

# EXAMINING THE ROLE OF FAMILY HISTORY OF US ENSLAVEMENT IN HEALTH CARE SYSTEM DISTRUST TODAY

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**Objective:** Black/African American people have long reported high, albeit warranted, distrust of the US health care system (HCS); however, Blacks/African Americans are not a homogenous racial/ethnic group. Little information is available on how the subgroup of Black Americans whose families suffered under US chattel slavery, here called Descendants of Africans Enslaved in the United States (DAEUS), view health care institutions. We compared knowledge of unethical treatment and HCS distrust among DAEUS and non-DAEUS.

**Design and Setting:** A cross-sectional random-digit dialing survey was administered in 2005 to Blacks/African Americans, aged 21-75 years, from the University of Pennsylvania Clinical Practices in Philadelphia, Penn.

**Participants:** Blacks/African Americans self-reported a family history of persons enslaved in the US (DAEUS) or no family history of persons enslaved in the US (non-DAEUS).

**Main Outcome Measures:** HCS distrust was measured by a validated scale assessing perceptions of unethical experimentation and active or passive discrimination.

**Methods:** We compared responses to the HCS distrust scale using Fisher's exact and t-tests.

**Results:** Of 89 respondents, 57% self-reported being DAEUS. A greater percentage of DAEUS reported knowledge of unethical treatment than non-DAEUS (56% vs 21%;  $P < .001$ ), were significantly more likely to express distrust, and to endorse the presence of covert (eg, insurance-based) than overt forms (eg, race-based) of discrimination by the HCS.

## INTRODUCTION

In the United States (US), it has long been established that Black/African American people, compared with White people, report greater distrust of the health care system (HCS),<sup>1-4</sup> which is warranted.<sup>5,6</sup> In contrast with mistrust, which is a general sense of suspicion based on historical experiences, distrusting beliefs by Black/African American people reflect a reasonable questioning of the values and motives of institutions that have not been trustworthy.<sup>7,8</sup> For Blacks'/African Americans' perceptions of the US

HCS, this untrustworthiness stems from practices or actions that reinforce racism and other forms of discrimination.<sup>7,8</sup> The HCS's untrustworthiness impacts health-seeking behaviors, leads to less medical attention, and exacerbates health disparities, especially for Black/African American people.<sup>1,9-11</sup> However, Black/African American people represent a diverse group of African-descendent people with widely varying backgrounds and family histories.<sup>12-14</sup> Yet, little has been done to examine differences in HCS distrust within US Black/African American ethnic subgroups.<sup>15</sup>

**Conclusions:** DAEUS express greater HCS distrust than non-DAEUS, patterned by awareness of unethical treatment and passive discrimination. Understanding how long-term exposure to US institutions influences health is critical to resolving disparities for all Black/African American groups. Rectifying past injustices through reparative institutional measures may improve DAEUS' trust and engagement with the US HCS. *Ethn Dis.* 2021;31(3):417-424; doi:10.18865/ed.31.3.417

**Keywords:** Trust; African Americans; Enslaved Persons; Patient Acceptance of Health Care; Racism; DAEUS

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Black/African American people in the United States are not homogenous culturally or ethnically, and not all people identifying as Black/African American have a family history that includes institutionalized oppression by US institutions. Coming from many distinct parts of the world, it is often not until reaching US borders that people of African-descendent groups are re-classified into a single racial category, despite personal preferences for self-identification by con-

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tinental origin.<sup>12,13</sup> For the purposes of this study, we use “Black/African American” as an all-inclusive term for anyone who self-identifies as descending from Africa and is living or born in America, both “African Americans” who were African-descendent people who voluntarily immigrated to America from Africa or other parts of the world and “Black Americans” who do not identify as African-descendant people who voluntarily immigrated to America.<sup>16</sup> These ethnic differences within the Black/

African American population may be an important distinction to make in terms of understanding historical experiences with the US HCS.<sup>16</sup>

The subset of Black/African Americans with a family history of slavery is an ethnic group whose needs differ from every other US minority population due to the unique US experience of hundreds of years of chattel slavery. Some states, academic, and medical institutions are considering or have implemented reparative initiatives<sup>17</sup> in acknowledgement of the persistent effects of slavery and accrued disadvantage for Black/African American people from families who suffered under it. This lineage-based group, hereafter referred to as Descendants of Africans Enslaved in the United States (DAEUS),<sup>18</sup> may also provide context for historical experiences with the HCS. We distinguish DAEUS, Black Americans with a family history of slavery, from non-DAUES, inclusive of Black Americans who do not report a family history of slavery and African Americans who voluntarily immigrated to the United States after the end of chattel slavery. Examining the experiences of DAEUS can help us understand the health effects of institutional racism in the United States.<sup>18</sup> DAEUS may have a different set of attitudes and beliefs toward the US HCS than those without this history of oppression, and while there is information on distrust by Black/African Americans overall,<sup>1-11</sup> there is limited information on how the subgroup of DAEUS views the US HCS.

As a first in health research, we examine HCS distrust among intra-ethnic subgroups of Black/African American people. Our analysis is

an intra-ethnic group comparison of DAEUS, with non-DAEUS, as defined above. While other studies have assessed intra-ethnic differences among Black/African American subgroups for chronic disease, infectious disease, and health behaviors,<sup>15,19-21</sup> our study advances the literature by focusing on intra-ethnic group differences in attitudes toward the US HCS. To our knowledge, intra-ethnic group differences related to perceptions of the trustworthiness of US HCS have not been assessed quantitatively nor been assessed by comparing two distinct subsets of African-descendent groups. Understanding specific populations’ perceptions of HCS trustworthiness can inform targeted interventions and strategies to reduce health disparities.

## **METHODS**

### **Study Participants**

A telephone-based survey to validate an instrument measuring distrust of the US HCS<sup>22</sup> was administered in 2005 to randomly selected healthy adults, aged 21-75 years, from the University of Pennsylvania Clinical Practices in Philadelphia, Penn. Participants of all race/ethnicities were invited to participate in the survey; however, only the respondents self-identifying as Black/African American received supplemental questions about their family heritage, and knowledge of unethical actions by the US HCS. Thus, this analysis only reports data from Black/African American respondents, as they were the only ones asked these specific questions. All procedures

were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants included in the study. The study was approved by the University of Pennsylvania institutional review board.

**Descendants of Africans Enslaved in the United States (DAEUS) Identity**

Black/African American respondents were asked the yes/no question: “Have there been people in your family’s history that were ever enslaved in the United States?”

**Awareness of Unethical Treatment**

Respondents were asked a yes/no question: “To your knowledge, has the US Health Care System ever

performed unethical treatment targeting Blacks/African Americans?”

**Health Care System Distrust Outcome**

Respondents answered questions on the nine-item validated HCS Distrust Scale.<sup>22</sup> The scale was designed to measure subdomains of distrust: competence (perceptions of the trusted party’s ability and knowledge to perform in the expected way) and values (fidelity, honesty, and belief that the trusted party will act in the best interest of the patient). Respondents rated each item on a 5-point Likert-type agreement scale. After reverse scoring positively worded items, we summed each item for a total scale value of 9 to 45, with higher numbers indicating greater distrust. For the competence subdomain, we summed the values of four items representing that construct, and for the values subdomain, we summed the values

of five items representing that construct. Although the final validated scale consisted of nine items, we also analyzed two additional items on discrimination beliefs from the full scale of items that were tested, due to published literature<sup>9</sup> suggesting that those items would be relevant for Blacks/African Americans specifically.

**Statistics**

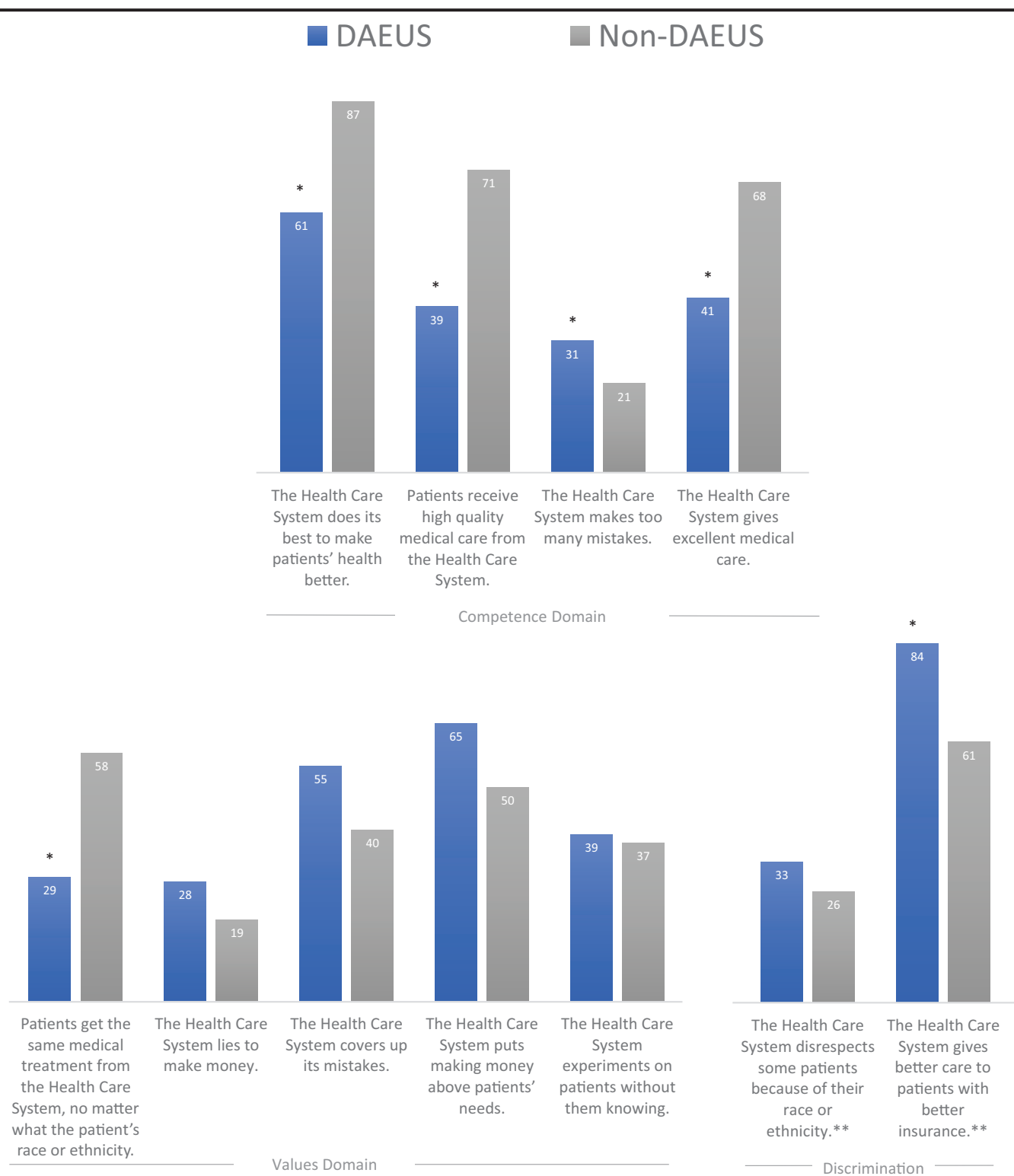
Characteristics of DAEUS and non-DAEUS respondents, and the percent of respondents “agreeing” or “strongly agreeing” to questions about HCS distrust were compared using Fisher’s Exact tests or t-tests; all p-values were two-sided.

**RESULTS**

The original telephone-based survey included a total of 144 Black/African American respondents, of

**Table 1. Characteristics of Black/African American respondents reporting as descendants of Africans enslaved in the United States (DAEUS) or non-DAEUS**

	DAEUS, n=51	Non-DAEUS, n=38	Total Respondents, N=89	P
All respondents, %	57	42	100	
Age, yrs. M(SD)	46 (10)	48 (10)	47 (12)	.30
Sex, %				.94
Male	20	18	19	
Female	80	79	80	
Income, %				.124
<20,000	27	37	33	
\$20,000 to ≤\$39,999	27	34	31	
≥\$40,000 to ≤\$59,999	20	5	13	
≥\$60,000	14	5	8	
Education, %				.195
High school or less	47	61	62	
Some college	37	29	29	
College or post-graduate	16	5	9	
Covered by health insurance, %	92	97	94	.291
Good to excellent self-rated health, %	69	71	70	.81
Aware of unethical treatment, %	56	21	46	<.001
Total Health Care System Distrust Score (M, SD)	27 (6.5)	23 (5.5)	26 (6.5)	.001
Competency domain, M(SD)	11 (3.2)	9 (2.5)	10 (3.0)	.002
Values domain, M(SD)	16 (3.8)	14 (3.5)	15 (3.8)	.004



**Figure 1. Health care system distrust scale items by Descendants of Africans Enslaved in the United States (N=89), percent responding agree or strongly agree.**

\*P<.05; \*\*Item not included in published validated HCS Distrust Scale

which 89 (62%) responded to the question on family history of slavery. Among these 51 (57%) were DAEUS. Though similar by age, sex, income, education, health insurance coverage, and self-rated health, more DAEUS than non-DAEUS reported awareness of unethical treatment by the HCS (56% vs 21%,  $P < .001$ ; Table 1).

DAEUS had higher overall distrust scores ( $P < .001$ ), and higher scores within each of the subdomains of competence ( $P = .002$ ) and values ( $P = .004$ ). Higher subdomain values reflected DAEUS' lower perceptions of the HCS's ability and motivation to offer equitable care. Other items were elevated for DAEUS, but not statistically significant. DAEUS were less likely than non-DAEUS to believe patients receive equitable treatment across races but were equally likely to report that the HCS disrespects patients based on race or unethically experiments on patients. A greater percentage of DAEUS believed that "the HCS gives better care to patients with better insurance" than non-DAEUS (Figure 1).

## DISCUSSION

Two key findings emerge that enhance our understanding of how DAEUS vs non-DAEUS view the US HCS. First, more DAEUS reported awareness of unethical treatment, which may reflect a conscious awareness of HCS practices that warrant distrustful attitudes or a greater socialization to notice or interpret the HCS' practices as unethical. Second, DAEUS were equally or more likely to report race-based differential treat-

ment and more likely to endorse beliefs in covert discrimination through insurance. A disappointingly high percentage (at least one-third) of all respondents endorsed aspects of distrust, which has implications for clinical care and lack of engagement with the HCS.<sup>9,10</sup> Our results reinforce the importance of inspecting intra-ethnic differences within the group designated as Black/African American.<sup>15</sup>

The association between DAEUS and greater knowledge of unethical treatment by the US HCS may result from more time generationally in the United States than non-DAEUS, allowing for more accrued exposure to unethical treatment by the HCS. Historical knowledge, either by personal experience or shared history, influences which types of care a patient seeks or rejects, or may determine whether or not a patient pursues care by conventional medicine at all.<sup>23</sup> There are many examples of unethical treatment by the HCS in both the slavery and post-slavery eras. For example, in the antebellum South, the medical field provided means for physicians to use medical theories to justify slavery and to justify unethical medical practice at both the institutional and the individual levels.<sup>24</sup> Even after the legal end of slavery by the Emancipation Proclamation in 1863 and the 13th Amendment to the Constitution in 1865, and well into the 1920s, there were reports of Blacks/African Americans being used unethically for experimentation in US hospitals.<sup>24</sup> Many of the documented incidents, such as the Tuskegee Syphilis experiment,<sup>25</sup> forced treatments, such as mandatory sickle cell anemia treatments for Black Americans only,<sup>4,26</sup> eugenic

sterilization of Black women until the 1970s,<sup>27,28</sup> and grave robbing of Black cadavers for medical experimentation,<sup>29</sup> are seen as legacies of the attitudes and behaviors created during the slavery era in the United States. Because many of these incidents are rooted in unethical medical justifications that began during the slavery era and proliferated thereafter, it is likely that those whose family members endured slavery in the past have greater knowledge of unethical medical practices. It is also possible that historically racist policies and experiences external to the HCS have led DAEUS to be more skeptical of US institutions

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*More DAEUS than non-DAEUS reported awareness of unethical treatment, which may reflect a conscious awareness of health care system practices.*

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in general, and thus creates a general mistrust of US institutions that spills into distrust of the HCS specifically.<sup>7</sup> Such historical knowledge may predispose those with a family history of slavery to have warranted skepticism toward the beliefs, intentions, and actions of the HCS's care and affect health-seeking behavior.<sup>30</sup>

In contrast, some non-DAEUS may have comparatively less accrued

time generationally in the United States. Non-DAEUS includes foreign-born African Americans, who are generally healthier than US-born Black Americans.<sup>31</sup> Even so, longer exposure to living in the United States erodes the health advantages of foreign-born persons<sup>32</sup> and understanding the effect of long-term exposure to US HCS and other institutions for DAEUS may be a clue as to how health patterns will emerge as foreign-born groups increase their generational time in the United States. Non-DAEUS may also include Black Americans who have had long generational time in the United States without a family history of slavery, and who may have had health advantages due to the lack of exposure to slavery. Being healthier may lead to less interaction with the HCS, which may also contribute to lower distrust scores among non-DAEUS.

Another possibility is that DAEUS are more attuned to notice unethical treatment or are more likely to attribute unethical treatment as racially motivated. Sensitivity to racism can result from personal or vicarious historical knowledge of prejudice, thus individuals knowledgeable about historical prejudice may be more likely to attribute a wider range of behaviors to prejudice than those unaware of these experiences.<sup>33</sup> Most non-DAEUS African Americans immigrated to the United States long after American chattel slavery and the Jim Crow era under established protections like the Civil Rights Act of 1964,<sup>34-36</sup> so they may have less exposure to US forms of discrimination. More recently immigrated African-descendent peoples are less likely than DAEUS to report that

US racism and discrimination affects them<sup>12</sup> and may attribute medical malfeasance to other reasons (ie, being foreign-born instead of being Black).

DAEUS may also recognize the evolution of racism in health care from overt to covert.<sup>37-39</sup> When race-based discrimination was framed as overt (being disrespected due to their race), there was no difference between DAEUS and non-DAEUS. Yet DAEUS were more likely to endorse discrimination framed as covert, with ambiguous representation of discrimination (equal treatment being received, regardless of race or ethnicity). Our findings that more DAEUS reported discrimination by insurance rather than race further support the interpretation of an endorsement of covert racism by the US HCS. One might expect similar beliefs about insurance discrimination by the US HCS among DAEUS and non-DAEUS since the national Medicaid and Medicare insurance system was not enacted until 1965,<sup>40,41</sup> long after the legal institution of slavery ended. Instead, we find that a significantly greater percentage of DAEUS than non-DAEUS believe that the US HCS gives better care based on insurance. Since Blacks/African Americans in the United States are historically and persistently less likely to have insurance than Whites,<sup>42</sup> DAEUS may perceive that the HCS uses a lack of insurance as a covert method to discriminate against Blacks/African Americans.<sup>39</sup> While a belief in discrimination based on insurance may have decreased since the Affordable Care Act's (ACA) insurance expansion that increased insurance coverage for Blacks/African Americans,<sup>42</sup> our

data were collected before the ACA; nonetheless, racial disparities in insurance coverage persist<sup>42</sup> and attempts to undermine the ACA's success may be viewed as an attempt to perpetuate covert racism in the US HCS.

### Study Limitations

While the first of its kind to assess DAEUS lineage and distrust, the distrust measure may not have fully captured the range of interactions with the HCS that might lead to distrust. Philadelphia, Pennsylvania is a favorable study location given its large and diverse Black/African American population but may not represent the experiences of all Blacks/African Americans. The study participants were a majority female, with at least a high school education, and are less likely to report discrimination than males or those with higher levels of education and income.<sup>43</sup> Thus, this study may underestimate distrustful beliefs held by Blacks/African Americans.

### CONCLUSION

In the United States, HCS distrust is high for Blacks/African Americans and further elevated for the subset descending from Africans enslaved in the US (DAEUS). Institutional racism reduces the trustworthiness of institutions and may have implications for how DAEUS engage in care. Distrust-reducing interventions may benefit Blacks/African Americans, and DAEUS especially, but patient-provider distrust interventions have had null to modest results.<sup>44</sup> Instead, rectifying distrust and covert discrimination through

reparative institutional-level measures such as health care credits for medical insurance, prescriptions, and mental health services should be explored.

CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Dean; Acquisition of data: Dean; Data analysis and interpretation: Dean, Smith; Manuscript draft: Dean, Smith; Statistical expertise: Dean; Administrative: Dean, Smith; Supervision: Dean, Smith

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