Racial-Ethnic Disparities in HIV/AIDS and Health Care in the United States: Evidence from a Sociological Field Research in Alabama's Black Belt

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Author Note

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Abstract

This paper examines African Americans' beliefs of psychosocial factors associated with racial HIV/AIDS and health disparities using an exploratory qualitative study. This research was conducted to determine how African Americans define their health and disease burden, the reasons for their plight; the problems they face; their coping strategies for providing daily necessities of shelter, transportation, and health care. If we ignore the voices of African Americans, we have dehumanized them, making their humanity invisible. Without hearing the voices of African Americans, our understanding of their social life and health issues is incomplete. Analyses from the top down miss the insights that only those experiencing racial health disparities can articulate. Their voices have important implications for policymakers interested in eliminating racial health disparities and promote equity in health. The focus groups discussions in the paper provide the voice, the presence, and the perspective of African Americans who live on the margins and are generally invisible to the rest of us. Issues surrounding racial health disparities are complex, difficult, and controversial. Results indicate that health insurance, lack of access to quality health care, environmental hazards in neighborhoods, poverty, lack of medical practitioners, unhealthy eating habits, poor life style choices, lack of African Americans in health care professions, lack of trust in white health care professionals and unemployment contribute substantially to racial health disparities in America. Health care is a by-product of the distribution of power and the organization of the society.

Keywords: Racial-Ethnic Disparities, HIV/AIDS, Health Care, Sociological Field Research, African Americans, Alabama's Black Belt

Introduction

Equity in health care is a major public health issue in the United States. The disadvantaged groups are negatively impacted. The first HIV infection cases were documented in the United States in 1979 (Newman, 2019). The disease was originally referred to as the "gay plague" because the first group to be identified with the disease was gay men from San Francisco, Los Angeles, and New York (Newman, 2019). The identification of HIV/AIDS with this group led to it first being defined as a sexual epidemic rather than a public health threat. Gay activists and public health officials mobilized to increase awareness and began to change the public's perception of the disease in the early 1980s (Newman, 2019).

Today, HIV/AIDS disproportionately affects African-Americans more than any other racial or ethnic group in the USA (CDC, 2017). Currently representing only 13% of the US population, African-Americans now comprise close to half of the total reported HIV/AIDS cases in the USA according to the Centers for Disease Control and Prevention (CDC, 2017). The situation remains dire and broader attention is necessary from the public health and medical sectors who serve the majority of African-American populations and the community at-large to work towards closing this health disparity gap because good health is a fundamental right for every human being without distinction of race, religion, and political belief, economic or social conditions (WHO, 2015). There is a need to improve equity in health.

Therefore, the purpose of this research was to add insights about disparities in HIV/AIDS and health by focusing on the voices of African Americans who are the most affected. We sought to know how they define their health and disease burden, the reasons for their plight; the problems they face; their coping strategies for providing daily necessities of shelter, transportation, and health care. If we ignore the voices of African Americans, we have dehumanized them, making their humanity invisible. As Eric Alterman argued in an essay for The Nation (Alterman, 2000:12), "While we hear that 43 million Americans lack health insurance, rarely do we read or hear about what it's like to raise a sick child without it."

Without hearing the voices of African Americans, our understanding of their social life and health issues is incomplete. Analyses from the top down miss the insights that only those experiencing racial health disparities can articulate. Their voices have important implications for policymakers interested in eliminating racial health disparities and promote equity in health. The focus groups discussions provided the voice, presence, and perspective of African Americans who live on the margins and are generally invisible to the rest of us.

It is the hope of the author that the analysis and suggestions presented in this research, as well as further work stemming from this research, will enhance understanding of HIV/AIDS and health disparities in the rural south, that they will contribute to better understanding by the public in general, and contribute to better understanding by planners, public health practitioners, and policymakers. The sociological tradition used in this research stresses the need to see a situation from the point of view of the people who are in it. Thus, it directs the investigator to seek out and listen to African Americans own statements of their experiences.

The Study Area

Alabama's Black Belt is easily identifiable to even a casual observer driving through the South. The concentration of rural African-American communities in the South is not accidental. Most of these places are directly connected with the abolition of slavery. There are rural African-American communities in other parts of the United States but they are relatively few compared to the number located in the South. Reconstruction and the implementation of Jim Crow laws ensured that these communities were socially and economically isolated (Zekeri, 2015). Economic arrangements, such as sharecropping and employment discrimination have made these places among the poorest in the nation (Zekeri, 2003; 2015). The area is one of the poorest in the nation and the majority of the residents are welfare dependent (Zekeri, 2015). The residents are, as the President's National Advisory Commission on Rural Poverty put it in 1967, "people left behind." It is also one of those categorized by the United States Department of Agriculture as counties of "persistent poverty" in 2017 (Zekeri, 2018).

Despite their persistence, rural black communities have become "places left behind" in many respects. Although much has been written about the return of African-Americans to the South, and the southern economic boom of the 1970s and 1980s, these developments have not rejuvenated rural black communities. There is ample evidence that economic development in the South is highly uneven, concentrated in urban areas, bypassing African-Americans in rural places (Falk & Lyson, 1988; Lyson 1989; Zekeri, 2003; 2015). The poverty-stricken character of these places contrasts sharply with the affluence of white society. This disparity reflects in some respects the stratification of African-Americans, namely the division between middle-class African-Americans and the so-called underclass.

Although the area was the cradle of the civil rights movement, the poor residents are still faced with many of the same inequities of years past. Living in the area has not been idyllic experience. Residents are still living in the same shacks and shanties described in numerous reports during the1960s, only now, in 2018, there have been more years of deterioration. The Black Belt's remote location, paucity of employment opportunities, and other requirements for industrial development are detrimental to both in-migration and population retention.

Research Method

Qualitative and quantitative methods were used for the study. The study focus groups are widely used in health research as well as in sociological research to gain perspectives, enlightenment, and insight into the minds of participants as they discuss topics of interest to the research (Wilkinson, 2003a). A focus group study is a structured series of group discussions designed to reveal perceptions and opinions on a defined issue involving carefully selected participants who share common characteristics (Bloor et al, 2001 Krueger & Casey, 2000; , Seale et al., 2003; Silverman 2000; 2001; Wilkinson, 2003a; 2003b).

The objective of the focus group interviews conducted in Bullock, Dallas, Lowndes, Macon and Wilcox Counties was to study the underlying beliefs and opinions on psychosocial factors and their impact on HIV/AIDS and health disparities. As Berg (2004) noted, focus groups are not intended to statistically represent the study population, but are an appropriate technique in situation where highly efficient collection of exploratory data is necessary.

African American participants that were HIV-positive were recruited from a HIV/AIDS clinic in Alabama. Others were recruited using a variety of methods, including community liaison recruitment, and a snowball technique where African Americans from churches, barber shops and beauty salons were encouraged to use their personal network and bring a friend to the focus groups. The community liaison was asked to recruit individuals to participate in the focus groups. This approach for recruitment was selected because individuals within the community have better access to residents and more credibility than a person outside the community.

Potential participants were advised that: (1) focus groups would last one to two hours and be held at varied times during the day and evening; and (2) they would be served a light meal during the meeting. They were advised that participation was optional and that they had the right to refuse to answer any questions and withdraw from the focus group anytime.

Follow up contacts with some individuals who had agreed to participate but did not show up revealed that the topic was perceived as a particularly sensitive one that individuals felt reticent about discussing, with their lack of knowledge about the issue at hand being offered as the most frequent explanation.

Written consent was obtained before starting the focus groups, and participants were provided light refreshments. The consent form and questionnaire were approved by Institutional Review Board at Tuskegee University. Before the focus groups sessions began, participants were asked to complete a questionnaire. The questionnaire included questions on demographics and psychosocial variables. The demographic information allowed for a better snapshot of the focus group participants. The questionnaire also stated the purpose of the session. Twenty focus group interviews were conducted over two years focusing on general perceptions of health and medical care; general perceptions of health care provider; general perceptions of medical research. Each topic consisted of an open-ended question followed by a series of probes. We took notes during the sessions. This allowed information such as intensity of discussion, facial expressions, and other interpersonal communication clues to be recorded. These data are stored and locked in the author's office. Personally identifiable information were collected and confidentiality is being maintained numbering the questionnaire.

Difficulties in recruiting participants, funding limitations, and the applied nature of this project informed the decision to conduct four focus groups in each county. The focus group methodology used here reflects decades of similar designs utilized in social science, health care, and marketing research (Seale et al., 2003).

Data Analysis

The content analysis approach (Seale et al., 2003; Silverman, 2000; 2001) was used in the study to analyze the data. Content analysis produces a relatively systematic and comprehensive summary or overview of the data as a whole, incorporating a quantitative element. In this research, a content analysis is used to address the research question of how often different psychosocial factors are mentioned as causes of racial health disparities in America.

Results

A total 215 African Americans from five counties in the Alabama Black Belt participated in the focus group interviews. Each of the focus group session averaged about 10 participants. Twenty-five percent were males while the majority (75%) were female. The mean age for the group was 50 years. Ten percent of the participants indicated graduating from high school, 60% reported attending some college, and 16.7% indicated graduating from a 4-year college.

Reasons for Disparities

When it comes to the health of African Americans, accurate representation of the historical context should include reference to the transatlantic slave trade, enslavement, emancipation, and the Jim Crow era. Many of the respondents (90%) believed that health disparities were justified by the unequal and inherently inferior status relegated to enslaved Africans. Respondents talked about how denied treatment for 399 men enrolled in the United States Public Health Service (USPHS) Study of Untreated Syphilis in the Negro Male (also known as the Tuskegee Syphilis study) helped create a culture of mistrust in the medical community (William, 1991; 1994; 1995). With heartless disregard for human life, the USPHS told the 399 African American men that they were part of special treatment program. Men came to believed that they were part of a type social club and burial society called Miss Rivers' Lodge. The men did not know that they had syphilis. For 40 years, even after penicillin was used to treat syphilis, the U.S. Public Health Service allowed these men to go without treatment. They kept testing them each year to study the progress of the disease. One focus group participant from our research said that "health care provider biases, prejudices, and stereotyping have contributed disparities in health care."

Sometimes personal racism is to blame for health outcomes. For example, in one study, doctors described African American patients no matter their education and income levels as less intelligent, likely to follow medical advice, and less likely to participate in rehabilitation, and as more likely to abuse alcohol and drugs than white patients (Van Ryn & Burke, 2000). Thus, we can list individual racial bias and bigotry as factors contributing to racial imbalances in the health care system. In America, race-ethnicity bias may be somehow a subconscious motivation in giving or denying access to advanced medical procedures. Racism continues as a regular feature of the American society, often something that whites, not subjected to it, are only vaguely aware of. African Americans, are however, on the receiving end, racism is an everyday burden.

Health Insurance

One of the many reasons given for the racial disparity in HIV/AIDS and health is lack of health insurance. Most of the focus group participants (83%) believed that lack of health insurance by African Americans explains a significant part of the health disparities (Table 1). They believed that a high percentage of African Americans in the Black Belt are uninsured or underinsured. African Americans are the least able to afford regular medical checkups, prescription medicines, and even over the counter medications (Zekeri, 2015). Although African Americans are aware of early detection and screening of cancer, they tended to have a fatalistic view of their health outcomes once they have cancer (Zekeri, 2015). Because of fatalistic views and lack of health insurance, African Americans are less likely to take advantage of preventive services (Zekeri, 2015).

Table 1. Reasons given for Racial/Ethnic Disparities in HIV/AIDS and Health Care in the United States by Focus Group Participants.

	Percent
Race	85.6
Health Insurance	83.0
Unequal access to quality health care facilities	75.0
Poverty	77.0
Not enough medical practitioners in black communities	85.0
Unhealthy eating habits	80.0
Dieting, Exercise, and Lifestyle Choices	88.0
Environmental Racism	56.7
Under-Representation of Blacks in Health Care Fields	85.0
Unemployment	73.3

Another finding from the sessions is that uninsured African Americans are less likely to seek medical help until their illness has progressed to a serious state. For an example, from previous research in the Black Belt, uninsured African Americans are more likely than those with insurance to be hospitalized for avoidable complications of conditions such as hypertension and diabetes – problems that could be managed in a doctor's office (Zekeri, 2013; 2015). Therefore, financial concerns, not outright racial prejudice, may lie at the heart of health policies.

Some focus group participants talked about how they reduced their medications (cutting their pills in half or taking medications every other day) or stopped taking their medicine altogether (those who could no longer afford their medications). Although some of the women in the group received Medicaid for their children, most had no health insurance for either their children or themselves. As one single mother reported,

> I do not have health insurance except for my baby. She is on her father's plan. When anybody is sick, we go to the doctor and pay for it. Health insurance would cost more than $300 a month for us.

What was also evident from the focus meeting is that the cost of medical care, particularly out-of-pocket expenses is a financial burden even to some African Americans with health insurance. Some participants said that illness or medical bills can lead to bankruptcy.

Unequal Access to Quality Health Care Facilities

The distribution of and access to health services for the African Americans in the Black Belt are significantly uneven. For many who lived in this poor geographic region, they have no adequate health care coverage package. More than half of the group participants (75%) believed that racial disparities in HIV/AIDS and health are based, in large part, on the unavailability of quality services in black communities. The availability and quality of health care services are not equally distributed in America. Several African American women commented that the likelihood that African Americans in the Black Belt would obtain early detection and screening for cancer and HIV/AIDS is hindered by lack of access to quality primary care physicians and health facilities. These rural poor have problems of access to health care as medical facilities and practitioners are not available locally. For example, lack of access to health care contributes to a decrease in the availability and use of mammography, and an increase in diagnosis at later stages of breast cancer for black women (Zekeri, 2015). There are immense physical and psychological barriers in these areas as well. The people interviewed responded that having money and health insurance in the Black Belt are not enough to make the residents feel safe.

Increasingly, hospitals and ambulances that serve these black communities are either closing, relocating, or becoming private. In Alabama, the likelihood of a hospital closing is directly related to the percentage of blacks in the community (Zekeri, 2015). Residents of Macon County felt stigmatized and discriminated against in terms of health care because John A. Andrews Hospital closed in 1987. Residents told the investigator that geographic availability and proximity are important determinants to seeking health care services early. In the Black Belt, many patients are treated in an outpatient or ambulatory setting, including physician offices and clinics. Home health care is usually less expensive and more convenient for the patient than the care provided in a hospital or skilled nursing facility (Zekeri,2015).

Poverty

Interestingly, another common context, other than health insurance and access to quality health care, that was routinely heard in focus groups, was poverty. Most participants

(77%) believed that high poverty among African Americans is another contributing factor to health disparities (Table 1). These African Americans felt that the variables that contributed mostly to their increased incidence of cancer, HIV/AIDS and other diseases were beyond control. In addition to poverty, oppressive forces such as segregation, substandard health care, and the subsequent feelings of meaninglessness, hopelessness, and social despair provide the environment for the emergence of cancer fatalism.

As one 30-year-old respondent put it *"because of poverty, blacks are less likely to take advantage of preventive services and the quality of the health care they receive tends to be lower."* Participants told investigators that blacks are more likely than whites to receive treatment in hospital outpatient clinics and emergency rooms, which are more often public than private. It was their perception that whites are more likely to go to a private doctor's office.

An African American mother of two, who works as a nurse's aide explained that *"poverty also can aggravate the hypertension suffered by African Americans, and various other acute and infectious diseases that are more common among people in the lower social classes. High rates of poverty among African Americans mean that they are less likely to receive early and adequate medical treatment."*

In the United States, health and access to health care are unequally distributed on the basis of socioeconomic status (Duncan et al., 2001; Haan et al., 1987). Money, or the lack of it, explains much of the disparity in HIV/AIDS and health of African Americans and whites.

Not Enough Medical practitioners

Not enough doctors and nurses in black communities – many participants alluded to these when asked to explain racial disparities in HIV/AIDS. Eighty-five percent of the participants indicated that lack of health care providers as the source of much of the problem. Participants stated inadequate providers make good health care difficult. An African American woman with four children said *"many doctors do not want to practice in rural areas, leaving a doctor shortage in Alabama's Black Belt Counties."* Some spoke of white health care providers who belittled their complaints, over-booked appointments and kept them waiting, and made it difficult for them to obtain the best care.

Physician availability fluctuates by region and type of locale. Few doctors locate in low-income rural communities like the Alabama's Black Belt, although some foreign-born doctors have done so. Alabama's Black Belt Counties cannot provide the expensive, sophisticated equipment and technical support personnel that many of today's physicians prefer, and they don't comprise enough patients to justify high capital costs (Zekeri, 2010; 2015).

Social Health Behavior

Approximately 80% of the participants believed that the racial and ethnic differences in health are due to African Americans' unhealthy eating habits. African Americans are much more likely than others to eat high-sugar, high salt, and high-fat foods. Bad health behaviors mentioned during the interview include smoking, abuse alcohol or other substances, failing to use seat belt or other poor safety behaviors such as not engaging in adequate physical activity.

Environmental Racism-Physical Environment

Physical environment factors include health threats from exposure to toxins and unsafe conditions, particularly in residential settings. Environmental racism, the tendency for the U.S. hazardous waste sites and polluting industries to be located in areas where the surrounding residential population is African American may also contribute to poorer health among African Americans (Zekeri and Habtemariam 2006). Although health care access and other social variables might account for some of the disparities in HIV/AIDS and health, more than half of the participants (56.7%) reported their perspective that differences in environmental and occupational exposures also play a role. A 50-year-old African American man felt that *"there is a disproportionate placement of pollution-intensive industries and hazardous waste sites in African American communities."*

During the focus group discussion, someone talked about the well-known recent example of environmental danger that took place in Flint Michigan which is 57% black, with nearly 40% of the citizens live in poverty. Crises started Flint in 2016 after it was revealed that officials failed to publicly acknowledge that the water supply had been contaminated with lead and had poisoned local children. Both Michigan and the Federal government declared a state of emergency. Lead poison is associated with a variety of illnesses, developmental delays, and behavioral problems (Doleac, 2017). In Flint, Michigan, residents suffer from heightened levels of stress, depression, and trauma (Goodnough $ Atkinson, 2016). In 2017, a government appointed civil rights commission issued a report blaming the crisis on "historical, structural, and systematic racism" (Almasy & Ly, 2017, p.1).

Black communities are affected by contaminated air and drinking water, the location of hazardous waste treatment and storage facilities. Furthermore, African Americans are more likely to live in polluted environments and are more likely than whites to work in hazardous occupations where they are exposed to toxic chemicals, dust, and fumes (Zekeri 2015). In the Alabama Black Belt Counties, exposure to pollutants from nearby industrial facilities, power plants, toxic waste sites present hazards for many.

Under-Representation of African Americans in Health Care Fields

Many of those who were interviewed (85%) believed that under-representation of African Americans in the health care fields is part of the problem. African Americans are seriously under-represented in the health care profession and this lack of representation is particularly significant for African American communities like Alabama's Back Belt that rely on African American physicians for care (Zekeri and Habtemariam 2006). Many study participants felt that with so few African American health care professionals in the Alabama's Black Belt, the control of the health care system lies almost exclusively in the hands of whites. One man said that *"even when blacks complain of chest pains and other symptoms of heart disease, white doctors are less likely to take the complaints seriously."*

Lack of Trust in White Health Professionals

Another issue that came out of the interviews and discussions is distrust in white health professionals by African Americans. African Americans are more reluctant than whites to seek treatment for HIV and AIDS because they distrust the government (Zekeri 2013; 2015). This is because of the infamous Tuskegee experiments conducted by the U.S. government for 40 years (from 1932 to 1972). For the experiments, 399 poor black men were recruited and led to believe that they would receive free medical treatment for what they called "bad blood," while, in fact, they were left untreated for syphilis so that the government health researchers could study the impact of the disease on them.

Unemployment

Many African Americans in the focus group interviews (73.3%) felt that unemployment makes good health care difficult and thus, contributes to disparities in HIV/ AIDS and health. A lack of jobs paying a living wage and health benefits abounds in the Alabama Black Belt (Zekeri & Habtemariam 2006; Zekeri, 2015) Many participants talked about the difficulty of finding employment, particularly a job that pays a living wage. The reason for their difficulty in finding a job becomes more apparent when we recognize that certain segments of the population have extraordinarily high rates of unemployment, particularly young African Americans and other minority groups without a high school diploma (Zekeri ,2015).

Many African Americans are unemployed or employed in jobs that do not provide health care insurance (Zekeri, 2007; 2013; 2015). Yet, access to health care services is related to ability to pay, and ability to pay is related to access to health insurance. Searching for work and coming up with nothing is a demoralizing experience. Consequently, some people in the Black Belt quit looking for a job after many unsuccessful attempts.

Discussion

African Americans' belief of psychosocial factors associated with racial HIV/AIDS and health disparities were examined in this exploratory qualitative study.

Reducing disparities in HIV/AIDS and health care between racial groups is currently a major focus of interest in the United States. In the past years, the United States Department of Health and Human Services has launched major initiatives in this area (Zekeri, 2015). Unfortunately, however, adequate information to describe social factors, most notably from African Americans' perspective, has generally been unavailable or extremely limited in academic studies. This study contributes to this gap in research on health disparities.

Issues surrounding racial health disparities are complex, difficult, and controversial. However, health insurance, lack of access to quality health care, environmental hazards in neighborhoods, poverty, lack of medical practitioners, unhealthy eating habits, poor life style choices, lack of African Americans in health care profession , lack of trust in white health care professionals and unemployment contribute substantially to racial health disparities in America.

African Americans face many barriers in obtaining quality health care. The biggest obstacle they must overcome is the lack of affordable insurance. Lack of transportation, the location of health care facilities, the unequal distribution of health care providers in the area, inability to pay for visits to the doctor or co-payments, and referral patterns all contribute to racial health disparities in HIV/AIDS in the area.

Of the many factors contributing to health disparities discussed, insurance coverage appears to be a key. Having health insurance, more than any other demographic or economic factors, determines the timeliness and the quality of health care. One reason for lack of health insurance is the higher poverty rate among African Americans.

Among African Americans, money problems are constant in most of the families and periodic in the others. Conversations during in-depth interviews and focus group discussions frequently turn to the money problem.

As one person put it:

> "Right now we're kind of stuck for money. We're just making it by. Like, we just keep up with the bills. I just paid the phone bill, and our money's about all out. So, we'll have to wait till next week before we do any work on our house. If there's any money next week."

The stress and worry about getting by is ever-present. Some help come from state Medicaid or the federal Medicare program for older people. But families sometimes incur medical costs when they have no insurance, and usually have to pay some portion of costs even when they are covered. There is often confusion about medical insurance or assistance – what it covers, when it expires, how far back it is effective, and whether the family is currently eligible. Medicaid is available to people with incomes below a certain level, even if they are not on welfare, but fluctuating incomes and re-certification problems leave many families without coverage.

Conclusion

A decade after the historic election of Barack Obama as president of the United States on November 4, 2008, America still struggles with the debilitating effects of personal and institutional discrimination based on race, religion, and ethnicity. Despite recent gains, African American still suffer noticeable disadvantages in health care, economic, politics, education, employment, and many other areas. When opportunities to health and health care system are unequally distributed according to race, all facets of life remain unequal.

Health care is connected to the American social structure. The political economy, corporates structure, and the distribution of resources and power influence health and illness. Health issues in the United States are an assortment of economic, political, cultural, and social forces outside the immediate control of the individual: a shortage of jobs that pay a living wage, persistence of discrimination, residential segregation, and social isolation. Health issue is a social problem, according to the socio-structural perspective; it is a by-product of the distribution of power and the organization of society.

Some innovative, energetic attempts are already being made in some Alabama Black Belt Counties and some communities to address the health disparity problems. However, the fledgling efforts need much more help, both financial and institutional, from outside the area, in part because the rural counties as a whole are not sufficiently affluent to combat local poverty and health care issues. The health care problems need to be better understood; and, a great deal of more resources must be devoted to them, simply to prevent health disparity from getting worse, and to hold on at present levels. Without a concerted effort in Alabama Black Belt Counties, a long-standing pattern of socio-economic and health disparity within the counties may grow much worse. Improvement will require even greater effort. Unless there is a commitment to reduce and prevent health disparities, the problem will cycle through still more generations and engulf more people and communities.

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