an open access journal detailing the first successful genomic sequencing of a HeLa cell line.² These accomplishments promised to change the way researchers understood environmental adaptation and energy regulation as metabolic processes of genetic mutation. This advance could possibly shed new light on the causative factors and mechanisms underlying the

development of Type 2 diabetes and other cardiometabolic disorders.

However, the international research community, particularly the National Institutes of Health, harbored concern about what the new discovery might mean for future research. Although the German team removed the online data, the family of Henrietta Lacks, who was the original source of the HeLa line, was especially concerned about the ethical implications of these discoveries. It seemed the scientific community was once again producing wealth and knowledge from the HeLa cell line without acknowledging its fraught history of bodily appropriation. As chronicled by Hannah Landecker (2000) and Rebecca Skloot (2011), the HeLa cell line was commodified without the knowledge of Lacks's family at a time when informed consent was not yet a legal norm. This time, however, the Lacks family demanded economic justice. In a statement released the day before the announcement, Francis Collins, director of the NIH, sought to reconcile the newly mapped HeLa line with the Lacks's demands:

Just like their *matriarch*, the Lacks family continues to have a significant impact on medical progress by providing access to an important scientific tool that researchers will use to study the cause and effect of many diseases with the goal of developing treatments.

(National Institutes of Health, 2013, August 7, emphasis added)

On closer reading and for the purpose of this article, the statement "Just like their matriarch, the Lacks family continues to...provid[e] access" reveals a vexed engagement with HeLa's history. Although Henrietta Lacks's consent to the use of her cervical cancer cells beyond the diagnosis and treatment of her condition was not required, the phrase "providing access" implies that she did. Collins's statement frames the family as a biological resource and locates labor value squarely within researcher expertise, reproducing HeLa's history of racialized and gendered forms of labor, kinship denial, and commodification that are often disavowed. Together, these issues make the intersections between genomics, race, and gender a fundamentally bioethical relationship.

Engaging with scientific and media narratives about Henrietta Lacks

and HeLa, this article charts the ways genomic research have facilitated the re-emergence of a particularly thorny term: *matriarchy*. Within the bioethical nexus of genomics, race, and gender, the invocation of matriarchy in these narratives makes the private “public,” a process Karla Holloway (2011) argues constitutes a control of race and gender (p. 7). Hence, they belie racialized gender constructs based on African descent that are rooted in socioeconomic history, revealing political and resource allocations erased by the matriarchal label and which I term *bioethical matriarchy*. In this sense, investigating bioethical matriarchy departs from Max Weber’s (1910) century-long call for an analysis of technology separate from an analysis of the “property relations” among economic actors (Weber, 2005, p. 27).

I make two arguments: 1) Although race and gender have occupied much scholarly and media attention, matriarchy, specifically black matriarchy, as both a racial and gender construct of otherness, has remained under-analyzed but yet routinely deployed in the social sciences, politics, and humanities; 2) Underlining patriarchal gift economies of exchange, bioethical matriarchy (or the bioethical matriarch) marks racialized and gendered forms of exchange arising from the absence of consent or of obligational precedents for reciprocation. Three fundamental questions drive this article’s inquiry: 1) What do novel matriarchal genomic origin narratives tell us about embedded racialized and gendered forms of exchange and their historical intersections with socioeconomic status and inequality?; 2) How are race, gender, and the social order reproduced or *regenerated* as a productive economic construct?; and 3) Can restorative or reparative justice render the bioethical matriarch whole? Arguably, the bioethical matriarch is positioned as *not whole*. As this essay will show, Henrietta Lacks’s matriarchal status derives not from any real power Lacks may have had, but from HeLa’s subsequent notoriety gained recursively as a fragmentary biospecimen.

To examine these questions, I build on previous ethnographic research conducted on Type 2 diabetes and race in New York and Northern California, and new ethnographic and archival fieldwork in

Baltimore, MD and Washington D.C. exploring the underlying role of race in both genomic and global health disparities research.³ I suggest that deconstructing the matriarch-status ascription addresses the intersections of genomics, racial labor, and gender beyond their component social, political, and biological parameters. At stake is whether the political and economic power enfranchising inherited rights to resources accrue to the matriarch as a result of this exchange.

The racial bioethics of the gift

Classical anthropology defined gift exchange as a circulation of property that sets in motion obligations to give, receive, and reciprocate (Malinowski, 1922; Mauss, 1990). Early functionalist projects focused on exchange as a social and political lens through which the value of the gift was seen as secondary to the function it served in cementing human relationships. However, women and slaves have each been exchanged historically as both fungible gifts and property (Du Bois, 1924; Strathern, 1988). W.E.B. Du Bois's (1924) theorization of *the gift as racial labor* preceded Mauss's notion of the gift as *political* (Mauss, 1990). I read Du Bois's definition of the gift alongside Catherine Waldby and Robert Mitchell's (2006a) account of 21st century "tissue economies," in which cells and tissues are transferred from poor, socially and economically disadvantaged "surplus" bodies to the wealthy and powerful in society, a transfer rationalized by narratives of citizenship and civic duty (Waldby & Mitchell, 2006b, pp. 56-57). And like Du Bois, Waldby and Mitchell put forward a redistributive and regenerative political economy for bodies made deficient in their material appropriation. Participatory inclusion by the poor and disadvantaged, particularly women, highlights Joan Scott's (1986) insistence upon placing gender front and center in any historical analysis of labor. Additionally, I bring the notion of racialized forms of gendered labor as fungible, or exchangeable property, to bear on Richard Hyland's (2014) assertion that gift-giving and exchange occur in sociocultural spaces outside and in spite of legal or moral sanction, where

according to Karla Holloway (2014), “the evolution of legal text did not...fully and /or finally determine social act” (p. x).

Outside of critical race and feminist studies and the medical humanities, few scholars have engaged the ways notions of patriarchy both inform conditions of exchange and misrecognize affective kinship structures.⁴ HeLa and its embeddedness in slavery’s historical rupturing of personhood generally and motherhood specifically, troubles neat scholarly notions of gift exchange, reciprocation, and consent, by introducing a body that has historically constituted a “point of convergence where biological, sexual, social, cultural, linguistic, ritualistic, and psychological fortunes join” (Spillers, 1987, p. 67). Racial and gender constructs overdetermine notions of individual sovereignty and subjectivity for women and blacks, whose bodies always have “a compromised relationship to privacy (Holloway, 2011, p. 9).

Genomic science offers new opportunities to make private bodies public, often under the neoliberal banner of individual sovereignty. Sometimes this sovereignty is defined in terms of an “inclusion-and-difference” paradigm, which is driven by older epistèmes circumscribing group difference in terms of biologically ascertainable “races” (Epstein, 2007, pp. 6-7). However, “race” is still often rendered a genotypically-fixed feature of the body (or a stable category, in equilibrium) that is scientifically discoverable, rather than an elusive or illusive target. This presents an intractable form of social and scientific classification that Alondra Nelson (2008) suggests has created new forms of social meaning around identity. Genetic tests as a commodity offer new tools for “self-fashioning” based on notions of scientific impartiality and fulfilling one’s “genealogical aspirations.” While Nelson cautions against prematurely assessing the social and political ramifications of newly marketed genetic “ancestry” testing models, she submits that the knowledge claims they make, as well as their subsequent interpretation by consumers, set in motion new forms of subjectification based on biological notions of racial difference (Bolnick et al., 2007; Nelson, 2008).

The personal fulfillment of diasporic genealogical aspirations and

the political imperatives of research inclusion underline a desire to make legible ancestries violently ruptured by slavery and colonialism and bodies marked anonymous historically. In particular, black feminist writers, specifically fiction writers, make visible these otherwise violent and anonymous historical silences and ellipses of memory. In Toni Morrison's *Beloved* (1988), the novel's protagonist, Sethe, attempts unsuccessfully to repress traumatic memories of slavery, bondage, and loss, which involved murdering her own two-year-old daughter to prevent her recapture by slave patrols pursuing runaway slaves in the north. Saidiya Hartman (2007) writes about the tension between slavery, memory, and the archive, and how each produces both contingent silences and a sense of irrevocable ancestral loss, asking, "Was my hunger for the past so great that I was now encountering ghosts? Had my need for an entrance into history played tricks on me, mocked my scholarly diligence, and exposed me as a girl blinded by mother loss?" (p. 16). In writing about the violent erasure of genealogical memory, Hartman blurs fiction with historical analysis—what elsewhere she calls "critical fabulation" (2008)—to excavate an unknowable maternal past. The erasures of memory and history instituted by racial slavery continued to haunt the life of Henrietta Lacks and the immortal life of HeLa, both situated in "a common historical ground, the socio-political order of the New World" in which, according to Hortense Spillers (1987), a "diasporic plight marked a theft of the body" (p. 67). The Lacks matriarchal narrative represents the private theft of the mortal black body that can be "killed" (Roberts, 2014), while HeLa represents an "immortal" public text read from genetic analyses of the cells, their genome, and their epigenome, all decoded from, to paraphrase Spillers, "an undecipherable kind of hieroglyphics of Black flesh" (Spillers, 2014, p. 67).

Deconstructing matriarchy

The *Oxford English Dictionary* defines a *matriarch* as "a woman who is the head of a family or tribe," and "an older woman who is powerful within a

family or organization.” Further, *Oxford* defines *matriarchy* as “a system of society or government ruled by a woman or women.”⁵ Discursively figuring Henrietta Lacks as “matriarch” positions her as a notable figure in her family, but this positioning elides her actual power in both her personal, family life (which we may not have access to) and larger cultural, historical, and social contexts reproducing dominant notions of race and gender.

Discursive framings of matriarchy in social and political scientific literatures have long labeled African-American and, by extension, Afro-Creole family structures as “matriarchal,” “matrilineal,” or “matrifocal” (Beckles, 1999; Clarke, 1999; Frazier, 1940; Hyman & Reed, 1969; Moynihan, 1965; Smith, 1956, 1988, 1996).⁶ Moreover, invocations of matriarchy have usually contained political motivations (Matory, 2005; Sanday, 1998). For example, the 1965 *Moynihan Report* attributed “matriarchal” family structures to “the culture of poverty” affecting a large percentage of the African-American population. Low rates of marriage, skewed representations in popular culture, and statistics on out-of-wedlock births, reinforced the notion of endemic African-American cultural pathology and family disintegration. And this biosocial “fact” of African-American matriarchy has seeped into genomic discourse.

According to Lisa Weasel (2004), the story of Henrietta Lacks reignited evolutionary debates about human origins (see Landecker, 2000), while reinscribing a narrative “from which race and gender cannot be extricated” (Weasel, 2004, p. 189). Race, a theoretical and methodological pre-occupation of nineteenth- and early-twentieth-century biological anthropology that sought to find its essence, later gave way to cultural and postmodern arguments emphasizing its socially constructed nature, only to reappear with vigor as a biological entity in the early twenty-first century (Bliss, 2012). Thus, in terms of racial history as a constructed lens through which to view the past, particularly the gendered past, genomic science offered new truth claims about the prehistory of race (Wailoo, Nelson, & Lee, 2012).

HeLa exemplifies and Henrietta Lacks personifies the regenerative

persistence of this sub-Saharan-African genetic possibility and ability, carrying with it the narrative baggage of the racialized black matriarch. Further illustrating the historical conflation of ancestry with gender, and race with genetics, researchers at the University of California, Berkeley in 1987 argued for an original mitochondrial ancestor of all humanity. The scientific narrative of the sub-Saharan, Out-of-Africa origins of humanity soon found itself in tension with Judeo-Christian origin narratives based on religious myth. Subsequently interpreted through a gendered Western religious lens, this mitochondrial ancestor, or “genetic matriarch,” was envisioned as Eve from the Biblical Garden and was sometimes referred to as “Mitochondrial Eve,” who in turn became known as “African Eve” (Oikkonen, 2015, p. 748). Some saw this development as a compromise between science and religion. Others saw it as a simplistic racialization of an extremely complex story of human variation. Analyses of race and gender, imbricated within evolutionary theory, had moved from the “bare bones” of the fossil (Fausto-Sterling, 2005) to gendered explanations of sub-Saharan-African genetic ancestry (Oikkonen, 2015).

In the above cases, scholarship about human genetic ancestry proved permeable to perennial constructions of race and gender. Empirical sample data, first *attributed* descriptively through observation, were subsequently *ascribed* interpretively using categories demarcating inherited social statuses (matriarchal, religious, racial, gender, etc.) and therefrom imbued with explanatory characteristics of hierarchal social value. As social facts, such ascribed statuses are then read scientifically as inherited, not achieved. Ascription or ascribed status refers to a social standing inherited from birth. By contrast, achieved status refers to a merit-based social standing accomplished during one’s lifetime. I base my understanding on earlier anthropological work on ascribed status and the sociology of ascriptive inequality to offer a broader analytic that moves beyond attribution as description to ascription as explanation (Davis, 1950; Linton, 1936; Parsons, 1970; Reskin, 2005; Reskin & Branch-McBrier, 2000).

In scientific circles, the use of the term “matriarch” to describe

Henrietta Lacks runs counter to anthropological definitions of patriarchy as an intergenerational female right to political and economic power. Patriarchal societies pass on status and wealth to children through the maternal line and, more importantly, women in these societies figure prominently in the total political and economic structure of the group. Patriarchal societies trace not only temporal but cosmological descent from a female ancestor/progenitor/goddess, sacralizing social practices that legitimates the social order between and among the sexes. Seen this way, patriarchy does not imply the political or economic power to subjugate others but the power to conjugate and regenerate the totality of social life (Sanday, 1998). In contrast, matrifocal (or matricentric) groups are female-headed households characterized in Creole societies by racialized forms of male exclusion from the larger socioeconomic sphere (Smith, 1996). Children in matrilineal groups inherit positive status and, often, rights to resources reckoned through the maternal line. Unlike the integral social role patriarchy serves, matrifocality exists within the interstices and at the margins of larger socioeconomic forces. Children in these families inherit neither positive status nor resources (or rights to them) from their mothers.

Other scholars have critiqued patriarchal discourses as self-indulgent practices in status elevation removed from their racialized context. For these scholars, patriarchy as a concept explains precious little while gratuitously describing a non-existent kinship structure. Patriarchy, as expounded upon by nineteenth-century scholars such as Edward Tylor and twentieth-century scholars such as W.H.R. Rivers, found little support from empirical studies, which thus stated that patriarchy no longer existed. If it ever did, it did so within overarching patriarchal kinship structures either through patrilineal marriage or matrilineal brother/uncle rubrics (Sanday, 1998). Patriarchy assumes inherited female rights to resources and influence in political decision making. Hence, in the Lacks case, the characterization of “patriarch” is curious, given that it finds little to no definitional or objective traction. Worse still, it crowds out conversations about matrifocality as an intergenerational process of

gendered dispossession marking racialized forms of male exclusion from the wider socioeconomic field (Brereton, 2002). Yet, it is not enough to simply dismiss Lacks's ascribed status of "matriarch" as a matter of poor word choice, however unintentional. Rather, because it circulates within wider scientific narratives on African origins and genetic "Eve"s, the usage of "matriarch" exemplifies larger problems around locating research wealth and engaging with the material-discursive makings of race and gender.

Finding Africa in the admixed matriarch

Building on contacts made and interviews conducted during Summer 2011, I attended in Spring 2012 the Genetics of the Peoples of Africa and the Transatlantic African Diaspora Conference, held at the University of North Carolina, Chapel Hill. An international meeting, the conference brought together biological anthropologists, geneticists, molecular biologists, and epidemiologists of color whose work addressed the genetics of health and health disparities in transnational and diasporic African-descent populations. The meeting raised three important and contentious issues: one epistemic, one definitional, and one methodological. The first issue centered on personal identification within a "racial" or "ethnic" group. The second revolved around the definition of an "African." The third centered on locating "Africa" in the "admixed" human genome.

Scientific discourses about Henrietta Lacks and HeLa cells have long reflected these epistemic, definitional, and methodological issues. When Walter Nelson-Rees received six cell samples from the Soviet Union in 1973, he believed them to have originated in female donors. The cells were all revealed to possess only X-shaped chromosomes, meaning they had the genetic markers for maternal origin and descent. Upon closer examination by Ward Peters in Detroit, all six "Soviet" samples were determined to have originated from a sub-Saharan-African female—to be specific, an "admixed African American" female, Henrietta Lacks.

The publication of the HeLa genome and epigenome in August

2013 was preceded and accompanied by debates about health disparities, genomic explanations for differential disease outcomes among racial groups, and the politics of racial classification and their intersections with power, purity, admixture, and ethnoracial self-identification. However, the dual lives of Henrietta Lacks and the immortal HeLa cell line trouble these health disparity debates, biological discourses on purity and admixture, and attendant claims to locate and source sub-Saharan-African genetic diversity in the human genome, figuring what Spillers calls the “undecipherability of black flesh” even in the face of these widespread, organizational attempts to decode it.

The epistemic question was raised by African-American molecular biologist Dr. Marcus Scribner⁷, who participated in the Chapel Hill meeting I attended. Visibly perturbed by the ways race had been linked to specific genomic scripts in an earlier presentation, Scribner said, “Ancestry tests for ancestors, not living people. It is an act of categorical misrecognition to attempt to explain genetic and genomic differences within human populations using the language of race.” Against efforts to define “an African” as a member of a sub-Saharan group on the continent, Scribner argued, “An African is someone who either originates from or lives within the African continent. It makes no difference whether what we call ‘European’ Y-chromosomes are found in North Africa, the US, and [*sic*] South Africa; or ‘Arab’ Y-chromosomes in the Sudan.”

Scribner traced the assumptions behind such claims to nineteenth-century biological anthropology and evolutionary theory, which equated an exaggerated Bantu phenotype as the prototypical “Negro”:

This was about Europe and America writing an evolutionary narrative to themselves about themselves and those below them as a result of contact, colonization and slavery. Knowledge produced for domestic consumption and the exercise of power, but wholly inaccurate.

However, the historical dynamics of power challenge genomic narratives about race. One researcher who traces genomic ancestry in Latin America said,

The population of the Dominican Republic has a heavy African component. In a continuum of Africanity, from lowest to highest you have: Mexico, Ecuador, Colombia, Puerto Rico, and the Dominican Republic. Yet national and cultural narratives in the Dominican Republic focus on their “European heritage.” Haitians are seen as the Africans although there are Dominicans with as much or more African genetic ancestry than Haitians.

Since the 1960s, several anthropologists and Afrocentric scholars have used the terms “Africoid” and “Africanity” to describe an essential sub-Saharan-African aesthetic (Maquet, 1972; Senghor, 1967). Over time, these two terms have been adopted by scholars in biological anthropology, diaspora studies, psychology, cultural studies, and increasingly, in the field of genetics. For example, “Africanity” was deployed originally in studies of African art and film but is now taken up in genomics to describe degrees of Africanity in a genetic sample (Lima et al., 2007). What is unclear is precisely how and when the aesthetic became seen as biological, with some researchers using Africanity to define a common “African American *cultural* DNA” (McDougall, 2011, emphasis added),⁸ but the epistemic and definitional interpretations of African ancestry in the latter deterritorialize sub-Saharan Africa geographically while simultaneously inferring its genetic locatability.

The central question, therefore, remains: How to source the wide genetic diversity of sub-Saharan Africanity in admixed African-descent populations? As one molecular epidemiologist told me,

It is extremely difficult to source (African) origins in an admixed population. And of course, there can be degrees of admixture even within the same population. The Southeastern United States has the least racially admixed and the Pacific Northwest the most racially admixed African American populations in the US. Testing Afro-Caribbean and Afro-Brazilian populations can perhaps tell us more about African ancestry than United States African Americans—too much admixture.

In agreement, another researcher offered a possible solution:

The high percentage of European Y-chromosomes in the African American population makes mitochondrial (mt)DNA a better locus of study. It is a circular genome that is maternally derived. It performs no recombination, is traceable and more copies of it are available for study.

Mitochondrial DNA (mtDNA) is derived *only* through maternal lines, and the genetic information it contains regulates energy production by utilizing oxygen to convert food to energy. This energy regulation mechanism represents human adaptation to a diverse set of environmental and historical challenges. African Americans have some of the highest rates of Type 2 diabetes in the US. However, their mtDNA contains diverse sets of sub-Saharan DNA. The genetic complexity of Type 2 diabetes includes co-factors that usually accompany the disease, including hypertension; hypercholesterolemia; eye, kidney, and heart diseases; chronically high blood sugar levels; and Alzheimer's disease. Diabetics rarely die from diabetes itself but rather from one or more of these cardiometabolic factors. Recently, the genomic research focus on this Type 2 genetic complexity, known as the Metabolic Syndrome (MetS), has been centered on examining mtDNA and its energy and metabolic system.

Epidemiological studies of metabolic diseases in African Americans must reckon with the ways slavery has structured mtDNA inheritance in African American populations. These epidemiological lines lead us to African-American women as embodiments of a particular history. While locating Africanity presents unique challenges, operationalizing admixture analyses in the US offers robust research opportunities, highlighting two important historical factors favoring African-American participation in genomic research. First, the United States was the only slave society that experienced an increase in its African descent population. Caribbean slave economies like Jamaica, for example, preferred working slaves to death and replacing them with new imports from Africa (Brown, 2010). Second, by 1830, four years before the end of slavery in the British West Indies, enslaved Africans in the US on average had three maternal ancestral generations preceding them, each

generation born in the US. From an epigenomic standpoint, African Americans, representing both a large sample pool and a diverse population in terms of admixture, demonstrate a longer history of environmental and epidemiological interaction with European populations. In terms of Africanity, this variously admixed population demonstrates a predictable pattern of mtDNA flow through West African maternal lines.

Embodying the diversity of sub-Saharan mtDNA in a racially admixed family, the body of Henrietta Lacks revolutionized cellular biology and spurred global biomedical research. The sequencing of the HeLa genome and epigenome in 2013 promised, or threatened, to change the way we understood metabolic adaptation to environmental change. It raised ethical questions about who should profit from that understanding. Race, gender, and ascribed, or inherited, matriarchal social status, intertwined within regimes of property ownership, and drew a bioethical line between novel forms of exchange and historical regimes of appropriation. Moreover, it accented the line between the racial gift as social exchange and the gendered commodity as market exchange.

Matriarchal wealth and racialized participation

It is not difficult to source the missing intergenerational wealth implied in the matriarchal designation given to Henrietta Lacks. The HeLa cell line has founded a global industry that has generated six decades worth of professional and scientific capital. A search on the PubMed Central database turns up over 70,000 research papers written over the last sixty years about HeLa and its central role in developing effective vaccines for both poliomyelitis and the human papilloma viruses. Yet, somehow achieving a just calculus of balanced reciprocity between the Lacks family, the scientific community, and the wider society benefiting from HeLa research remained an unformulated equation.

The publishing of the HeLa genome and epigenome prompted media speculation about negotiations between the NIH and the Lacks family concerning the possible payment of royalties to the family. As

reported in *Nature*, this presented a dilemma for Francis Collins:

Some Lacks family members raised the possibility of financial compensation, Collins says. Directly paying the family was not on the table, but he and his advisers tried to think of other ways the family could benefit, such as patenting a genetic test for cancer based on HeLa-cell mutations. But they couldn't think of any.

(Callaway, 2013, p. 133)

Although financial compensation was not ultimately granted, two members of the Lacks family were subsequently included on the ethics board charged with formulating the appropriate conditions for obtaining HeLa genome samples for research. Board inclusion was framed as an equitable step toward medical justice, despite the family's deepening intergenerational poverty, relative scientific illiteracy, and sparse social capital—and all of this in fact risked furthering the exploitation that inclusion sought to redress. Johns Hopkins University, moreover, created two scholarship programs in the name of Henrietta Lacks and promised that 40% of new hires at the university would come from inner city Baltimore. For the Lacks family, monetary recompense is for the most part generated through speaking appearances and private donations made by those particularly touched by the story of Henrietta Lacks and HeLa.⁹

Henrietta Lacks's birth in the former slave quarters of a Virginia tobacco plantation highlighted the sociogenesis of a racialized social hierarchy that would later relegate her to the colored ward of a hospital in which she sought treatment for cervical cancer, and from which her now immortal cells were harvested. Over sixty years later, her cells continue to replicate in laboratories around the world, persisting alongside questions of ethics, consent, and social justice. And having "contaminated" upwards of 20% of the cell lines used in research globally, she continues to cross biological boundaries expounded by the social order that characterized the world in which she lived and died.

The history of Henrietta Lacks's life and HeLa's immortal behavior transgresses the rational boundaries of society and science, labor and expertise, and their constructed social mechanisms of racial inclusion and

exclusion. For one African-American geneticist, Dr. Richard Ralston, research inclusion constitutes a vital component of producing both knowledge and justice through “participation” by minorities, both as research subjects and researchers. He asks, “If we don’t care enough about what is happening in our own families and communities, then who will?” Ralston is one of a cohort of geneticists and molecular epidemiologists of color trained at historically black colleges and universities. Aware of the history of the Tuskegee syphilis study, he believes that custodianship of African-descent DNA is a matter of social justice and ethical responsibility. However, at the meeting in Chapel Hill, he saw attempts to collect this DNA as driven more by economic and scientific motives than by a desire to reduce health disparities, noting, “I know a lot of people working in genomics. Trust me, most of them don’t give a damn about black people. But they can’t ignore the amounts of money coming into genomic research.” Ralston’s belief in the importance of African-descent sampling exists in historical tension with dual suspicions about the interests of the market and the curiosity of science.

The Lacks case reflects these suspicious histories and constitutes neither accident, nor coincidence, nor even malign intent, but rather the genomic fulfillment of long-standing social, economic, and structural processes. It reveals impoverishment structures existing within larger patriarchal wealth accumulation networks and offers an optics for examining kinship and making legible the sociocultural construction of both racial research categories and health disparities. I submit that these biosocial forms of wealth accumulation and status regulation are not acquired through merit but are ascribed by birth within hierarchal gift relations reflecting gendered and raced disparities in both social capital and social justice. Such disparities render elusive ethical notions of informed consent and research equity.

Discussion

In this article, I explored the rise, fall, and genomic resurrection of matriarchy. This genomic moment, when the political economy of race and matriarchy took on new salience in authoring new participatory regimes of wealth accumulation, relied on older, gendered forms of social engagement and obligations to give and receive that legitimated appropriation in the absence of informed consent. The racial body as a diverse, regenerative product of power and history marks mercantile colonial, capitalist industrial, and contemporary biocapital epochs. Authorial power and historical narratives recirculating matriarchal discourses insinuate an elevated kinship status neither ascribed by birth nor achieved through merit, and in so doing reproduce the social order.

From a social justice standpoint, the failure to reciprocate to the donor defines Mauss's notion of sacrificial exchange (Mauss, 1990, p. 82). The challenge of modernity, Mauss argues, is to transform the economy of human relationships from one based on sacrificial exchange to one based on balanced reciprocity (1990, pp. 82-83). In the case of the HeLa cell line, its perpetual self-laboring, recent genomic and epigenomic sequencing, and discursive accession to matriarchal status and wealth are as ascribed economically as they are intergenerationally. Difficulties persist in determining whether and how the Lacks family might benefit from the commodification of HeLa in scientific knowledge production.

Weber (1910) earlier advocated understanding technology as separate from materialist history and analyses of property relations. In the case of genomic technology, this article suggests otherwise. In regenerating and thereby naturalizing the social order as a social fact, the historical violence of racialized reproduction carries greater socioeconomic value than kinship, which, when emptied of meaningful social content, "can be invaded at any given and arbitrary moment by the property relations" (Spillers, 1987, p. 74). African Americans have been historically commodified as legal property, objectified economically as alienated racial labor, and mined biologically as a natural resource. Property, labor, and resources as gift objects, serve as "marker(s) in the economy of human relationships," highlighting specific sociohistorical bonds in which the

failure to reciprocate, as with the example of the NIH's treatment of the Lacks family, precedes any legal enforcement or moral or ethical sanction (Hyland, 2014, p. 50).

The matriarchal label attached to Henrietta Lacks forecloses a clearer understanding of an "irredeemable past" in which the "present was the future that had been created by men and women in chains, by human commodities, by chattel persons" (Hartman, 2007, p. 233). Sethe, in Toni Morrison's *Beloved*, struggles against such a social order, one built on racialized and commodified reproduction that legitimates acts of bio-appropriation based neither on consent nor reciprocity. However, such culturally legitimated acts, based not on the "protected relationships" assumed by Mauss, insist on the right to obligate the giver to gift through participation in asymmetrical forms of exchange (Hyland, 2014, p.52). To paraphrase Sanday (1998), Sethe refuses to conjugate merely to perpetuate and consequentially subjugate her descendants to biological lives or existences conditioned upon reproducing intergenerational obligations to exchange sacrificially as a gift of their racialized labor to the nation. Seen through this prism, I suggest the impossibility of achieving matriarchal justice or assuming matriarchal power to effect the ethical reformation of racialized social practices. I build on the work of Joan Scott (1986) in positing that kinship alone does not reproduce gender, but that both gender and race are constituted in large part separately from kinship by political and economic forces operating in the wider society (p. 1068).

Conclusion

In this article, I focus on matriarchy, specifically black matriarchy, as a vital yet unexamined contextual analytic in the social and political sciences. I presented a case of how the economically (re)productive, commodified, and laboring black female slave re-emerged as an economically (re)producing, commodifiable, laboring, status-elevated black matriarch. Neither an accident of racial, gender or sexual history, nor a coincidence of physiological pathology and reproductive regeneration (or for that

matter an exemplar of social deviance), she eventually crossed the segregated lines of kinship, desire, and race to redefine exchange, integration, and contamination in both society and biology.

This article has attempted to show how the political economy of patriarchy as deployed in media and scientific narratives around HeLa link to older histories of racial and gendered practices of exchange and appropriation. “She,” whether the primordialized “Mitochondrial Eve,” racialized “African Eve,” or the “admixed” Henrietta Lacks, demonstrates how “she” was rendered fecund and exploitable in scientific knowledge production. Consequently, as an ascribed matriarch having no real ability to effect change in the social order, her descendants live in relative poverty. She and most black “matriarchs” in the US struggle against a downward intergenerational spiral of health and economic disparities, kinship instability, and their disparate intersections with social, economic, and medical justice.

The concept of bioethical patriarchy highlights the ethical importance of examining discourses that valorize sacrificial exchange and the elevated status claims ascribed to the obligated. I suggest paying future attention to how and why discourses of race and gender continue to operate productively within a social system of organized scientific and economic practices involved in the perennial deciphering of black flesh. In this social system of organized technoscientific practices, a political economy of racialized participation mobilizes both researchers and targeted risk populations in extra-legal cultural spaces. However, this widening of attention from the fragmentary biospecimen to the whole person now leaves us several very important questions to consider: As a politics of reparation, should a framework for redress prescribe reparative or restorative justice? In other words, can *restorative* justice make the bioethical patriarch “whole” in a *legal* sense? Or, can *reparative* justice render the bioethical patriarch “whole” in an *economic* sense? And what is more “just”? To “repair” or to “restore?” These abstract yet vital questions expose the very real sociocultural dynamics of sacrificial exchange and the failure, inability, or sheer unwillingness to reciprocate.

Examining efforts toward achieving social justice via programmatic mechanisms of inclusion and consent requires making robust analytical distinctions between the sacrificial inequality of participation and the bioethics of appropriation, along the axes of power they inhabit. The future will determine whether the true bioethical value of the gift can facilitate balanced reciprocity commensurate to the imagined biovalue of race and gender.

Acknowledgements

I want to thank my colleagues in the Race, Genomics, and Media Working Group and the Science and Justice Center at the University of California, Santa Cruz for our productive discussions. I also extend my appreciation to Sandra Harvey, Fatimah Jackson, and Marcia Ochoa, who each contributed uniquely to the direction this project took, and to the reviewers for their insightful and provocative comments at each stage of writing.

Notes

¹ See Adey et al., (2013).

² See Landry et al., (2013).

³ This article is informed by archival research at the Tozzer Library at Harvard University and the George Gey Collection in the Alan Mason Chesney Archives at Johns Hopkins University. In addition, I carried out over 100 hours of observation at health disparities conferences and meetings, in California, Texas, Washington, DC, and North Carolina.

⁴ See Hoad (2005) and Comaroff (2007). Comaroff locates (through Hoad, 2005) the rationality in Mbeki's irrational refusal to accept definitions of HIV/AIDS that characterize it as a sexually transmitted disease, arguing that these definitions perpetuate Western racist stereotypes and the Euro-

American propensity to use African bodies for experimentation and profit (Hoad, 2005, p.104). For Mbeki, AIDS marks the impact of the living legacies of imperialism on African immune systems. From this perspective, remedies lie less in costly or hazardous drugs, which prolong neocolonial dependency, than in the reversal of inequality (Comaroff, 2007, p. 214). Comaroff avers that the HIV/AIDS epidemic in (South) Africa, like the natural disaster Hurricane Katrina, dialectally exposes history, power, and capital. For an important exception, see Hyman & Reed (1969).

⁵ See http://www.oxforddictionaries.com/us/definition/american_english/matriarch and http://www.oxforddictionaries.com/us/definition/american_english/matriarchy.

⁶ One notable misapplication of the matriarchal meme was reflected by the misreading of Edith Clarke's *My Mother Who Fathered Me* (1957), which was interpreted as a case in point of Caribbean social pathos. Intended as an ethnographic examination of the social vitality of Jamaican kinship practices within the context of the island's independence, Clarke wished to emphasize the social relationships generated by the kinship structure, not to critique the structure itself. R. T. Smith (1988) argues that much of the scholarly misrecognition concerning West Indian kinship is due to a lack of understanding of the epistemes of the people themselves. Empirical methodologies misread how meaning is constructed within kinship groups by placing undue emphasis on class, politics, or cultural essentialisms (Smith, 1988, p. 28).

⁷ I use pseudonyms for all the narrators in this article.

⁸ See de B'éri (2007). Although sympathetic to Herskovits's (1990) earlier attempt to refute Hegel by demonstrating a persistent and significant African socio-historical presence, I caution against equating

cultural persistence with racial biology. The theoretical application of Hegelian dialectics to understanding former slave societies begins with DuBois (1994) and radiates through Fanon (1963). DuBois's "double consciousness" (1994, p. 2) is, in Fanon's work, a "Manichaeism" dissonantly experienced subjectively and objectively. Marxist dialectics do not analyze slavery, gender, or the colonial encounter; race, power, violence, and the ideology of difference trouble the relative social and racial homogeneity assumed within Marxist imaginaries (Fanon, 1963, pp. 40-46).

⁹ As of late 2016, members of the Lacks family had spoken at over 120 schools over the previous five years.

References

Adey A., Burton J.N., Kitzman J.O., Hiatt J.B., Lewis A.P., Martin B.K., Qiu R., Lee C., & Shendure J. (2013). The haplotype-resolved genome and epigenome of the aneuploid HeLa cancer cell line. *Nature*, 500(7461), 207-211.

Beckles, H. (1999). *Centering woman: Gender relations in Caribbean slave society*. Kingston, Jamaica: Ian Randle Publishers.

de B'éri, B. E. (2007). The semeiotic of Africanicity in Gaston Kaboré's film *Buud Yam*. *Tydskrif vir letterkunde*, 44(1), 98-109.

Bliss, C. (2012). *Race decoded: The genomic fight for social justice*. Palo Alto, CA: Stanford University Press.

Bolnick, D. A., Fullwiley, D., Duster, T., Cooper, R. S., Fujimura, J. H., Kahn, J...TallBear, K. (2007). The science and business of genetic ancestry testing. *Science*, 318, 399-400.

Brereton, B. (2002). *Race relations in colonial Trinidad, 1870–1900*.

Cambridge, UK: Cambridge University Press.

Brown, V. (2010). *The reaper's garden: Death and power in the world of Atlantic slavery*. Cambridge, MA: Harvard University Press.

Callaway, E. (2013). Deal done over HeLa cell line. *Nature*, 500(7461), 132-133.

Clarke, E. (1999). *My mother who fathered me: A study of the families in three selected communities of Jamaica*. Kingston, Jamaica: University of West Indies Press.

Comaroff, J. (2007). Beyond bare life: AIDS, (bio)politics, and the neoliberal order. *Public Culture*, 19(1), 197.

Davis, K. (1950). *Human society*. New York: MacMillan.

Du Bois, W.E.B. (1994). *The gift of black folk: Negroes in the making of America* (Vol. 18). Oxford, UK: Oxford University Press.

Epstein, S. (2007). *Inclusion: The politics of difference in medical research*. Chicago, IL: University of Chicago Press.

Fanon, F. (1963). *The wretched of the earth*. (R. Philcox, Trans.). New York, NY: Grove.

Fausto-Sterling, A. (2005). The bare bones of sex: Part 1—sex and gender. *Signs: Journal of Women in Culture and Society*, 30(2), 1491-1527.

Frazier, E. F. (1940). *The negro family in the United States*. Chicago, IL: University of Chicago Press.

Hartman, S. (2007). *Lose your mother: A journey along the Atlantic Slave Route*. Farrar, Straus and Giroux.

- Hartman, S. (2008). Venus in two acts. *Small Axe*, 12(2), 1-14.
- Herskovits, M. J. (1990). *The myth of the Negro past*. Boston, MA: Beacon Press.
- Hoad, N. (2005). Thabo Mbeki's AIDS blues: The intellectual, the archive, and the pandemic. *Public Culture*, 17(1), 101-128.
- Holloway, K. F. (2011). *Private bodies, public texts: Race, gender, and a cultural bioethics*. Durham, NC: Duke University Press.
- Holloway, K. F. (2014). *Legal fictions: Constituting race, composing literature*. Durham, NC: Duke University Press.
- Hudson, K.L., Collins, F.S. (2013). Family matters. *Nature*, 500, 141-142.
- Hyland, R. (2014). Gift and danger. *Journal of Classical Sociology*, 14(1), 45-53.
- Hyman, H.H., & Reed, J.S. (1969). "Black matriarchy" reconsidered: Evidence from secondary analysis of sample surveys. *Public Opinion Quarterly*, 33(3), 346-354.
- Landecker, H. (2000). Immortality, in vitro: History of the HeLa cell line. In P. Browdin (Ed.), *Biotechnology and culture: Bodies, anxieties, ethics* (pp. 53-72). Bloomington, IN: Indiana University Press.
- Landry, J. J., Pyl, P. T., Rausch, T., Zichner, T., Tekkedil, M. M., Stütz, A. M., ... & Gagneur, J. (2013). The genomic and transcriptomic landscape of a HeLa cell line. *G3: Genes/ Genomes/ Genetics*, 3(8), 1213-1224.
- Lima, R. M., De Abreu, B. S., Gentil, P., de Lima Lins, T. C., Grattapaglia, D., Pereira, R. W., & De Oliveira, R.J. (2007). Lack of association between vitamin D receptor genotypes and haplotypes with fat-free mass in postmenopausal Brazilian women. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 62(9), 966-972.

- Linton, R. (1936). *The study of man*. New York, NY: Appleton-Century-Crofts, Inc.
- Malinowski, B. (1922). *Argonauts of the western Pacific*. London: Routledge & Kegan Paul.
- Matory, J. L. (2005). *Black Atlantic religion: Tradition, transnationalism, and matriarchy in the Afro-Brazilian Candomblé*. Princeton, NJ: Princeton University Press.
- Maquet, J.J.P. (1972). *Africanity: The cultural unity of black Africa*. (J.R. Rayfield, Trans.). Oxford, UK: Oxford University Press.
- Mauss, M. (1990). *The gift: Forms and functions of exchange in archaic societies*. New York, NY: W. W. Norton & Company.
- McDougall, H. (2011). Reconstructing African American cultural DNA: An action research agenda for Howard University. *Howard Law Journal*, 55(1), 63-99.
- Morrison, T. 1987. *Beloved*. New York: Vintage Books/Random House.
- Moynihan, D. P. (1965). *The negro family: The case for national action*. Washington, DC: Office of Policy Planning and Research, United States Department of Labor.
- National Institutes of Health. (2013, August 7). NIH, Lacks family reach understanding to share genomic data of HeLa cells. *News Release*. Retrieved from <http://www.nih.gov/news-events/news-releases/nih-lacks-family-reach-understanding-share-genomic-data-hela-cells>.
- Nelson, A. (2008). BioScience genetic genealogy testing and the pursuit of African ancestry. *Social Studies of Science*, 38(5), 759-783.
- Oikkonen, V. (2015). Mitochondrial Eve and the affective politics of human

ancestry. *Signs*, 40(3), 747-772.

Parsons, T. (1970). Equality and inequality in modern society, or social stratification revisited. *Sociological Inquiry*, 40, 13-72.

Reskin, B. (2005). Including mechanisms in our models of ascriptive inequality. In L. B. Nielsen & R. L. Nelson (Eds.), *Handbook of Employment Discrimination Research* (pp. 75-99). Dordrecht, Netherlands: Springer.

Reskin, B. & Branch-McBrier, D. (2000). Why not ascription?: Organizations' employment of male and female managers. *American Sociological Review*, 65(2), 210-233.

Roberts, D. (2014). *Killing the black body: Race, reproduction, and the meaning of liberty*. New York, NY: Vintage.

Sanday, P. R. (1998, July). Matriarchy as a sociocultural form. Paper presented at the 16th Congress of the Indo-Pacific Prehistory Association, Melaka, Malaysia.

Scott, J. W. (1986). Gender: A useful category of historical analysis. *American Historical Review*, 91(5), 1053-1075.

Senghor, L. S. (1967). The study of African man. *Mawazo*, 1(4), 3-7.

Skloot, R. (2010). *The immortal life of Henrietta Lacks*. New York: Crown.

Smith, R. T. (1956). *The negro family in British Guiana*. London, UK: Routledge.

Smith, R. T. (1988). *Kinship and class in the West Indies: A genealogical study of Jamaica and Guyana*. Cambridge, UK: Cambridge University Press.

Smith, R. T. (1996). The matrifocal family: Power, pluralism, and politics.

New York: Routledge.

Spillers, H. J. (1987). Mama's baby, papa's maybe: An American grammar book. *diacritics*, 17(2), 65-81.

Strathern, M. (1988). *The gender of the gift: Problems with women and problems with society in Melanesia*. Berkeley, CA: University of California Press.

Wailoo, K., Nelson, A., & Lee, C. (Eds.). (2012). *Genetics and the unsettled past: The collision of DNA, race, and history*. New Brunswick, NJ: Rutgers University Press.

Waldby, C., & Mitchell, R. (2006a). *Tissue economies: Blood, organs, and cell lines in late capitalism*. Durham, NC: Duke University Press.

Waldby, C. (2006b). Umbilical cord blood: From social gift to venture capital. *BioSocieties*, 1(1), 55-70.

Weasel, L. H. (2004). Feminist intersections in science: Race, gender, and sexuality through the microscope. *Hypatia*, 19(1), 183-193.

Weber, M. (2005). Remarks on technology and culture. *Theory, Culture & Society*, 22(4), 23-38.

Bio

James Doucet-Battle is an Assistant Professor in the Department of Sociology at the University of California, Santa Cruz. His research interests lie at the intersection of diaspora and transnational studies, science, technology and society studies, development studies, and health disparities.