



Health Disparities and COVID-19 Pandemic: Increasing Clinical Research Participation among African Americans

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Kashica J. Webber-Ritchey , *DePaul University*, kwebberr@depaul.edu

Abbi D. Lane-Cordova , *University of South Carolina*, lanecord@mailbox.sc.edu

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Abstract

Health disparities in African Americans is a persistent issue. Higher rates and severity of the novel coronavirus-19 [COVID-19] among African Americans only widens health disparities. Effective COVID-19 treatment options are imperative, requiring representation of African Americans in clinical research. However, low participation and under-representation of African Americans is complex in nature. This article describes health disparities, the impact of COVID-19, and participation in clinical research among African Americans. We offer strategies for researchers to enhance the inclusion of African Americans. We also offer strategies in conducting clinical research during COVID-19.

Keywords

African Americans, health disparities, COVID-19, and research participation



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Kashica J. Webber-Ritchey, DePaul University
Abbi D. Lane-Cordova, University of South Carolina
Corresponding Author: Kashica Webber-Ritchey, kwebberr@depaul.edu

ABSTRACT

Health disparities in African Americans is a persistent issue. Higher rates and severity of the novel coronavirus-19 [COVID-19] among African Americans only widens health disparities. Effective COVID-19 treatment options are imperative, requiring representation of African Americans in clinical research. However, low participation and under-representation of African Americans is complex in nature. This article describes health disparities, the impact of COVID-19, and participation in clinical research among African Americans. We offer strategies for researchers to enhance the inclusion of African Americans. We also offer strategies in conducting clinical research during COVID-19.

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HEALTH DISPARITIES AMONG AFRICAN AMERICANS

Non-Hispanic Black adults (ages 65 years or younger) have higher levels of chronic diseases such as hypertension, diabetes, and stroke when compared to non-Hispanic White adults (Centers for Disease Control and Prevention, 2017; (Cunningham et al., 2017) and higher mortality from cardiovascular disease and cancer (Cunningham et al., 2017). Cancer is the leading cause of death among African Americans (Jemal et al., 2017). Evidence also supports how African American, Hispanic or Latino, and American Indian or Alaska Native communities are disproportionately affected by the novel coronavirus, COVID-19 (Centers for Disease Control and Prevention [CDC], 2020d; Yancy, 2020). Approximately 90% of disproportionately Black counties reported a COVID-19 case and 49% reported a COVID-19 related-death versus 81% and 28%, respectively, for all other counties (Millett et al., 2020). Cities such as Milwaukee, St. Louis, Chicago, New York City, which are characterized by large African American populations, are being hit hard by COVID-19 (Millett et al., 2020). Age-adjusted COVID-19 related hospitalization rates show that non-Hispanic Blacks have a rate at 178, which is approximately five times that of non-Hispanic Whites at 40 (CDC, 2020b).

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Health disparities among African Americans arise from an interplay of racial, social, and gender disparities in which the main social determinants of health are racism, poverty, educational level, environmental and living conditions (e.g., housing and exposures within the environment), access to healthy foods, violence, and inequities in criminal justice (Noonan et al., 2016). The call to eliminate health disparities and achieve health equity in African Americans is not a new issue (Noonan et al., 2016).

COVID-19 highlights the disparities experienced by African Americans. Social conditions, structural racism, and other factors contribute to the higher risks linked to COVID-19 in African American communities (Millett et al., 2020), and structural racism is the root cause of health disparities (Yearby, 2020). Table 1 provides an overview of some of these factors. Social distancing, one highly effective way to prevent the spread of COVID-19, is not easily actionable for some African Americans (Yancey, 2020).

Table 1. Factors Contributing to Higher COVID-19 Risks

Conditions	Description
Living	Residence in densely populated area increasing exposure to COVID-19. Living in low-income households, crowded conditions elevating exposure, and minimum options to quarantine (Adamkiewicz et al., 2011; Centers for Disease Control and Prevention [CDC], 2020b; U.S. Bureau Labor Statistics, 2018).
Working	Serving as an essential worker, lack of ability to take a sick leave or stay home from work (CDC, 2020b).
Health	Pre-existing health/medical conditions; Uninsured or underinsured, resulting in lack of access to healthcare service and absence of timely care (CDC, 2020b; 2020c).
Structural Racism	The structure of health care, education, employment, housing, and public health systems that create inequalities among racial and ethnic minority groups (Yearby, 2020).

Participation in research is crucial to assess the safety and efficacy of new treatments for African Americans to reduce health disparities (Harris et al., 1996). The underrepresentation of African Americans in clinical research is complex, with multiple contributing factors (e.g., socioeconomic and environmental) that create barriers to participation are described in Table 2.

Due to a long history of racism and incidences of unethical conduct in the medical and scientific community, African Americans are reluctant to participate in research (Harris et al., 1996; Schaff et al., 2010; Otado et al., 2015). Mistrust of medical research and the health care system is extensive (Scharff et al., 2010) and heavily cited as a barrier to research participation (Harris et al., 1996; Schaff et al., 2010; Williams et al., 2010). Researchers should address all barriers to participation, and addressing mistrust is paramount.

Table 2. Barriers to Research Participation among African Americans

Past abuse in medical experimentation (e.g., Tuskegee Study)
Fear and social stigma (i.e., stereotyping or labeling as a research participant)
Negative personal experiences with the health care system, such as institutional racism and differential treatment
Feelings of mistrust
The nature of the experimentation involved in higher risk intervention research
Educational level (i.e., education disadvantage)
Communication issues (i.e., absence of addressing concerns during recruitment phase and duration of the study)
Logistical issues (e.g., time commitment and expenses as a research participant creating a general inconvenience)
Lack of awareness (i.e., ineffective recruitment efforts by researchers)
Compensation
Lack of interest and confidence in clinical research

Note. Adapted from literature (Centers for Disease Control and Prevention, 2020a; Ford et al., 2013; George et al., 2014; Huang & Coker, 2010; Luebbert & Perez, 2016; Otado et al., 2015; Savitt, 2002; Scharff et al., 2010; Tanner et al., 2015; Washington, 2006).

RESEARCH PARTICIPATION IN CLINICAL TRIALS AMONG AFRICAN AMERICANS

Historically, African Americans have been underrepresented in clinical trials (Harris et al., 1996; Tufts Center for the Study of Drug Development, 2020) even when the illness disproportionately affects the African American population, such as cardiovascular disease, cancer, and diabetes (Centers for Disease Control and Prevention, 2017; Cunningham et al., 2017; Khan et al., 2020). Approximately 4% were non-Hispanic Blacks when compared to non-Hispanic Whites at 81% among clinical trial research for cardiovascular and diabetes mellitus drugs (Khan et al., 2020). Moreover, the enrollment of African Americans in pivotal clinical trials, such as multiple myeloma clinical trials are 0.5% to 19.9% (Bhatnagar et al., 2017) while African American participation in human immunodeficiency virus (HIV) vaccine trials are 17.3% (Huamani et al., 2019). The participation of African Americans in global clinical trials for oncology treatments are 2.7% (U.S. Food & Drug Administration, 2017).

The problem of underrepresentation in clinical trials is important because the efficacy and acceptability of treatment options may vary based on an individual's racial or ethnic background (Buchard et al., 2003). Clinical trials aid in the development of effective treatment options such as drug efficacy and safety—but how will this be achieved when research conducted lacks adequate

representation of African Americans? Achieving health equity cannot occur unless research includes African American participants (Warren et al., 2019). Researchers must build trust to obtain adequate representation of African Americans in research to reduce health disparities (Akintobi et al., 2020; Luebbert & Perez, 2016). An integral component of trust-building is establishing effective partnerships with the community (Akintobi et al., 2020). Table 3 describes best practices for recruitment, retention, and inclusion of African Americans in clinical research.

Table 3. Recruitment, Retention, and Inclusion Strategies for African Americans

Strategy	Description
Develop a clear recruitment and retention plan	Researcher dedicates time prior to the implementation of a clinical trial to: <ul style="list-style-type: none"> • develop and implement culturally tailored study materials (Luebbert & Perez, 2016), • pay special attention to inclusion and exclusion criteria (Langford & Bateman, 2020), • minimize participant burden in both trial enrollment participation in the study (Langford & Bateman, 2020), and • ensure that adequate resources are allocated for recruitment and retention of diverse participants (Jimenz & Czaja, 2015).
Utilize multiple recruitment strategies	Word of mouth, inform about the potential impact of study findings on health disparities, and circulate culturally-tailored materials such as flyers or advertising in newspapers within African American communities (Otado et al., 2015; Scharff et al., 2010).
Increase knowledge of social issues within the African American community	Conduct training for all research staff on the research process and on sociocultural factors of the African American population (Luebbert & Perez, 2016).
Field based approach	Dedicate time to go into the communities to have a presence,

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	develop community partnerships, build relationships, and establish rapport with community members (Otado et al., 2015; Scharff et al., 2010).
Culturally competent research teams	A study team of African American investigators and coordinators who actively engage with target African American communities, demonstrating trust and respect to study participants and potential participants, to deliver culturally relevant information about the research project (Otado et al., 2015) and potential impact of the study findings on health disparities (Scharff et al., 2010).
Establish effective partnerships	<p>Involve the community in all phases of the research process: design, implementation, and evaluation to elevate communities as senior partners (Akinobi et al., 2020).</p> <p>Seek information from participants about the criteria that they use to evaluate trust in capacities of investigators and health care providers and institutions (Crawley, 2000).</p> <p>Obtain multi-leveled commitment to ensure tailored and culturally sensitive approaches (Sabatello et al., 2021).</p> <p>Work collaboratively with health care systems and providers to provide access to studies where participants reside and currently receive care and to increase awareness about clinical trials. (Langford & Bateman, 2020).</p>
Address health literacy levels of study participants	Assess readability levels of study materials; develop study materials that are understandable to participants that possibly low literacy readers (Taani, 2020).

Post-visit follow-ups	Make phone calls to participants to inquire about their general well-being (Otado et al., 2015).
Provide frequent reminders	Contact participants with reminders prior to upcoming appointments (Otado et al., 2015).
Offer additional incentives for each follow-up visit	Offer parking validation tickets, snacks, or lunch coupons (Otado et al., 2015).
Flexible scheduling	Acknowledgement and respect of participants' time and schedules by including after work hours and weekend study visits (Otado et al., 2015).
Displaying respect	Encouraging participants to voice their concerns related to the study and in general and listening to those concerns; being sensitive to their needs (Otado et al., 2015).
Convenience of participation	Addressing the logistic barriers to participation [i.e., covering transportation costs, visits/meetings conducted at a site nearby public transportation, childcare availability at the visit for parents, and providing travel vouchers] (Otado et al., 2015).

In light of the underrepresentation of African Americans in clinical trials, determining the efficacy of COVID-19 vaccines or treatments are bleak. African Americans possess mixed feelings toward vaccines due to previous measles, mumps, and rubella (MMR) vaccines (Pew Research Center, 2017) and are less likely to receive other types of vaccines such as influenza vaccine and pneumococcal vaccine (U.S. Department of Health and Human Services, 2018). However, African Americans (41%) reported benefits in allowing access to experimental COVID-19 treatments before clinical trial completion (Pew Research Center, 2020). Most African Americans (54%) also reported they would get a COVID-19 vaccine if available today (Pew Research Center, 2020). The identification of effective and trustworthy COVID-19 vaccines and treatments requires adequate representation of African Americans in clinical trials. Once efficacy and safety is determined of treatment options for African Americans, those options should be affordable and readily accessible (Wen & Sadeghi, 2020).

CONDUCTING RESEARCH DURING COVID-19

Clinical research has been affected by COVID-19 in which studies have been halted as a result of redirection of resources and in-person-visits (Tuttle, 2020). The disruption in clinical trials conducted and its impact on patient care is potentially devastating. For example, clinical trials for oncology patients are needed during this time and should resume (Cooney, 2020). Due to

adherence to social and physical distancing, face-to-face interactions in the homes, churches, and other community settings have been prevented which present challenges to community engagement. Social distancing limitations have influenced the ability to establish human connection and in-person exchanges (Akintobi et al., 2020). We offer strategies to consider in conducting research during COVID-19 (see Table 4) that should be applied in addition to the strategies used to recruit and retain African American participants.

Table 4. Recommendations for Conducting Research during COVID-19

Strategy	Description
Modify research and data analysis	As research involving face-to-face interactions is minimized, prepare for remote data collection and ensure proper connections for videoconferencing (Clay, 2020).
Consult with your institution	Researchers will need to follow guidelines and directives by their institution in resuming research, screening research participants (Clay, 2020).
Protect research participants	Benefits to patients must outweigh the risk (Clay, 2020). Inform about required changes in protocol and the potential risk(s) associated with study participation (McDermott & Newman, 2020).
Maintain communication with research team and staff	Frequent communication is important to keep the research project going and safeguarding the mental health of your team members. (Clay, 2020).
Maintain communication with study participants	Use telephone, email, and the electronic health record portal to provide study updates (Tuttle, 2020).
Adhere to social distancing policies	Incorporate the telephone, video tools, or wearables for data collection (Langford & Bateman-House, 2020). Require masks and physical distancing and restrict visitors to the absolute minimum number needed (Tuttle, 2020).
Implement new modes of community engagement	With face-to-face interactions limited, utilize webinars and digital technology formats (Akintobi et al., 2020).

To conclude, COVID-19 sheds light on the interplay of racial and social disparities coupled with social determinants of health that contribute to health disparities in African Americans.

COVID-19 has exacerbated disparities but also presents an opportunity to work to achieve health equity in African Americans (van Dorn et al., 2020; Hooper et al., 2020). Researchers are encouraged to pay close attention to building trust when conducting research among African Americans. Our hope is that this discussion adds perspective regarding the need to identify effective recruitment and retention strategies that aid in the inclusion of African Americans in clinical research to address health disparities.

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