

Self-Care Among Chronically Ill African Americans: Culture, Health Disparities, and Health Insurance Status

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Little is known about the self-care practices of chronically ill African Americans or how lack of access to health care affects self-care. Results from a qualitative interview study of 167 African Americans who had one or more chronic illnesses found that self-care practices were culturally based, and the insured reported more extensive programs of self-care. Those who had some form of health insurance much more frequently reported the influence of physicians and health education programs in self-care regimens than did those who were uninsured. It is concluded that the cultural components of self-care have been underemphasized, and further, that the potential to maximize chronic illness management through self-care strategies is not realized for those who lack access to health care. (*Am J Public Health*. 2004;94:2066–2073)

There is widespread consensus that self-care practices play a critical role in the management of chronic illness, yet we know relatively little about the daily self-care practices of chronically ill African Americans. We know even less about the self-care practices of the 23% of African Americans who have no health insurance.¹ African Americans shoulder dramatically disproportionate rates of disease, unemployment, poverty, and premature death.^{2,3} Some indicators show that Black–White disparities have made no sustained improvement since the end of World War II.⁴ Given the extent and effects of health disparities for African Americans, it is essential to examine a wide range of health-related factors much more closely in order to identify potential avenues especially appropriate for public health efforts.

The topic of self-care has emerged in the last 30 years as a particular focus of health concerns, but it was not widely viewed as a legitimate area of inquiry among health professionals until the 1980s.⁵ Prior to that, an ideology of self-care was limited to use in political and health consumer activist contexts such as the feminist movement's demand for sovereignty of the body. Although indigenous traditions of self-care were present among African Americans from their arrival in the United States,⁶ civil rights emancipatory projects focused on protesting the exclusionary, dehumanizing, and stratified nature of medical

care.⁷ The concept of a “right” to self-care practice never materialized as a galvanizing issue for African Americans. More visible were battles to reverse entrenched patterns of limited access to health care that resulted in segregated, substandard care, and the need for health professionals to care for protesters injured by police in violent civil rights encounters.^{7,8} Nevertheless, among African Americans, the maintenance of indigenous traditions of self-care was essential for survival in the South under Jim Crow and in northern, ghettoized cities.

In this article, we examine the social, cultural, and historical roots of African Americans' approaches to self-care, as well as the daily self-care practices of people in our research. Our aim is to demonstrate cultural influences on self-care approaches and how self-care practices are tied to broader social and cultural themes. Culture constitutes a shared system of meaning, the way that people experience, perceive, and interpret their world. Cultural guidelines pass from one generation to the next through a process in which individuals develop a cultural lens for understanding the world.^{9(p3)}

Culture is fluid, ever-changing. People may move between cultures while simultaneously inhabiting a relatively unique coculture (or “subculture”) with its own concepts, rules, and social organization, as do African Americans. Cocultures have their own unique and distinc-

tive features, even as other features overlap with those of the larger culture. Members of a coculture may adhere to values specific to their group, such as particular values associated with self-care practices, while at the same time espousing values of the larger society. We will show how African Americans' self-care practices emerge from strategies for survival and long-term efforts to overcome adversity. By addressing African American self-care practices in their cultural context, we aim to facilitate culturally sensitive public health approaches to the health of African Americans.

SELF-CARE: HISTORY, THEORY, AND DEFINITIONS

Despite the relatively short history of self-care research, there is no shortage of self-care definitions and concepts. Self-care has emerged as a multidimensional construct with definitions varying as to who is involved, why self-care occurs, what is entailed, and how self-care is accomplished.¹⁰ Dean's definition includes “the range of health and illness behavior undertaken by individuals on behalf of their own health.”^{11(p34)} The World Health Organization defines self-care as “the activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health,”^{12(p181)} thus recognizing how self-care skills and knowledge stem from lay and professional experience. Vickery and Iverson¹³ differentiate between medical and health actions: medical self-care deals with medical problems while health self-care is for health maintenance and improvement. Here, as with many self-care models, the individual is seen as the pivotal decisionmaker, a Western assumption that is erroneously construed as a cross-cultural universal.

In Segall and Goldstein's typology,¹⁴ self-care regulates body processes, prevents disease, and alleviates symptoms and illness. Self-

care practices are thus regulatory, preventive, reactive, and restorative. Orem's model¹⁵ is particularly influential and is the subject of ongoing empirical refinement and investigations of cross-cultural applicability.^{16–19} Orem defined self-care as learned behavior that was purposeful, with patterned and sequenced actions, and suggested that individuals acquire the capacity for self-care during childhood, principally in the family, where cultural standards are learned and transmitted intergenerationally.^{15(p95)} She observed that self-care develops throughout the life course, and that such behavior varies according to an individual's group affiliation in habits, beliefs, and practices that constitute a cultural way of life.^{15(p227)}

Despite the breadth of Orem's approach, the frequent focus of empirical research has been on delineating and measuring discrete components of self-care, characterized by a pervasive tendency to examine questions of self-care from a biomedical perspective that is ahistorical and devoid of context. Such an approach has the effect of obscuring the complexity of culture and its relevance for self-care, and how biomedical precepts about self-care layer onto preexisting cultural approaches. Dill and colleagues²⁰ observe that definitions of self-care are largely composed of immediate responses to symptom experiences and to preventive or health maintenance activities. They propose a synchronic model that examines the repertoire of self-care behaviors that individuals develop over time, identifies the sources of particular symptom responses in the context of that repertoire, and explores diverse linkages among sources of care. Such an approach is best suited to a qualitative, interpretive approach in which personal meanings, unique linkages among forms of care, and the relationship between self-care behavior and the individual's social context can be identified.²⁰

THE CONTEXT OF AFRICAN AMERICAN SELF-CARE

African Americans have a long tradition of health and healing practices that shape, in part, what they do to care for themselves in the present day. African American traditional medicine can be traced back beyond enslavement in the United States to their native cultures in Africa.^{6,21,22} They used magical and herbal

cures from their homelands, but over time they also borrowed additional herbal lore and curative practices from Native Americans and adopted colonial European approaches such as purgatives, bleedings, and preventive measures based on classical humoral pathology, leading to an amalgamated ethnomedical system with many regional variants.²³ This system reflects spiritual power in action and is part of a sacred worldview.^{6,24}

Forming a foundation for an ethos of resistance in response to slave owners' emphasis on the soundness of slaves for work and sale, African American spirituality transformed itself, creating an internal world resistant to the power of slave owners.^{6(p39)} Moreover, this view of health was relational, linking the well-being of the individual to the health of the larger community and the community to its spiritual life, culminating, as well, in a collective version of self-reliance.^{6(p197–198)} Continued reliance on this system was further fostered after emancipation for a variety of reasons: access to mainstream care continued to be denied or was of poor quality because of racism, abuse occurred in the name of scientific experimentation such as the Tuskegee experiments, and resistance to the oppressive tactics of the White mainstream persisted in life and in death.^{6,7}

African American self-care practices continue to be affected by the overriding struggle for survival in the face of racism and oppression. Survival and efforts to overcome adversity are core themes in historical documents and academic work,^{25–27} as well as in the vast array of cultural expressions, such as music, art, oral, and literary traditions, that symbolize the ongoing impact of and resistance to racial oppression. One specific survival response can be seen in the concept of John Henryism, which reflects the African American cultural ethos of overcoming adversity through self-determination and hard work; this construct has been applied to the study of hypertension.^{28,29}

Cultural values and practices among African Americans have been called a "survival arsenal."³⁰ They are embedded in a variety of African American social institutions, including family structure and organization and the church, and encompass spirituality, social support, and traditional, nonbiomedical health and healing practices. These emphases are central to self-

care practices. The family is the repository of specific cultural beliefs and health practices and is a primary source of cultural meaning.³¹ Much has been written on the adaptive value of the African American family, and its great importance has been linked to cultural survival.^{32–34} Considerable work has also addressed the imparting of Black consciousness and Afrocentric values in the socialization of children, as well as the development and protective function of Black identity throughout the life course.^{35,36}

A large body of work now emphasizes the supportive nature of African American extended kin relationships.^{37,38} Dilworth-Anderson³⁹ observes that the mutual aid system is rooted in a larger African and antebellum context, in which group affiliation was promoted over individuality. Mutual aid has been demonstrated to be an important part of self-care strategies in the management of illness.^{40,41} Similarly, spirituality is central: the Black church has developed and sustained itself as a vital institution for the survival and advancement of African Americans, who were refused access to the institutional life of White American society, and who rejected the hypocrisy of White Christianity.^{42,43}

The church continues to fulfill many functions of social organization, such as education, social welfare, civic duties, and business enterprises, as well as serving as an outlet for social expression, a vehicle for social protest, and a refuge from racism and discrimination.⁴⁴ The church has addressed everyday problems of human existence and survival,⁴⁵ providing specific services such as health care, housing, violence prevention, financial aid, child care, services for the elderly, family counseling, hospice, the provision of food and clothing, and educational scholarships.^{46,47} No wonder the church has been characterized as a healing resource.⁴⁸

The continued strength of self-care practices is affirmed in an analysis of national survey data among African Americans, in which almost 70% reported that their families used home remedies and 35% reported that they used home remedies themselves.⁴⁹ Traditional medicine has continued to be an integral part of self-care not only because of continued poverty, institutional racism, and underuse of biomedicine,^{50,51} but also because of its centrality

in African American cultural history and its perceived efficacy and benefits. Self-care practices are grounded in these social and cultural practices.⁵⁰ Their cultural values, together with responses to racism and structural inequalities, have shaped how African Americans care for their chronic illnesses.⁵² These strategies vary widely, depending on people's past and present social history, the availability of economic resources, and access to health care. However, there has been little work that explores self-care among African Americans.^{51,53–56}

We report findings from a study of middle-income and low-income African Americans who had 1 or more chronic illnesses. The main objective of this analysis was to explore the cultural factors that underpinned the development of self-care processes and the use of these practices in daily life after diagnosis of a chronic illness. Our analysis found that while cultural factors were at the root of self-care practices, socioeconomic status and health insurance status were also significant because of their role in shaping access to health care resources.

METHODS

Findings reported in this article were based on 3 large qualitative studies that examined the same questions about daily management of chronic illness but included people from different age groups and with varying health insurance status. They are combined here to illustrate self-care practices across the life span. Respondents were African Americans aged 21 to 91 years who had 1 or more chronic illnesses. The most common illnesses were diabetes mellitus, asthma, and heart disease or hypertension. A total of 167 African Americans were included in the study. Data collection has been completed in 2 of the 3 studies.

Respondents were recruited from a variety of sources in 2 urban counties in California between June 1994 and August 2002; 28% were recruited from field contacts and contacts in social service agencies, 24% from clinics and home care services, 20% from participant referrals, 19% from flyers, 5% from the Internet, and 4% from religious organizations. The criterion for entry into all studies was the self-reported presence of 1 or more chronic illnesses, and in the first study an additional cri-

terion was complete lack of health insurance. In all 3 studies, we sampled across a range of illness severity, from mild to severe, and a range of people, from those recently diagnosed to those who had had a chronic illness for many years. Our aim was to capture people's retrospective views about the development of self-care measures as they looked back on their illnesses, as well as to gain the perspectives of those who were in the process of discovering what illness management entailed. In addition to African Americans, 3 other racial/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 interviewing approach,^{57,58} we interviewed all respondents 3 times in a 1-year period. Interviews were conducted by the second and third authors, who were 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. Interviews were semistructured with many open-ended questions, lasted for approximately 1 to 2 hours, and focused on respondents' health, experiences with their illnesses, self-care practices (what they did to take care of their health), 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 data were divided into low-income and middle-income groups. Krieger and colleagues⁵⁹ 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. A further step was taken in separating the data by health insurance status: uninsured, Medicaid, Medicare, or privately insured. Each income 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 were identified (e.g., spirituality) and compared with other emergent categories. Codes were developed, generated from meanings in the data. We coded the entire data set for specific topics using QSR Nud*ist (QSR International Pty Ltd, Melbourne, Australia), a data-sorting software program, resulting 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.⁶⁰ 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, Medicare, and uninsured, and then analyzed by group. The coded data and the narrative analysis yielded the same themes regarding self-care and served as a cross-check on each other.

RESULTS

Demographics

The 167 respondents ranged in age from 21 to 91 years. Respondents reflected diversity in socioeconomic status, ranging from those who were middle-income, worked as professionals, were home owners, and had medical insurance, to those who were low-income, unemployed, lived in public housing or homeless shelters, and had no medical insurance. Educational levels were comparable across all 3 studies, with between 70% and 75% reporting a high school education or less and 25% reporting at least a college degree. Some of those who were unemployed at the time of the study and were categorized as low-income had formerly been middle-income. Downward mobility was especially found among those who were currently uninsured. All respondents were living in the community at the time of the study. See Table 1 for demographic characteristics and health insurance status.

The Cultural Basis of Self-Care Practices

Self-care practices among African Americans were found to be culturally based. That is, respondents described idea systems and behavioral practices that were shared by the sample with respect to general issues of self-care

TABLE 1—Demographics and Health Insurance Status of Respondents (N = 167)

	Medicare (n=8)	Medicaid (n=20)	Private and HMO (n=39)	Medicare and Medicaid (n=29)	Uninsured (n=71)
Age, y					
Range	52–78	25–91	21–83	41–89	22–63
Mean	65.50	47.05	51.31	67.17	45.89
Gender, no. (%)					
Female	4 (50.0)	13 (65.0)	26 (66.7)	23 (79.3)	24 (33.8)
Male	4 (50.0)	7 (35.0)	13 (33.3)	6 (20.7)	47 (66.2)
Marital status, no. (%)					
Married	0 (0)	5 (25.0)	10 (25.6)	2 (6.9)	4 (5.6)
Unmarried ^a	8 (100)	15 (75.0)	29 (74.4)	27 (93.1)	67 (94.4)
Education, no. (%)					
High school	5 (62.5)	15 (75.0)	9 (23.1)	22 (78.6)	28 (39.4)
College/postgraduate ^b	3 (37.5)	5 (25.0)	30 (76.9)	6 (21.4)	43 (60.6)
Work life, no. (%)					
Currently working	0 (0)	5 (25.0)	19 (48.7)	0 (0)	19 (26.8)
Unemployed	0 (0)	6 (30.0)	2 (5.1)	0 (0)	44 (62.0)
Other ^c	8 (100)	9 (45.0)	18 (46.2)	29 (100)	8 (11.3)
Occupation, no. (%)					
Business and professional	1 (12.5)	3 (15.0)	19 (48.7)	5 (17.2)	18 (26.1)
Clerical	1 (12.5)	6 (30.0)	7 (17.9)	1 (3.4)	10 (14.5)
Skilled and unskilled labor	6 (75.0)	11 (55.0)	12 (30.8)	21 (72.4)	40 (58.0)
Other ^d	0 (0)	0 (0)	1 (2.6)	2 (6.9)	1 (1.4)

^aWidowed, divorced, separated, never married.

^bThe majority of uninsured reported some college but no degree.

^cRetired, disabled, student.

^dStudent, homemaker, never worked.

for protecting health, preventing illness, and promoting healing and recovery from illness. These cultural approaches to self-care formed the basis from which individuals developed strategies specific to the particular parameters of their illnesses. Three culturally based factors that were central to the development of self-care approaches were (1) spirituality, (2) social

support and advice, and (3) nonbiomedical healing traditions. These cultural factors were present regardless of socioeconomic status and encompassed a diverse range of activities.

Spirituality and Daily Life

Respondents called attention to underlying spiritual philosophies that were important in

how they proceeded to manage their illnesses. Almost all respondents reported that their belief in God or a higher power helped them to manage their illness. The majority were Protestant (Table 2). Those who did not claim a religious affiliation frequently said they were “spiritual,” but claiming a specific religious affiliation did not necessarily mean a person was a member of a church, and people sometimes claimed the denomination associated with their upbringing, whether they attended church currently or not. Spirituality was usually a part of daily practices. For example, a 45-year-old middle-income university administrator had asthma. She observed, “I start my day with a happy moment. I wake up every morning and before my feet hit the floor I say a prayer.”

Spirituality was also used to ameliorate the effects of structural inequalities. For example, a 35-year-old low-income, unemployed, uninsured man who had asthma described how he used his spirituality to shield himself from discriminatory treatment. He reported, “To maintain one’s spirituality, a high sense of spiritual identity is something you work at daily because there are affronts that you experience daily, so you have to keep yourself healed, physically, spiritually, and mentally on a daily basis, daily practice.”

This integration of mind and body was also expressed by people with a more secular outlook for whom illness management obstacles and strategies reflected racial and class consciousness more than spiritual identity. Both passive and active types of self-care responses to racist encounters were identified. Although this is the subject of another report, we give 1 example of an active response: a 40-year-old man who was employed and uninsured verbally challenged what he believed was racist and class-based bias in the emergency room where he received most of his treatment for hypertension. He described himself as direct, participatory, and demanding in medical interactions: “I had to ask for these things, but if I was White or insured I wouldn’t have to.”

Respondents cited the importance of focusing on inner strength derived from their religion and cultural values in order to effectively manage their illnesses. For example, a 60-year-old middle-income man who had heart disease and kidney disease said, “I need to challenge

TABLE 2—Religious Affiliations of Respondents (N = 167)

	Medicare (n=8)		Medicaid (n=20)		Private and HMO (n=39)		Medicare and Medicaid (n=29)		Uninsured (n=71)	
	No.	%	No.	%	No.	%	No.	%	No.	%
Protestant	4	50.0	6	33.3	18	46.2	18	62.1	30	42.3
Roman Catholic	1	12.5	4	22.2	5	12.8	5	17.2	10	14.1
Other ^a	1	12.5	1	5.6	12	30.8	3	10.3	12	16.9
No religious affiliation ^b	2	25.0	7	38.9	4	10.3	3	10.3	19	26.8

^aIncludes Christian sects and other religions of the world.

^bNot currently a member of a church.

myself, to force myself to just go on because, well, somewhere in my psyche, I doubt if it's machismo or anything like that. But I have this inner spirit and strength that just makes me just tax myself and in doing that, I get better."

The development of spiritual strength was also used to combat the problems of being uninsured. For example, a 50-year-old unemployed and uninsured man who had a chronic back problem reported, "I just tell the Lord, 'Please, I just hope I don't have no problems because I don't know how in the hell I'm going to pay for it.' It's the mind, it's the mind that heals a lot of things on your body. That's how I deal with it. If I can be strong-minded and not cause my mind to break down and cause it to really bring me down, physically or mentally. [Otherwise] I would probably be dead already."

Social Support and Advice

Most respondents had kin or close friends who lived in the same geographic locale, and, with few exceptions, they were involved with them on an ongoing, often daily, basis. Emotional support was highly valued and multifaceted, coming from a wide variety of sources. Reports of receiving no support were rare, and almost everyone had someone they could turn to for emotional support. Both men and women reported their mother was a major source of support and advice. For example, a 30-year-old low-income, unemployed, uninsured woman who had asthma, bronchitis, and debilitating gynecologic problems said, "It [self-care] has a lot to do with my mother—not a doctor—my mother telling me certain things. Giving me advice. I have done a lot of the things she has told me."

Such social support went from child to parent as well. For example, a 70-year-old middle-income woman who had hypertension and was on kidney dialysis reported how her daughter was a constant source of reminders about self-care: "She fusses, 'Mama, you shouldn't go out at night,' and 'Mama, you know you're supposed to stay off that leg.'"

Other relatives were also an important source of support. For example, a 43-year-old low-income, unemployed man who was uninsured and who had been recently diagnosed with a heart condition said, "I don't want to tell them [family] because Ma will worry herself to

death. I wouldn't want to worry her about her baby. I'm the baby of the family. I have a couple of brothers I will tell, and the next thing I will hear is, 'Boy, do this, do that.'"

Friends were also important in reinforcing self-care. For example, a 45-year-old middle-income African American woman who was an accountant and had diabetes reported, "A lot of times I'll take my insulin and won't eat. So that drops my blood sugar down. And everyone gets on me about that. 'Did you eat?' 'Nope.' My friend's mom downstairs helps me a lot, she feeds me. She's like my mother. She makes sure that I eat. Sometimes I do forget and sometimes I don't want to eat. I'm not hungry."

Nonbiomedical Healing Traditions

Respondents of all ages reported the use of nonbiomedical healing traditions in their families as children, and some continued with these traditions in adulthood. For example, a 55-year-old unemployed, uninsured, low-income man who had asthma, allergies, and hepatitis C, said, "She [mother] gave us medicine, a lot of medicines—castor oil, cough syrup, aspirin, and eat right—that was what she used to tell me all the time." A 63-year-old, middle-income, retired woman who had hypertension and diabetes said, "There is kitchen medicine. There have been some things that I have used that have worked well—old family recipes that I'm not willing to divulge."

Some respondents continued to be actively influenced by family members who used traditional medicine. For example, a 23-year-old low-income, unemployed and uninsured man had asthma as well as brittle bones from rickets in childhood. He said, "My mother, she's got over a hundred different teas at the house that you can take for every particular cold through anything. This natural foods grocer, she went in there, and she was like, 'This is heaven.' My mom, she teaches me about the stuff, but it is so much [information] that it is a blur."

Not everyone subscribed to the use of traditional medicine at the time they were interviewed, however. While some were noncommittal, a few reported negative experiences. For example, a 32-year-old low-income woman who was employed as a home health aide commented on her grandmother's efforts

to provide a remedy for her asthmatic child: "Don't try to give me this old folks' remedies. Like my grandmother tried to do that and she ended up harming my son more than helping."

Among people aged younger than 50 years, there was also considerable interest in other types of complementary medicine, regardless of income level. For example, a 40-year-old middle-income loan specialist who had asthma reported, "I think I am in love with the holistic type of healing, even though I half-heartedly pursue it. But I like it better [than biomedicine], the thought of it." When a local low-income clinic began offering free acupuncture, uninsured respondents reported they felt positive about it.

Health Insurance and the Influence of Biomedical Perspectives

African Americans integrated basic cultural approaches to self-care with the development of specific biomedical self-care approaches and applied them to their chronic illnesses. (In anthropology, this process is subsumed within the concept of medical pluralism.) But the development and maintenance of self-care strategies also hinged on socioeconomic and health insurance statuses. Those who had some form of ongoing health insurance much more frequently reported the influence of physicians and health education programs in self-care regimens than did those who were uninsured.

The insured reported more extensive, biomedically informed programs of self-care such as diet and exercise regimens. The case of a retired 48-year-old man who had diabetes and multiple sclerosis and who was insured through a health maintenance organization (HMO) illustrates how cultural approaches to self-care could be integrated with biomedical approaches when adequate private insurance coverage was in place. He described his overall approach to his illnesses: "If I let it get me down, confine me, physically and mentally, then I ain't gonna be worth nothing. But if I can stay positive about it, I'm doing good. I'm definitely praying about it, constantly. I find praying about it helps me focus on the positive. Even if I fail, I'm still going to try. So if I go out on my bike and I scrub, I'm not gonna give it up." He saw his physician frequently: "I talk with him and read the pamphlets he gave me for the diabetes."

His physician also referred him to courses on diabetes run by the HMO: “They signed me up to the diabetes clinic, where I’m required to go every so many days, and they give you nutrition, diets and whatever. It’s a packet that you have to sign and agree to. I just have to get out and go. You know, I gave my word, I told ‘em I’m coming.” He has been to the hospital library twice to read about diabetes. He gets social support and advice from friends and relatives: “A lot of people give me advice. And my thing is, I’m going to do what the doctor says. The doctor says for me, specifically, this is gonna work.”

Diagnosed with diabetes 1 year earlier, he was recently hospitalized, at which time it was decided he needed to be on insulin. He was determined not to undergo another hospitalization: “I don’t want to go back in there. So you work at it. Just tell yourself, ‘No, I ain’t going back.’ Right now I’m doing proactive as much as I can. I exercise. I walk and I lift weights. I took those two 8-pound weights. I carry them when I walk, which is 16 pounds. It helps, you know, exercise helps keep the sugar down. So I just try to do that and stay focused on that. Because sometimes you don’t feel like doing it.” He watched his diet carefully, and his family was very supportive: “My wife says she wants to eat what I eat. I figure why should they [wife and children] have to suffer? But she wants to. They’re [meals] low sugar, low sodium, more vegetables, less starch, very small portions.”

Those who had regular medical care reported how physicians helped to tailor specific approaches to a chronic illness. For example, a 33-year-old low-income woman who was unemployed and received Medicaid had diabetes and high blood pressure. She reported how her physician had educated her about necessary changes to her diet when she was diagnosed with these conditions, which subsequently affected her food shopping and eating habits: “When I grocery shop, I have to watch what I buy, and I have 3 kids, so it’s kind of hard because I can’t put them on a diet. They need sugar and stuff like that. So I have to really, really help myself and discipline myself . . . not to eat it, or whatever. So since I was diagnosed, I have eaten healthier.”

Similarly, a 35-year-old low-income woman, a homemaker who received Medicaid and had

asthma, reported following her physician’s advice: “I don’t drink, I don’t smoke. If I do drink, it’s apple cider. I can’t walk the hills unless I sit down, I still get short of breath. Two months ago I had so much weight, and my doctor advised me to lose weight. I went from 230 to 202. I changed my diet and it is better. Now with my diet consisting mostly of fish and chicken and salad and stuff, I feel better. The weight problem was part of me not walking. So now that I’ve lost that, it’s a little easier for me to walk places.”

However, those who were uninsured reported less continuity in medical input about self-care. One reason they gave was the discrimination they experienced in their efforts to receive basic care. A 42-year-old woman said, “You are treated different when you don’t have insurance. Sometimes I think you are treated different based on your color, on your race. They were borderline rude [in a clinic]. Sort of an indifference.”

Uninsured people were asked to discuss their self-care practices in detail. A 45-year-old man who had been uninsured for 8 years had had asthma since childhood. He relied on borrowing inhalers from friends to manage his asthma. Summing up his situation he said, “I probably suffer more than I should because I don’t have the money to pay for medication.” Unemployed after a long career in the travel industry, his daily self-care emphasized trying to avoid pollen and dust. As a child, he and his siblings took a lot of castor oil, Three Sixes (patent cough medicine) for colds, and hot toddies for the flu. He didn’t recall any special remedies for asthma.

He assumed there were other approaches for treating asthma but he had been frustrated in his attempts to learn more: “I’m sure there are different ways to treat asthma other than an inhaler. But through the years I don’t really know of any other remedies to try and control it myself.” He explained what he meant: “I’ve had a lot of problems with doctors, when I’m trying to talk to them about my problem, and they’ll cut you off. You know, like, ‘You’re not important, you’re wasting my time.’ That’s been a real problem for me. It makes you think that no one really cares, especially when it’s done often. It’s not like its 1 or 2 doctors, it’s a lot of them. I have gone to a lot of different doctors.” As part of his overall effort to

stay as healthy as possible, he reported he did 3 hours of exercise a week, such as walking, calisthenics, and stretching exercises.

In the absence of continuity of care, uninsured people tended to rely on cultural approaches to self-care, especially basic precepts they had learned in their families. For example, a 40-year-old unemployed, uninsured man who had hypertension said, “Basically I try to eat a healthy, balanced diet, but I like junk food. Because ever since I was a child my mom always taught me that eating a meat, vegetable, and a starch is a good healthy diet. She said, ‘Add a fruit here and there.’”

Regular exercise was reported less often by persons who were uninsured, but when it was, walking was most commonly reported. For example, a 52-year-old middle-income man who was diabetic and employed in temporary clerical jobs was uninsured. He said, “If I take a really, really long walk and walk for hours or miles, then it lowers my blood sugar. Definitely has an effect.” Rare were comments such as that of a 50-year-old, middle-income, uninsured man who had high blood pressure, lupus, and arthritis: “I do yoga, and that kinda puts me in a frame of mind where I can accept the pain.”

DISCUSSION

This research demonstrates several important phenomena regarding self-care among African Americans. Key aspects of African American culture are central to the development of self-care strategies. There is a basic approach to self-care that builds on widespread values and practices, including spirituality, social support and advice, and traditional medicine. Each of these cultural practices is important in shaping people’s understandings of self-care. While these practices have been separated for purposes of discussion, they are in fact interrelated; for example, social support and advice may emphasize the use of traditional medicine or the importance of spirituality. These practices are part of an overall cultural ethos regardless of social class or income level. Together, they form the basis for self-care activities that are further refined in order to manage specific chronic illnesses.

However, when this basic approach to self-care was applied to specific health concerns,

the development of additional strategies of self-care was influenced by access to health care. Access to health care made a difference in how people managed their chronic illnesses. Those who had some form of health insurance had many more opportunities to discuss their chronic illnesses with physicians and other health professionals, who were important sources of information and reinforcement of activities aimed at both illness management and prevention. The ongoing nature of this interaction between people and their primary care providers was critical to the development of a self-care approach targeted to specific illnesses. Such interactions resulted in a comprehensive approach to self-care by insured people that incorporated both basic cultural approaches to self-care and biomedically influenced approaches. The combination of approaches often led to highly effective self-care for chronic illness.

In contrast, most of those who were uninsured were left to their own devices. Their attempts at self-care vied with other health and social concerns such as their efforts to gain access to health care, find employment, get enough medication, obtain information about their illnesses, and make ends meet in daily life.⁶¹ In the absence of regular health care, they relied even more heavily on self-care precepts gleaned earlier in life, such as taking a basic approach to healthy diet. They were often without the economic means to actually maintain a healthy diet, however. They did not have ready access to health professionals who could suggest and reinforce steps they could take to integrate their cultural approach to self-care with a biomedical approach.

This research has implications for health disparities. In this study, lack of health insurance had a significant, and deleterious, effect on people's ability to develop complex self-care approaches that reflected both cultural and biomedical precepts of self-care. Combined with their low-income, often unemployed status, uninsured people lacked the economic resources to implement self-care regimens that integrated cultural and biomedical approaches. Access to basic health care was extremely limited, and the cursory attention that uninsured people received when they did seek medical care rarely encompassed directions for self-care.⁶¹ Although health disparities are directly

related to social and economic conditions—conditions that must change for health to improve significantly²—rectifying disparities in access to health care is 1 starting point. Within that realm, access to biomedical input could facilitate the refinement of self-care practices with respect to illness management.

This study had several limitations. The sample was drawn from 1 geographic location, from volunteers who were recruited through a variety of means such as flyers and referrals. Nevertheless, these qualitative findings have implications for how self-care is conceptualized, demonstrating that when self-care is conceptualized as primarily a biomedically derived approach to health, critically important cultural practices directly germane to self-care are overlooked. Self-care needs to be understood as a process that not only evolves over time but develops in relation to the types of illnesses people experience and their specific concerns about their health.

Underlying culturally based self-care practices are important not only in general; they give rise to the development of illness-specific self-care schemes for chronic illnesses. However, regardless of the sophistication of biomedically influenced self-care schemes that people may evolve, cultural approaches to self-care are ongoing and an intrinsic part of daily life. Those approaches not only form the precursor to the incorporation of biomedically derived self-care approaches, they offer a complementary philosophy that both enhances the incorporation of these approaches and interacts with them, as others have also found.⁶²

Studying self-care thus necessitates examining the cultural basis of self-care in a given racial/ethnic group, how biomedically derived constructs are applied, and how the 2 types of self-care approaches are integrated. However, lack of access to health care clearly interferes with this integration and tailoring process. More needs to be learned about how self-care is shaped when people do not have access to health care. Studies are also needed that explore how to build effectively on the cultural basis of self-care in order to help people maximize appropriate management of their illnesses.

In conclusion, although self-care has emerged as an important component of health maintenance, prevention, and illness manage-

ment in recent decades, the cultural components of self-care and their relevance for illness management have been underemphasized. Greater attention to the ways in which culture is implicated in self-care practices could greatly advance our ability to facilitate chronic illness management. At present, with the exception of church-based interventions, public health practice overlooks the feasibility of building on cultural principles and practices of self-care to educate people about management of specific chronic illnesses, an avenue that promises to have great potential. Moreover, comparison of those who are uninsured with those who have some form of health insurance suggests that self-care is an important adjunct to chronic illness management; however, its potential for maximizing that management is not realized for those who lack access to health care. In the face of ongoing health disparities, public health efforts to build on the cultural aspects of self-care would be one step toward reducing morbidity and mortality among racial/ethnic minorities. ■

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Contributors

G. Becker designed the study, developed the interview schedules, led the data analysis, and drafted the article. R.J. Gates participated in the conceptual development of the article, wrote parts of the article, conducted interviews, and analyzed data. E. Newsom managed the research, conducted interviews, participated in data analysis, and edited the article.

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Human Participant Protection

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