Handbook of Health Psychology

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African American Health

Publication details
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Published online on: 18 Dec 2018

Accessed on: 24 Aug 2023
African American Health is a complex topic that subsumes many diseases. Hence, the phrase is often used to reflect a general trend of disease states and etiological mechanisms that combine to produce reliable predispositions, onset, manifestation, and resolution of health conditions (CDC, 2017). Interestingly, it also describes patterns of factors associated with resilience and longevity. In this chapter we explore several common diseases among African Americans, describe contributory factors that influence the course of diseases, discuss disparities in health related to these diseases, and present rational solutions for reducing health disparities as well as morbidity and early mortality in African Americans. We briefly delineate some of the complex factors associated with the conceptualization of health and pathology in African Americans. We chose to focus on a cross-section of disorders for which African Americans seek formal treatment for in the healthcare system. These disorders include chronic pain, diabetes, migraine headache, depression, and dementia.

Conceptualization of Health Among African Americans

In the current chapter, we conceptualize health and disease as products of genetic, biological, and psychological factors all co-occurring in a social context (see Figure 24.1). Simply stated, the social context is the environment in which an individual experiences social interactions. The model presents the interactive relationship between human genetic predisposition and environmental exposures. There can be manifestations of health that are strictly genetic, others that are strictly environmental, and yet others that result from the interaction of genetics and environmental exposures.

One major example is sickle cell disease (SCD), a complex genetic disease affecting one in ten African Americans (American Society of Hematology, 2016; Edwards, Johnson, Goli, & Byrd, 2005). The initial onset of symptoms can be altered by environmental factors but the initial manifestation is reliable and consistent across cultures. The course of the disease, however, appears increasingly susceptible to environmental factors such as access to healthcare, nutrition, and many other factors. The literature on the interaction of the genetically bound manifestations of SCD and social and environmental factors like racism, perceived discrimination, and social inequity as a major contributor to clinical outcomes is steadily growing. For example, in one study, perceived racism was intimately associated with increased cardiovascular reactivity and slowed recovery times from a provocative stressor (Merritt, Bennett, Williams, Edwards, & Sollers, 2006). Similar influences of social and environmental experiences are observed in cardiovascular diseases, dementia, and other conditions discussed in this chapter (Whitfield et al., 2010).
The use of the terms “race” and “ethnicity” have been complicated in medicine and research (Edwards, Fillingim, & Keefe, 2001). Advances in genetics are beginning to clarify some of the historical beliefs that race simply may be a social construct. Genes and gene interactions are only one mechanism, often misunderstood, by which heritable characteristics and predispositions are transferred from a parent organism to its offspring. African Americans have more in common with many other populations genetically, than they differ. It has been found that individuals from different populations (between-group variance) have more genetic similarities than individuals from the same population (within-group variance; Whitherspoon et al., 2007). We are learning that although genetic differences may be small between racial groups, the areas that are different seem to be potent in transmitting intergenerational risk for certain diseases (Reich, 2018).

Many early conceptualizations of heredity focused exclusively on genes and the expression of genetic code transferred during reproduction. In response to known limits of genetics in the human phenotype and behavior, more modern approaches conceptualize heredity as the transfer of characteristics of the parent organism to offspring via a range of mechanisms that include both genes and social institutions. This becomes particularly important in the conceptualization of African American health (Edwards & Byrd, 2008).

Biological contributors to health and disease in this model are thought to represent the total of all life functions and those factors that contribute to or alter life functions in African Americans. They include, but are certainly not limited to, factors such as nourishment and appropriate macronutrient intake, vitamin balance, presence of appropriate levels of serum and tissue electrolytes, blood pressure, blood sugar levels, hydration, and a range of other factors. It is notable that biological and genetic factors are often closely related but the two remain distinct. In many cases, biology is predetermined by genetic factors (e.g., skin color or tone). But increasingly we are aware that risk and resilience to

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Figure 24.1  Sociocontextual Model of Health and Diseases in African Americans
African American Health

disease is an interaction, or more specifically the mutual influence, of genes with environmental factors. Gene expression influences biology, and changes in biological demand may alter genes.

Psychological factors have been shown to alter biological patterns of functioning, and are used in many medical settings as an intervention to alter the management and trajectory of disease in African Americans. For example, relaxation training and cognitive behavioral therapy have been found to reduce reports of chronic pain among patients who did not respond positively to medication or other medical interventions (Ehde, Dillworth, & Turner, 2014). Similarly, learning to control negative thinking and emotional processes has been associated with many positive health behaviors, the reduction of blood pressure in patients with hypertension, and increased glycemic control in patients with diabetes (Harvey, 2015; Trudel-Fitzgerald, Gilsanz, Mittleman, & Kubzansky, 2015).

Stress is often associated with poor behavioral control, poor compliance, and worse clinical outcomes among patients with many chronic illnesses. Whether via yoga, relaxation training, religion (O’Connell-Edwards et al., 2009; McDougald et al., 2009), or formal therapeutic interventions at the individual or community level (Collins-McNeil, McCabe, Sharpe, Hawkins, & Edwards, 2015), controlling negative thinking and emotional and behavioral factors are generally associated with better clinical and social outcomes, whereas stress is associated with poorer outcomes in African Americans (Harrison et al., 2005).

Integration of race and culture into understanding clinical outcomes among African Americans is essential to address the underassessment and under-management of pain in this population (Booker, 2016). The social context in which African American health occurs exerts a significant influence on almost all known factors of African American life. Biological and psychological factors are influenced by the environment, and hence, influence African Americans’ health. The social context is broadly defined as by the primary proximal or distal environments that are interfaced or perceived as interfaced while functioning in a particular setting. Aspects of the social context include socioeconomic status, racism, discrimination, social inequity, housing (or lack thereof), and proximity to essential services and resources.

Collectively, our model of African American health, as shown in Figure 24.1, suggests that health outcomes are the result of multiple known and often unrecognized factors. This includes direct and indirect effects of each of these determinants, as well as interactive effects among them.

Disparities in Particular Conditions

Chronic Pain

The International Association for the Study of Pain (IASP) summarizes chronic pain as a subjective persistently unpleasant sensory or emotional experience in response to actual or perceived tissue damage that is not reliant on the target’s effective communication of such pain (IASP, 2016). This definition is important because it suggests that ethnic, educational, and experiential factors that may alter the expression or communication of pain do not alter its existence. Hence, ethnic populations such as African Americans, Latinos, and others who may not be able to conform to describing or converting their internal experience into ratings (e.g., numbers or pictures that represent the experience of pain, a standardized assessment technique) are no less deserving of effective pain management. Although the biology that moves a stimulus from a peripheral neuron into the central nervous system and ultimately to higher brain centers for interpretation are relatively consistent across humans, how those stimuli are interpreted at the level of the cortex is quite variable and dependent on individual experiences, culture, and a range of other sociocultural, demographic, and educational factors (Mechlin, B., Heymen, S., Edwards, C. L., & Girdler, S. S., 2011).

Some estimate chronic pain to be present in up to 40% of community populations (Mossey, 2011), with African Americans and other communities of color being significant overrepresented.
Factors such as the language used to communicate about the experience of pain, culture, religious beliefs, and individual differences may contribute substantially to health disparities in the identification and treatment of chronic pains among African Americans. For example, biological differences in cardiovascular and somatosensory reactions to generally noxious stimuli may account for substantial ethnic differences in reactions to pain. Damage to peripheral nerves and the body’s neurohormonal system, secondary to comorbid diseases like hypertension and diabetes, may delay or alter neurological responses to noxious environmental stimuli allowing for greater tissue damage before recognition of the stimulus. Limited formal education or inexperience with pain may further diminish the likelihood that a patient will be able to convert their internal experiences into standard assessment methods. These factors are common among aging cohorts of African Americans.

Other factors such as religion, medical distrust, and culture may also account for significant variance in responses among ethnic populations to painful stimuli. Fears of interacting with healthcare providers from other cultures, the lack of providers with similar external racial and cultural characteristics, communication problems and being labeled “drug seeking,” difficulty in understanding consent forms and regulations (Edwards & Rogers, 2007), and experiences with a history of sub-standard pain care as well as validated anxieties about involuntary enrollment in studies as a “guinea pig” all fuel delays in African Americans pursuing medical care, even when insurance and access are provided. Often a remnant of a history and legacy of a profound racial and social divide in the United States, and for too many a representation of their current reality, disparities in access to effective pain management still exist. Religious beliefs about the productive and expected role of suffering on earth combined with obstacles to care produce a significant untreated and undertreated African American population suffering with chronic pain. These factors appear consistent across diseases such as sickle cell disease, osteoarthritis, and peripheral neuropathy secondary to diabetes and hypertension.

Diabetes Mellitus

Diabetes mellitus has become one of the most prevalent chronic diseases in the US with 798,000 new cases diagnosed every year. Approximately 17 million people in the US, or 6.2% of the population, have diabetes. Almost 5.9 million people (or one-third) are unaware that they have the disease. The disease burden includes the prevalence of major depression being approximately twofold higher in individuals with diabetes than in those without. Unfortunately, African American women with type 2 diabetes represent one of the highest-risk groups in terms of prevalence and diabetes disease burden (Samuel-Hodge et al., 2000).

Including prediabetes (a condition that leads to diabetes if not treated and managed) to these numbers suggests over 100 million Americans have either diabetes or prediabetes (Center for Disease Control and Prevention [CDC], 2017). Of those individuals, 12.2% are African American men and 13.2% are African American women. This percentage is double that of European American women (6.8%). Moreover, African Americans with diabetes are twice as likely as European Americans to experience complications such as blindness (retinopathy), end stage renal disease, lower extremity amputations, and other serious complications (Centers for Disease Control and Prevention [CDC], 2017). Specifically, in the southern US, African Americans with diabetes have poorer glycemic control and higher blood pressures and they are at greater risk for diabetes-related complications and death than European Americans (Chronic Disease and Injury Prevention, Division of Diabeties, Heart Disease, Obesity and School Health, 2018). These disparities have drawn attention to the need to develop accessible and efficacious programs to improve disease management and reduce the negative impact of diabetes for African Americans.

A published review of 16 community-based interventions found that only one half contained representative samples or discussions of populations that have been historically and disproportionately
burdened by diabetes, including African and Mexican Americans, American Indians, and Native Hawaiians (Satterfield et al., 2003). The value of community-based and culturally tailored interventions for diabetes in African Americans is increasingly a topic of research pursuit. Reducing the morbidities associated with diabetes continues to be the goal of early intervention among African Americans (Collins-McNeil, Holston, Edwards, Benbow, & Ford, 2009).

Type 2 diabetes occurs when the body is no longer able to use insulin effectively, or what has been termed “insulin resistance.” (See Chapter 31 for a full understanding of diabetes mellitus). Effective self-management of type 2 diabetes typically involves a complex regimen including healthy eating, weight control, medications, blood glucose monitoring, exercise, and stress management over long periods (van Tilburg et al., 2001). Impediments to self-management of type 2 diabetes among African Americans include poor understanding of the relationship between diabetes and diet; denial that diabetes is serious; and lack of confidence, coping skills, and competence to carry out the treatment regimen. In addition, negative attitudes and emotional distress can contribute to poor diabetic control. Interventions that combine counseling for dietary management, weight reduction, and physical activity are pivotal in reducing morbidity associated with type 2 diabetes mellitus. Moreover, self-management behaviors are influenced by culture and lifestyle, including food choices (Gould, Kelly, Goldstone, & Gammon, 2001). A better understanding of the influences on diabetic outcomes among African Americans remains a research priority.

The single most daunting attribute of type 2 diabetes is the increased risk of cardiovascular disease, and the association among depression, diabetes, and CVD in the general population is well established (Leon & Maddox, 2015). The presence of major depression in individuals with diabetes results in symptom amplification; that is, even when controlling for severity of diabetes symptoms, individuals with diabetes and comorbid depression experienced more symptoms associated with their diabetes than their non-depressed counterparts (Badescu et al., 2016).

**Cardiovascular Disease**

Cardiovascular disease (CVD) is a collective term for diseases of the heart and blood vessels (Australian Government Department of Health, 2016). In general, CVD refers to conditions that involve narrowed or blocked blood vessels that can lead to coronary heart disease, heart failure, cardiomyopathy, congenital heart disease, peripheral vascular disease and stroke. CVD is the leading cause of death for women; one in four women are affected by CVD (CDC, 2017). African Americans have higher rates of CVD mortality than other racial or ethnic groups (Villiblanca, Wardford, & Wheeler, 2016).

CVD is the leading cause of death of women in the United States. CVD is a particularly important problem among minority women. More specifically, CVD accounted for 40.6% of deaths among African American women in 2000. African American women tend to develop heart disease at an earlier age and have the highest incidence and prevalence of type 2 diabetes (Leon & Maddox, 2015).

**Migraine**

Migraine headache is a neurological disorder characterized by recurrent attack of unilateral and sometimes retro-orbital pulsing, throbbing, and often debilitating headache. It can present with or without aura but is often comorbid with photo- or phonophobia, nausea, and vomiting. The prevalence of probable migraine, a label sometimes given to individuals that don’t fully meet clinical criteria for migraine, is significantly higher among African-Americans than European Americans (Silberstein et al., 2007). In many cases, patients may be missing an element that would be used to diagnose migraine in the context of all other symptoms and signs of migraine headache. Although many patients will have at least some impairment in their functioning with probable or full migraine
headache, African Americans with migraine are more likely to be diagnosed with depression, and have their headaches underdiagnosed and under treated (Heckman & Britton, 2015).

An analysis of National Hospital Ambulatory Health Care Survey data found that 91% of patients presenting for care for migraine headache were European Americans compared to 6% African Americans (National Hospital Ambulatory Medical Care Survey, 2015). In a study comparing health-care utilization and treatment for headaches between African Americans and European Americans, only 46% of African Americans compared to 72% of European Americans had sought treatment for migraine headaches (Nicholson, Rooney, Vo, O’Laughlin, & Gordon, 2006). Patient–physician communication and level of trust that patients have in their healthcare environment also differed, and may affect the clinical outcomes among African American patients seeking care (Martin, Roter, Beach, Carson, & Cooper, 2013), but few studies have directly assessed this complicated clinical process (Patwardhan, Coeytaux, Deshmukh, & Samsa, 2007).

Researchers in recent years have begun to explore interventions for migraine headaches that reduce racial/ethnic disparities in treatment by providing modestly priced non-invasive neuromodulatory interventions that can be used at home, without the need for travel time to medical facilities (Wilkinson et al., 2017). Because there are few side effects and the medications are easily accessible, ongoing trials exploring the differences in vestibular responses between African Americans and other populations (Black et al., 2016).

**Depression**

African American women have been identified as a group at high risk for depression (Barbee, 1992), although the evidence is conflicting. African American women are less likely to have diagnosed depression disorder (16%) than European American women (22%). However, of those Africa American women suffering from depression, almost half (47%) are afflicted with severe depression (U.S. Department of Health and Human Services, 2003). Depression has been positively associated with metabolic syndrome, a precursor of CVD, among women younger than 40 years suggesting that early detection and treatment of depression may potentially forestall the risk of CVD (Martin, Neale, Batterham, & Tapsell, 2016).

**Dementia**

“What is good for the heart is good for the head” has become a common medical maxim for preserving cognitive functioning and healthy aging. What is not always taken from that conversation is “what is bad for the heart is bad for the head.” African Americans have almost two times the risk of developing dementia, but are less likely than European Americans to receive an early diagnosis and treatment (Barnes & Bennett, 2014). Genetic and environmental factors appear significantly influential in the early manifestation of dementia symptoms among African Americans (Cukier et al., 2016; Sims, Allaire, Gamaldo, Edwards, & Whittfield, 2009; Whitfield, Kiddoe, Gamaldo, Andel, & Edwards, 2009). Poor diet, lack of exercise, environmental exposure to toxins, poor stress management, and a range of other psychosocial and environmental factors have also been associated with early onset of symptoms as well as poor clinical outcomes and mortality in African Americans (Rakesh, Szabo, Alexopoulos, & Zannas, 2017). There is a shift toward inclusion of psycho-education as an early remediation for risk of dementia as the population of African Americans with dementia grows (Llameque et al., 2015).

Dementia in African Americans is often comorbid with disorders like chronic pain (Edwards et al., 2005), CVD, diabetes, obesity, and migraine headaches (Barnes & Bennett, 2014). This significantly magnifies the disease burden for those stricken with the disease as compared to many other populations (Ellison, 2017).
Addressing African American Health Disparities

As shown in the studies reviewed in this chapter, it has become commonplace to compare African Americans to other populations as an index of their health status. This approach has become pervasive in research and very few studies are conducted for the express purpose of understanding African American health without comparison to other populations. In order to understand how African Americans compare to other populations in terms of their health status, we must first understand that factors that are associated with wellness and pathology within this population. An effective comparison of apples to oranges requires that you first understand what an apple is and what an orange is not. Similar principles apply to the study of African Americans: Studying African Americans without comparison to other groups is a legitimate research pursuit.

One of the failures of comparative studies is that African Americans are often compared to European Americans. As a result of their generally higher socioeconomic status, European Americans, in general, have access to many health resources, such as proximity to a major healthcare facility, particularly among rural communities. Comparisons of African American to European American health in many areas may be premature until there is an adequate understanding of the genetic, biological, and psychosocial contexts for health behaviors and the factors that drive pathology in each of these diverse populations (Whitfield, Allaire, Belue, & Edwards, 2008).

One of the most effective and readily available mechanisms to reduce health disparities and increase the health and quality of life of African Americans is to increase their representation in clinical trials and research studies. We recognize that there are other factors, but we believe that representation in trials is an issue that can be resolved immediately with effort. In many studies, researchers are allowed to justify not recruiting African Americans to clinical trials. As such, many studies have inadequate representation of African Americans. Other studies make assumptions of homogeneity and fail to analyze their data by race/ethnicity.

Capital Investment Model for Recruitment of African American Research Participants

We propose a model for including African American participants in clinical trials, the Capital Investment Model (CIM; see Figure 24.2). Note that the name of the model reflects the mechanism of action. The capital investment model consists of three sequential and iterative stages: (1) Capital Preparation, (2) Participant Recruitment, and (3) Capital Dissemination.

The CIM model is based on several principles that provide logic for the execution of practical steps towards effective participant recruitment. First, the model assumes that not all individuals are equally informed about the mechanics of research. There are broad and diverse understandings of what “research” means, the definition of informed consent, the process by which placebo vs. active treatment is decided, and the need for placebo controls, among other issues that researchers often take for granted. Education and information about the research process become cornerstones of the current model.

Figure 24.2 Capital Investment Model of Participant Recruitment
A second assumption of the CIM is that not all individuals are equally motivated to participate in research. Given various levels of education and insight into research as well as diverse interpretation of the historical ills associated with research, it is natural that there would be varying degrees of motivation among a sample of potential participants. This assumption is particularly relevant among older minority individuals whose experiences of racism, discrimination, and inequity may be quite different from younger cohorts.

The third assumption of the CIM is that, in the absence of individual knowledge, potential research participants are likely to seek information from trusted community leaders, peers, and institutions. This assumption is relevant to understanding the importance of education and dissemination within communities of interest. Our best efforts to populate studies with appropriate samples can be easily derailed by inaccurate information provided by trusted, but non-scientific, sources. Consequently, there is a need to educate the community as well as individuals, not only about specific studies but also about the broader context in which those studies are conducted.

The fourth assumption is that not all researchers’ motives are equal and genuine. As a consequence, there is the need for research participants to be discerning consumers of science. This is not to say that every potential participant needs to be a scientifically trained researcher with a doctoral degree. It does suggest that researchers who have an invested interest in empowering research participants will ensure that they are also consumers of science and invested stakeholders who can make good decisions about study participation.

The last assumption is likely the most important: all researchers and research participants are created equal. Many researchers operate under the belief system that their scientific needs have the highest priority and that research participants are expendable, easily replaceable, and undeserving of the highest levels of respect. Unfortunately, this mentality has resulted in numerous researcher atrocities and the underrepresentation of ethnic elders in clinical research.

The CIM is premised on mutual respect between scientists, communities, and individuals who choose to participate in a study. The very best scientific ideas have no relevance until they can be evaluated in a representative and diverse sample. Moreover, the scientific community must acknowledge that the welfare of research participants should take priority over individual research ideas. In many situations, the individual’s willingness to participate in a study is contingent on how they view the study’s potential to improve health outcomes, not only for themselves but also for the community at large. As a consequence, we recognize that one of the greatest failures of the scientific community is represented by the inability to tie our research priorities to those of individuals and communities.

The CIM concept operates on multiple levels within an environment that fosters interaction and communication between scientists, communities, and individuals. These relationships are developed and maintained through a systematic process that involves integrating and assimilating into known community institutions, incorporating the needs of potential populations into the overall goals of the research study and disseminating the study’s results.

We now describe each of the components of the CIM from three perspectives: the researcher’s, the community’s, and the individual’s.

**Capital Preparation**

**Researcher’s Perspective**

Capital preparation is the first step in the CIM paradigm that must be addressed by the research team. Capital preparation involves going into the community in which you plan to recruit, and developing relationships with key stakeholders and community leaders. These leaders include local...
political figures, pastors, community advocates, and local physicians. Communicating the benefits of research participation is a necessary component in demystifying research. During this time, the Principal Investigator (PI) should make sure he or she is working very closely with stakeholders in addressing the healthcare issues that are of concern for that particular community. Finally it will be important for the research team to hire or work with local individuals from the community who can act as a liaison between the research team and the community. All of these preparatory activities are necessary for the development of a strong partnership between the researcher and community that will be instrumental for recruitment.

We distinguish this phase in our model (Figure 24.2) because we believe that this is an essential phase for effective relationships with participants that ultimately leads to their willingness to engage in research studies. We also believe that in a time of financial and time limitations, this is the phase that is most likely to be neglected.

Community’s Perspective

The community must adapt their beliefs about the research process. Unfortunately, there has been a failure of the African American community to conceptualize their power to influence individual decision making towards the reduction of morbidity. A fear of exploitation from the medical community has resulted in the community’s resistance to partner and collaborate with individuals from major academic institutions. In the future, community-based organizations must acknowledge and embrace their role in all aspects of a research project, from inception to data dissemination. This will necessitate community leaders acting as liaisons of health promotion and improvement for the community through the development of community advisory boards and advocacy groups.

Individual’s Perspective

Within ethnic minority communities, there is a significant fear of being a guinea pig. This mentality has developed from historical inequities that have facilitated mistrust towards the medical and scientific communities. A serious misconception of what “research” is and its importance also contributes to resistance of individual participation in research. Research scientists and community organizations must systematically work together to educate and inform individuals of the urgency and need for their participation in research. The individual must also understand that not all researchers have less than genuine intentions and, as a research participant, they have a right and responsibility to seek out information that will elevate their level of trust.

Participant Recruitment

Recruitment is a necessary but insufficient component of effective participant management. Recruitment is used to refer to a single interaction that serves a single purpose: providing a medium for those who are already inclined to participate in research. It does not alter the probability of recruiting others, successful future recruitment, or successful interpersonal interactions, nor does it increase the probability of participation of individuals who are not already inclined to engage in research. As shown in Figure 24.2, effective participant recruitment requires efforts before and after the process begins. Each stage of effective recruitment is intimately connected to the successful execution of the previous stage and future stages. It facilitates future recruitment efforts and increases the probability of participation by those who are not immediately inclined to do so through the integration of current research efforts as part of an individual, community, and societal goals.
Recruitment is the next step that involves the actual accrual of research participants for the study. First, it is important for the researcher to understand that recruitment of ethnic minority elders and those who are most respected in the community is much more time and labor intensive than recruiting non-minority participants. Therefore, an appropriate timeline should be developed for the recruitment period to reflect the additional time that will be needed. Community activities such as health fairs and seminars can be used to obtain participants.

It also is important for the researcher to utilize the partnership that has been formed with community stakeholders to help with recruitment, for example, providing lectures at local churches and community events or forming a community advisory board. The researcher should also make sure that potential participants understand and feel comfortable with actual research processes, such as informed consent. This is especially important given that many African Americans feel that signing informed consent documents relinquishes their rights as a participant and provides legal protection for the researcher (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999).

The community also has a responsibility to play an active role during the recruitment phase of the study. Whether it is the community advisory board or key stakeholders, the community must get involved at the grass roots level and monitor recruitment. The success of recruitment is contingent on the community making sure that the study is visible and accessible to all individuals. It is also important for community leaders to assure members of the community that appropriate safety measures have been taken to protect the confidentiality of the data and that this will be monitored through the study’s entirety.

As in the earlier phase, it is paramount that the individual become an informed consumer of research. This means finding out what the study is about and contacting leaders in the community with ethical questions or other concerns. It is important for individuals to understand that they have the power to ask questions and make an informed decision concerning participation in a study.

The final step in the CIM involves making the results of the study accessible to the community through dissemination of the study’s findings. This can be achieved through various community forums, including seminars and working with local physicians who can share the information with their patients. In addition to sharing the results with the community that participated, study findings also should be used to develop and implement larger-scale programs that implement key findings from the study.

Capital dissemination is dependent on the community stakeholder who will facilitate the implementation of programs that can be viewed as tangible outcomes by the individuals that participated in the study as well as the community at large.
Individual’s Perspective

The researcher and their institution should be held accountable for providing the results in a manner that is appropriate and respectful to the community. Again, it is important that both the community and the individuals who participated in the study are provided with information concerning its results and their applications to their own healthcare. Dissemination of the results should be presented in a format that can be understood by lay people. This allows the individual to be an active participant throughout the entire research process. A list of key recommendations for each stage of the process is included in Appendix A.

Conclusion

The term African American Health is sometimes overused to represent what is a very complex and often individualized response to provocation from genes and the environment. Better understanding of the complex dynamics that contribute to both health and pathology from genetic, biological, and psychosocial sources may add to our knowledge in a way that African American health status begins to increase, and the relationship to other populations is altered. Early diagnosis, assessment, and effective interventions based on such principles may raise the health status for all African Americans. Assumptions of homogeneity among any group are increasingly obsolete in an environment of individualized medicine. Scientists must advocate for the inclusion of time and funding for community-level capital investments as standard operating procedures.

References


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APPENDIX A
How Not to Recruit African Americans to Behavioral-Based Clinical Trials and Research

1. Rely on famous names and senior academic status as your recruitment strategy
   a. You are accomplished in your field, your colleagues know you, and African American research participants should too. Don’t they read the journals???
   b. “African American research participants TRUST me because I have been here for a long time.”

2. “I wasn’t there so it’s not relevant”—Historical misdeeds are not important to me or potential African American participants. Neither of us were there at that time.
   a. Ignore Tuskegee.
   b. Ignore other research ills.
   c. Ignore current media on research ills and participant deaths confirm history.
   d. Ignore that many current and historical research ills have been worse than legend and myth.

3. “My needs are most important as the researcher because I have the most knowledge.”
   a. Never include African Americans in the research conceptualization.
   b. Never do a needs assessment prior to planning research.
   c. Make sure that participants call me “doctor” and that I don’t know any of their names.

4. “It worked in the past and it should work with African American participants.”
   a. Never use consultants from the community you are trying to engage.
   b. Remain rigid and hold to the research principles you were taught in graduate school.
   i. Never consider changing your recruitment methods even when they don’t work.

5. “We don’t need a recruitment strategy. Our research is top notch.”
   a. Never setup community-based outreach and recruitment.
   b. Never setup shop in the community you want to recruit.
   c. Do as little service for the community as is possible.

6. “If we hire A++ marketing, then we never have to go to their neighborhood.”
   a. Colorful handouts are all African Americans research participants’ need!
   b. When discussing your research, make sure to use big long technical words so that potential African American research participants know that you are educated and smart.
7. Ignore the African American churches, civic organizations, and respected community leaders.
   a. When you are forced to interact with these African American institutions, treat them as disposable. Remember that they are here for your consumption.
   b. Take as much of their valuable time as you need without compensation.
   c. Make sure that the relationships are all about you. Tell potential African Americans over and over about your curriculum vita and your last promotion. African American participants love to hear about you and what they can do for you.
   d. Make sure that the research you are asking African American churches to assist with has little benefits for them, requires great efforts on their behalf, and leads to a single interaction where they will never see or hear from you again.

8. “Recruiting African American staff and investigators is way too expensive for this project. We will simply use our undergraduate and graduate students as our community liaisons.”
   a. Try not to meet with African American community leaders more than once.
   b. Always make sure that participants and community stakeholders come to you at the university or college. You should never hold meetings in the community!
   c. Make sure that all of your staff looks like you instead of the community you are trying to recruit.

9. “We recruited six African Americans in the last study. Isn’t that enough?”
   a. Keep samples of African Americans small so that you never have to breakout with analyses based on demographics or sub-populations.
   b. Just represent the majority and guess at what’s happening with sub-populations.

10. “Once I get my data, I am out of there.”
    a. Never go back and provide feedback on the outcome of your published or unpublished data.
    b. Make sure that African American research participants never feel connected to your research! It’s yours because your institution owns it.
    c. Never ever publish in lay books, newspapers, or magazines. And above all, never give interviews to the media. Keep your results close at hand and make sure that no participants ever value their time with you.