# Socioeconomic Status and Dissatisfaction With Health Care Among Chronically III African Americans

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Addressing differences in social class is critical to an examination of racial disparities in health care. Low socioeconomic status is an important determinant of access to health care.

Results from a qualitative, in-depth interview study of 60 African Americans who had one or more chronic illnesses found that low-income respondents expressed much greater dissatisfaction with health care than did middle-income respondents.

Low socioeconomic status has potentially deadly consequences for several reasons: its associations with other determinants of health status, its relationship to health insurance or the absence thereof, and the constraints on care at sites serving people who have low incomes. (*Am J Public Health*. 2003;93:742–748)

Although there has recently been a growing tendency to disentangle ethnicity and socioeconomic status (SES) in studies of the health of African Americans<sup>1,2</sup> (Thomas Denberg, written communication, January 2002), relatively few studies have examined African Americans' perceptions of health care, and even fewer have examined those perceptions in relation to SES.<sup>3-5</sup> Various authors have called attention to the simplistic ways in which SES is often used, 6-8 and the relative infrequency of studies of class-based differences in health within ethnic groups as opposed to studies that compare ethnic groups (T. Denberg, written communication, January 2002).

SES is intimately associated with racism, which has restricted socioeconomic attainment for members of minority groups. Williams observes that SES is not just a confounder of racial differences in health but part of the causal pathway by which race affects health. He also notes that race is an antecedent and determinant of SES and that racial differences in SES reflect, in part, the successful implementation of discriminatory policies premised on the inferiority of certain racial groups.

A recent Institute of Medicine report<sup>6</sup> documents the many studies that have demonstrated widespread racism in health care. One manifestation of racism is the finding that Whites are more likely than African Americans to receive a broad range of specific med-

ical procedures, <sup>10–12</sup> and that African Americans are more likely to receive undesirable interventions such as amputations. <sup>13–15</sup> Research that indicates that physicians tend to perceive African Americans and members of low- and middle-SES groups more negatively than they do Whites and upper-SES patients <sup>16</sup> illustrates the effects of racism on the delivery of care.

National opinion surveys indicate that African Americans are more likely than Whites to rate the health services in their communities as fair or poor. <sup>17</sup> Blendon et al. found many more negative attitudes expressed by African Americans overall toward the nation's health and social institutions, and they suggest that these attitudes are at least partially grounded in the circumstances and experiences that fail to eliminate historical racial disparities. <sup>17</sup>

Although life expectancy for African Americans has more than doubled during the 20th century, African Americans continue to bear a higher burden of death, disease, and disability than Whites. <sup>18</sup> African Americans have an overall death rate that is 1.6 times higher than that of the White population, and elevated mortality rates for African Americans compared with the White population exist for 8 of the 10 leading causes of death. <sup>9</sup> Moreover, health care facilities serving the poor in the segregated inner city are fraught with problems of decreasing and inferior services. <sup>19</sup> Dwindling health care resources for

low-income people have provoked concern on the part of policy analysts without any significant action being taken.<sup>20,21</sup>

Low SES is an important determinant of access to health care. Persons with low incomes are more likely to be Medicaid recipients or uninsured, have poor-quality health care, and seek health care less often; when they do seek health care, it is more likely to be for an emergency.<sup>22–26</sup> Blendon et al.<sup>27</sup> found that 1 in 11 African Americans reported not receiving health care for economic reasons compared with 1 in 20 whites, and that 1 in 4 African Americans who reported that they had a chronic or serious illness did not have an ambulatory visit in the year preceding the survey, compared with 1 in 6 White persons who were surveved. Not only were African Americans less likely to be covered by a private insurance carrier, they were less likely to have any insurance. In a separate study, 17 they found that 1 in 4 African Americans reported problems paying for medical bills, including paying for physicians, hospitals, and prescription drugs.

The question has been raised of whether financial resources may be more relevant to policy interventions than considerations related to race and ethnicity.28 But ethnicity, or cultural background, is extremely important as well. Expressed through interpersonal interactions, culture is constantly redefined and renegotiated, and it must be interpreted within the context of individual history, family constellation, and SES.8 Ethnicity is not simply a demographic variable. Without acknowledging both cultural background and social class, analyses of specific cultural groups are incomplete and may overlook important factors that profoundly affect people's health. The health care experiences of African Americans are affected by their awareness of the long history of racism in American health care<sup>29</sup> that resulted in such infamous

episodes as the Tuskegee experiments,<sup>30</sup> the barring of African Americans from entering the medical profession until recently,<sup>31</sup> and various other overt expressions of racism. The cultural history of health care for African Americans in the United States is thus a critical factor in analyzing the current state of health care delivery.

In this article, we report on findings from a study of middle-income and low-income African Americans who had one or more chronic illnesses. The main objective of this analysis was to compare satisfaction with health care by persons categorized as low income with those categorized as middle income. This analysis yielded distinct differences between how middle-income and low-income African Americans in this study viewed their health care.

## **METHODS**

Our findings are based on 2 large qualitative studies that examined the same questions about the daily management of chronic illness but included different age groups. They are combined here to illustrate the issues African Americans experience with health care. Respondents were African Americans aged 21 to 63 who had one or more chronic illnesses. The most common illnesses were diabetes mellitus, asthma, and heart disease or hypertension. The total number of African Americans included in the study was 111. Persons who were Medicare recipients were omitted from this analysis because Medicare enables low-income people to seek care in sectors of the health care system that would otherwise be unavailable to them, which leads to another level of analysis that is beyond the scope of this article. The total number of African Americans discussed here, therefore, is 60.

Respondents were recruited from a variety of sources in 2 urban counties in California between June 1994 and June 2001. This was primarily a community study, with few respondents being recruited directly from clinics: 39% from flyers, 32% from contacts in social service agencies, 15% from clinics and home care services, 10% from religious organizations, and 4% from participant referrals. The criterion for entry into the studies was the presence of one or more chronic ill-

nesses. The sample reflected a range of illness severity from mild to severe.

In addition to African Americans, 3 other ethnic groups were studied: Latinos, Filipino Americans, and Cambodian Americans. They are omitted from this analysis in order to focus on patterns particular to African Americans.

Following key tenets of the in-depth interview approach, 32-34 all respondents were interviewed 3 times in a 1-year period by the second author, who was of the same ethnicity as the respondents. Gender-based distrust was not observed among men, all of whom knew they would be interviewed by a woman prior to being interviewed. Interviews were semistructured with many open-ended questions, lasted for approximately 1 to 2 hours, and focused on respondents' health, experiences with their illnesses, economic situation, and use of and access to health care. Each interview was tape-recorded and transcribed verbatim. All but 2 respondents were born in the United States, and all were interviewed in English.

The first step in the analysis for this article was to divide the data into low-income and middle-income groups. Krieger and colleagues<sup>7</sup> propose a multifaceted analysis of social class for public health research that includes individual, household, neighborhood, and poverty-area levels, and this approach was adapted to this primarily qualitative study. In differentiating persons categorized as low income from those categorized as middle income, we examined the following categories: income history, occupation and employment history, medical insurance history and current status, and living arrangements. The socioeconomic data were also analyzed by age and gender.

Each group was analyzed separately, and cross-group comparisons were then made. A specific data analytic procedure was followed. Core categories that reappeared in the data repeatedly (e.g., health insurance) were identified and compared with other emergent categories. Codes were developed, generated from meanings in the data. The entire data set was coded for specific topics with NUD\*IST (QSR International Pty Ltd, Melbourne, Australia), a data-sorting software program, which resulted in over 100 discrete codes.

A case-by-case narrative analysis was also conducted. Narratives are the stories people tell about their experiences; they provide important insights into their perspectives on those experiences. Narrative analysis, which emphasizes the topics that dominate respondents' reports and the way they are addressed, leads to the identification of themes across the data set. For this analysis, transcripts were sorted into privately insured, Medicaid, and uninsured, and then analyzed by group. The coded data and the narrative analysis yielded the same themes regarding satisfaction with health care and served as a cross-check on each other.

#### **RESULTS**

### **Demographics**

The 60 respondents ranged in age from 21 to 63. Respondents reflected diversity in SES, ranging from those who were middle class, worked as professionals, were home owners, and had medical insurance to those who were poor and unemployed, lived in public housing, and had no medical insurance. All respondents were living in the community at the time of the study. See Table 1 for demographic characteristics.

# Relationship Between SES and Insurance Status

Using selected markers of SES,<sup>7</sup> we divided the sample into low income and middle income. Of the total sample of 60 persons, 32 were categorized as low income and 28 as middle income. Persons categorized as low income had a history of unsteady income, with significant periods of unemployment and public assistance that often carried into the present. Middle-income persons had long, steady work histories, a concomitant steady income, and had seldom or never received public assistance.

Type of housing was also indicative of income level. In this study, neighborhood or poverty area was not a useful descriptor of income level, but subsidized housing was. Persons categorized as low income most often lived in subsidized housing, and none were homeowners. In contrast, middle-income persons were often homeowners, and none lived in subsidized housing. Eighty percent of re-

TABLE 1—Demographic Characteristics (n, %) of Study Participants by Type of Insurance (N = 60)

	Private (n = 28)		Medicaid (n = 18)		Uninsured (n = 14)	
Age						
Range	21-63		25-59		23-59	
Mean	44.50		43.50		43.21	
Sex						
Female	19	67.9	13	72.2	9	64.3
Male	9	32.1	5	27.8	5	35.
Marital status						
Married	7	25.0	3	16.7	2	14.
Unmarried (widowed, divorced,	21	75.0	15	83.3	12	85.
separated, never married)						
Education						
High school	3	10.7	12	66.7	8	57.
College/postgraduate	25	89.3	6	33.3	6	42.
Work life						
Currently working	18	64.3	5	27.8	6	42.
Unemployed	1	3.6	7	38.9	6	42.
Other <sup>a</sup>	9	32.1	6	33.3	2	14.
Occupation						
Business and professional	15	53.6	3	16.7	1	7.
Clerical	6	21.4	5	27.8	2	14.
Skilled and unskilled labor	6	21.4	10	55.6	10	71.
Other <sup>a</sup>	1	3.6	0	0	1	7.

aRetired, disabled, or student.

spondents lived in neighborhoods that were primarily African American, and 20% lived in integrated neighborhoods.

In this study, SES translated directly into health insurance status: persons categorized as low income had a history of being uninsured or Medicaid recipients, while middle-income persons reported a history of private insurance. At the time of the study, all those who were currently uninsured or who were Medicaid recipients met the other criteria for categorization as low income; that is, there were no uninsured people in this study who were experiencing a temporary economic setback. Twenty-eight were privately insured, 18 Medicaid recipients, and 14 completely uninsured.

The type of insurance that respondents had dictated the sector of the health care system in which they were seen. At least 15 different sites were used by the 60 respondents. These sites encompassed a wide spectrum of health care delivery. Middle-income persons went to

private physicians or had health plans that provided comprehensive care through a health maintenance organization (HMO). Persons who had Medicaid coverage were seen primarily in hospital low-income clinics. Those who were completely uninsured primarily used emergency rooms and free clinics.

### **SES and Perceptions of Health Care**

Level of satisfaction with health care was strongly related to the sector of the health care system in which people were seen. The primary finding to emerge from this research was that low-income respondents reported higher levels of dissatisfaction with health care than middle-income respondents. No differences were found in responses relative to respondent age, however.

Middle-income persons received their health care through private practices and HMOs. They seldom complained about the sector of the health care system in which they were seen. For example, a 49-year-old woman who was an administrator in a university had high blood pressure as well as lifelong respiratory and vision problems. She said, "I've always had good medical care. They like to experiment, and I've never minded being experimented on. So if they say, 'Just to be on the safe side, let's make sure it's not something,' I've never minded that."

When middle-income respondents did complain about the sector of the health care system in which they were seen, their complaints were usually mild. Another woman, a 40-year-old loan specialist who had asthma, upon being given a new physician in her HMO, said, "He's the new doctor, he probably doesn't have any patients, I hadn't been in in a couple of years, so they tossed me over to him. My old doctor, she knows how to treat my asthma. His treatment of my asthma is less aggressive than hers is, so if this keeps up [difficulty breathing without relief], I will request her again."

Middle-income respondents reported lengthy periods of being seen by one physician, sometimes for many years. Almost without exception, middle-income persons reported that their physicians knew about their health problems in detail and reported ongoing dialogues between themselves and their physicians about the management of their chronic illnesses. Reports of satisfaction with health care were widespread. Middle-income respondents reported frequent routine visits. They reported having trust in, and good rapport with, their physician. They believed their physician was knowledgeable and seldom questioned the treatment plans their physician had developed for them.

For example, a 48-year-old man who had diabetes and multiple sclerosis took an early retirement from his civil service job at a nearby naval base. When asked about his relationship with his physician, he said, "He's young, so we talk, and you know, he listens." Rare were comments such as that by a 29-year-old woman who worked in health care administration and had asthma: "Sadly, I've had [a particular HMO] all my life, and I've never really had a primary physician, just because they change so much. So I really cannot say that I've ever had anyone take a real personal interest in my health."

# Dissatisfaction With Health Care Among Low-Income Persons

In contrast to middle-income respondents, expressions of dissatisfaction with the health care system by low-income respondents were common. Although middle-income respondents sometimes reported problems with the health care system, such as getting their insurance to cover a medication or approve a treatment, those efforts were never of the same magnitude as for low-income persons, who reported fighting to receive basic health care.

Low-income persons spent much greater portions of time dealing with the health care bureaucracy. They were preoccupied with how to access the system and what to do in an emergency. They reported that dealing with the health care system was an ongoing challenge and drain on their energies. For example, a 42-year-old unemployed woman who had asthma and heart disease said, "If you miss an appointment [arrive late] at their clinic, or with their doctors, you have to wait in line for another appointment. And weeks go by. I be forever not seein' the doctor. Yeah, I be sick, and I be sayin' the only way that you get seen out there be if you dyin'." Few low-income respondents reported routine visits to a physician, in contrast to middleincome respondents, most of whom saw their physicians routinely. Low-income respondents were much more likely to see physicians only when a new health problem arose.

Low-income respondents made frequent comments about the deficiencies of the health care system. All but 8% saw their health care as being second-rate. Despite their sustained efforts to use the system effectively, few reported satisfaction with the overall system. Instead, they reported dissatisfaction with its inefficiency, as one unemployed 40-year-old woman did who had asthma and high blood pressure and had had a stroke: "You know, this is the hospital, and this is where your doctors are. But you can't see your doctor. If you call in there and say, 'Oh, I'm sick,' you have to go into emergency and be there 10 hours instead of just havin' a general practitioner or somethin' up there."

Being turned away was also reported. Another woman, 35 years old, who had asthma and was unemployed, described how she was

refused care at a community clinic when she sought urgent care for an episode of asthma: "I said, 'You can't see me?' He says, 'No, you have a doctor, you have to go there.' I'm sayin' 'But I'm sick, and the whole point is you're close, they're farther.' And he wouldn't see me."

One source of dissatisfaction was the rapid turnover of physicians in public hospitals and low-income clinics, which made it difficult for low-income respondents to form relationships with physicians who were treating them. Lowincome respondents seldom reported having a regular physician for any length of time. While 15% of low-income respondents reported being followed by a specific physician for a period of a year, the remainder reported not seeing the same physician twice. Those who did see the same physician over a period of time reported more positive feelings about their health care than did those who seldom saw the same physician again. Low-income persons also reported reluctance to become attached to physicians who treated them in these settings because they anticipated that their physician would move on before long and they would be given a new physician.

Low-income respondents who did have a regular physician usually reported high satisfaction with their health care. For example, a 49-year-old unemployed man who had diabetes and heart disease reported how he had finally acquired a regular physician and how it positively affected his attitude: "I didn't have a primary doctor, so they sent me to [clinic]. And I bounce and bounce about. Then I got a good doctor. She works in a private practice too, but she was my doctor. That was the first doctor that I ever had any trust and faith in."

Low-income respondents without regular physicians frequently reported that they felt that physicians were inattentive to their problems. They said that physicians did not listen to them, were condescending, did not explain things thoroughly, and brushed off their queries. Low-income respondents who did not have a regular physician questioned physician knowledge and wondered whether they were receiving good health care.

Those who were patients in public hospitals and clinics where the need to train medical students and residents existed side by side with the need to provide care were especially likely to be doubtful of the knowledge level of practitioners. For example, a 60-year-old former home health aide who had had multiple strokes described her experiences with physicians when she was recovering from a stroke: "I know this one [an attending physician], I call him 'Goofy.' He acts like it. Him and this lady doctor. She has just started internin'. I guess she don't know nothin'." Asked how it made her feel, she responded, "It makes you mad."

# **Questioning Whether Discrimination Is Present**

Although middle-income persons occasionally described specific medical encounters in the past as racist, they rarely reported discrimination by their current physician. An exception was a 63-year-old minister who had diabetes and was on renal dialysis, having been refused a renal transplant. He reflected on his experiences with physicians, acknowledging that while there were numerous physicians who had treated him with concern, there were nevertheless many he had encountered who did not: "They don't expect you to ask questions, and when you do, it frustrates them. They don't know that you and I are different from them. We don't even react the same way. And they haven't thought of how you should be, but you should conform to their way of thinking. And that's not the way it is. And they know nothing about your culture, period. So my confidence is

Low-income persons were likely to suspect or identify behavior they viewed as discriminatory or racist. A high level of mistrust was reported by low-income respondents who questioned whether various health encounters were signs of discrimination; these included seeing White people who arrived for appointments after they did being called first, physician reluctance to try different medications or treat a condition more aggressively, indifferent care, and waiting for hours in emergency rooms to be seen. In addition, some respondents reported that they felt they were treated like second-class citizens. For example, a 45-year-old unemployed and uninsured man who had asthma said, "Some of the people there [at the clinic] got a funky at-

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titude. You know, you're payin' for this, somebody payin'. They ain't got a right to treat you like garbage in the first place. That is wrong. Period."

#### **Changes in Health Care Coverage**

During the course of the study, 5 people experienced changes in their health care coverage. In all but one case, these changes represented a change for the worse-from private insurance to Medicaid, or from Medicaid to no insurance at all. For example, a 36-yearold unemployed woman who had asthma lost her Medicaid and became uninsured when her son moved out to live with his father. Asked why she switched to a different provider, she said, "I have no Medi-Cal [Medicaid]. My son moved away. So I started going to [county hospital]." Fears about losing Medicaid and becoming uninsured were everpresent. Another woman, 40 years old and unemployed, who had asthma and high blood pressure and had had a stroke, described her struggle to retain her Medicaid: "I'm on appeal. So while I'm on appeal, they haven't taken my Medi-Cal. I'm goin' to fight for my Medi-Cal."

# **DISCUSSION**

Despite recent survey research that suggests that African Americans as a group are relatively well satisfied with the quality of their health care, 35 this research demonstrates that satisfaction is likely to be very different for low-income than for middle-income African Americans, with respect to both quality and quantity of health care. Research has found that satisfaction is linked to a range of factors, including ethnic group, patient education, hospital identity, registration expediency and wait times, perceived competence and attitudes of providers, and resolution of the problem,<sup>36</sup> as well as patients' perception of a relationship of trust, providers' answering of questions and provision of adequate information, and patients' feeling of being involved in decisions about their care.37

But health insurance status is also important. In one study, those who were privately insured were significantly more satisfied than those who received Medicaid or were uninsured on 8 dimensions of patient satisfac-

tion,<sup>38</sup> and in another study, women of lower SES had poorer primary care experiences than women who had higher incomes.<sup>39</sup>

Taken together, the research to date suggests that, although multiple factors affect patient satisfaction, SES is among the most significant because it dictates the sector of the health care system in which people receive care. In this research, while low-income respondents had many complaints about their health care, middle-income respondents had few. This research thus underscores the importance of considering both ethnicity and social class. Lumping together on the basis of SES people who have vastly different experiences of health and health care may be highly misleading.

In conjunction with social class, the health care setting that is used may be a particular focus for questions of satisfaction, as some settings are more highly bureaucratized than others, which may differentially affect patient satisfaction. A recent survey by the Commonwealth Fund<sup>35</sup> found that of the various ethnic groups surveyed, African Americans were the most likely to rely on hospital-based services: 11% relied on emergency rooms and 9% on ambulatory clinics. In our study, lowincome respondents also tended to use hospital-based services, and they generally found them wanting. Those who have low incomes may particularly experience problems in access and in the receipt of quality health care, which reinforces their mistrust. The continual aggravation of trying to gain access and get their health care needs met leads them to view themselves as receiving inadequate health care.

Mistrust of the system fostered mistrust of individual practitioners among these respondents. The great frustration experienced by low-income persons in dealing with the health care system apparently affects interactions with individual providers. They view themselves as receiving second-rate health care, and this leads them to be more suspicious of practitioners' skills and intentions. Moreover, long experience of receiving medical treatment in public hospitals and clinics has led to a recognition that they are often being treated by physicians-in-training. They know that such physicians are learning medicine and are often not yet expert at what they do. Accord-

ingly, they question physician knowledge, especially when medications appear to have little effect and they continue to feel ill. But they also hesitate to form bonds with physicians-in-training because, if they are followed by the same physician for a period of months, they know that, given the training system, such physicians will move on and they will be assigned someone new.

Dissatisfaction with health care is a deterrent to seeking care. Because of the difficulties low-income persons often encounter in gaining access to care, they may seek health care only when they feel it is absolutely necessary. When they do seek medical care, it is often for an emergency. Because many do not have any regular health care, they seek medical care through emergency rooms and free drop-in clinics. They do not have consistent follow-up for health problems.<sup>23</sup>

In this study, low-income persons were infrequently seen for routine checkups compared with middle-income persons. Routine checkups are a primary teaching vehicle for helping patients to understand and manage their chronic illnesses. Moreover, they facilitate the building of rapport between patient and practitioner. It is therefore not surprising that middle-income persons in this research expressed positive regard for their physicians in most cases, while low-income persons did not.

Class-based discrimination apparently interacts with racism in complex ways. In Ren et al.'s study of African Americans, <sup>4</sup> they found that those with more education were more likely to report racial discrimination than those who were less educated, leading them to hypothesize that more highly educated African Americans may be better able to articulate, rather than internalize, their experiences of discrimination, while those with less education may be bothered by racial discrimination but more adversely affected by the day-to-day struggles of economic hardship.

This study, however, suggests that low-income African Americans are fully able to articulate their experiences of discrimination and that they view not only individual interactions as discriminatory but the overall system in which they receive care as a testament to ongoing discrimination as well. T. Denberg (written communication, January 2002) observes that social stratification is not necessar-

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ily restricted to income, education, and occupation, but to how individuals are perceived or valued in society. The comments of respondents in this study suggest that they interpreted their treatment in this system to be an indicator of their low value to society, which resulted in resentment, anger, and efforts to fight for their rights.

Undoubtedly, a significant underlying problem is the structure of the health care deliverv system itself. Williams observes, "Institutional policies have played a major role in creating large racial differences in SES. Because of the persistence of the institutional mechanisms underlying racial inequality, there has been remarkable stability in the racial gap in SES over time."9 The long-term and short-term effects of the US history of underfunding health care programs for the poor are well-known. 6,19-21,40,41 Although there have been improvements in access to health care for children in many states, the recent past has been a particularly stagnant period with respect to implementing new policies to rectify the problems of equity in the health care system for adults.

Persons who have low incomes are at the greatest risk of death and disability. They are seen in the sectors of the health care system that are most seriously underfunded, and consequently their access to routine health care is fraught with limitations. 41 While reducing poverty and altering SES in everyday life may be a challenging long-term process, providing everyone with equal access to quality health care would clearly have a major, and positive, effect in reducing health disparities.

This study had several limitations. The sample size was small and was drawn from one geographic location. Also, the sample was drawn from volunteers who were recruited through a variety of means such as flyers and referrals. Nevertheless, these qualitative findings suggest specific directions for further research. First, the research clearly suggests that studies of satisfaction with health care should encompass both ethnicity and social class. Second, the research suggests that satisfaction comprises a variety of elements, including satisfaction with individual providers, with a particular health care setting, and with discrete components within that setting such as rate of provider turnover. Third, perceptions of racism and discrimination as well as perceived attitudes of providers appear to significantly affect satisfaction level. Finally, satisfaction is apparently heavily influenced by health insurance status.

In conclusion, despite the current emphasis on eliminating health disparities, this goal cannot be achieved without concomitant reductions in disparities by social class, as racial disparities hinge, in part, on social class disparities. Low SES has potentially deadly consequences for several reasons: its associations with other determinants of health status, its relationship to health insurance or the absence thereof, and the constraints on care in sites serving people who have low incomes. To reduce health disparities, it is necessary not only to overcome the present policy inertia and develop universal health insurance that is equitable but also to undermine racist and class biases in the health care system. Only by addressing these 2 different, but interrelated, problems will it be possible to effect changes in the health of low-income African Americans and reduce health disparities.

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#### **Contributors**

G. Becker designed the research, developed the interview schedule, led the data analysis, and drafted the manuscript. E. Newsom conducted the interviews, participated in data analysis, and edited the manuscript.

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## **Human Participant Protection**

The study protocol and consent form were approved by the institutional review board of the University of California, San Francisco

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