

Black Mental Health in the USA: Nothing for Us without Us 3



Community-based participatory research with Black people and Black scientists: the power and the promise

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Community-based participatory research (CBPR) is a collaborative approach that involves active participation and input from members of the community on all aspects of the research process. CBPR is an important research method as it can empower communities to work with academicians and other scholars for more robust and culturally appropriate interventions. Although CBPR is useful regardless of race or ethnicity, it is particularly important for Black scientists and communities. This is because CBPR seeks to address social and health inequities by engaging with historically excluded communities, as well as to produce research that is relevant to the community. Successful CBPR initiatives can improve Black mental health through collaboration, empowerment, and cultural sensitivity, as the current under-representation of Black scientists hampers mental health equity efforts. Equal funding of Black scientists is key to conducting community-engaged research. We discuss CBPR and its importance for Black mental health, case studies of CBPR conducted by Black scientists, Black leaders, and community members, and what is necessary for Black people to attain mental health in an inherently racist society.

Introduction

For centuries in the USA and globally, the lives and lived experiences of Black individuals have been undervalued in research. From early definitions of mental illnesses (eg, drapetomania) designed to obfuscate and create pejorative and unfounded narratives of so-called Black-specific mental illnesses,¹ to more contemporary arguments of Black intellectual inferiority based on so-called genetic analysis,² theories on Black people being poor and uneducated abound. Yet, people of the African diaspora have thrived, despite a research system that has neither valued nor provided equal opportunities for Black people to identify, prioritize, or equally participate in research directly affecting their mental health.

Black scientists comprise less than 1% of researchers receiving independent research funding from the US National Institutes of Health (NIH),³ an organization funded primarily by the taxpayer. Black scientists are more likely to propose topics and conduct research relevant to Black and racially diverse communities; therefore, their under-representation in the research community has implications for research into Black mental health.² The pernicious influence of this low representation of Black scientists is extensive. Scarce funding for Black researchers only exacerbates health disparities that exist among Black people in a system designed to be inequitable. For instance, for people with an opioid use disorder in the USA, there is a two-tiered addiction system, with one tier for how Black people access treatment and one tier for how White people access treatment.⁴ Black people are more likely to access methadone through highly regulated opioid treatment programs in areas of high crime and drug use, whereas White people have access to the less regulated medication buprenorphine through primary care offices in more affluent White areas.⁴ This is one example of the social, political, and structural biases that

exist in the American mental health-care system, which makes it difficult for Black people to access equitable care.⁵ Advancing solution-focused interventions to dismantle racist and biased practices in federal grant funding is key to reducing health disparities, as is providing opportunities and capital for Black scientists to conduct health-related research outside of traditionally exclusionary systems. Funding Black scientists could prove useful in identifying population-level and community-level solutions to these problems, as Black scientists are more likely to pursue research in these areas, although they are the least likely to be funded.⁶ Community-based participatory research (CBPR) is one such approach that is often used in community and population health research pursued by Black scientists and that empowers Black people and other key stakeholders as partners in research, rather than disempowering them by only engaging them as study participants.⁷

CBPR is a collaborative approach that involves active participation from members of the community of interest in all aspects of the research process.⁸ CBPR recognizes that community members have unique knowledge, skills, and perspectives that can inform research questions, study design, data collection, data analysis, and dissemination of findings. Although we focus in this Series paper on how CBPR can be used to improve research and mental health for Black Americans, it should be noted that CBPR can be used regardless of the race or ethnicity of the researcher or scientists. By embracing CBPR, we can strive to expand the benefits of our efforts for Black people across different geographical regions and socioeconomic status levels. Embracing CBPR means recognizing that mental health research and services should not be limited to specific areas or economic backgrounds, but should be accessible and inclusive for all individuals.

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CBPR aims to promote the equitable distribution of power and resources between researchers and community members, and to prioritize the needs and concerns of the community in the research process.^{5,9,10} CBPR seeks to address social and health inequities by engaging with communities that have historically been excluded from research, and by producing research that is actionable and relevant to the community. CBPR typically involves partnerships between academic researchers and community-based organizations, with the goal of creating positive social change and improving the health and wellbeing of the community. The process might involve capacity-building activities, such as training community members in research methods and analysis, and could result in the development of interventions or programs that are co-designed and co-implemented by community members and researchers.

A CBPR approach might be particularly useful when adapting interventions for use with racially and ethnically minoritized or underserved populations. Black scientists, due to their lived experience and increased likelihood to study topics that are more reflective of the Black experience,² should be leading and teaching others how best to advocate for community involvement and partnership to benefit Black communities. CBPR can promote relationships among partnership members (eg, organizations, leaders, and advocates) and uncover the insights each group brings. By including community partners in the research process, CBPR has the potential to ensure that interventions are adapted to be culturally appropriate and acceptable for the community in which the intervention will be implemented.¹¹ Specifically, adapting interventions in partnership with community stakeholders can help to ensure communities' authentic lived experiences are reflected in the research process itself, to influence the questions that are proposed, and to enhance cultural and local sensitivity and facilitate sustainability.

Mental health CBPR with Black people: frameworks and case studies

Suspicion. Mistrust. Fear. Anger. These are some of the emotions many people in Black communities experience when they think about traditional research methods and outcomes of studies regarding their emotional, spiritual, and physical health. The history of abuse in the name of research for people of African descent and among Indigenous communities continues to unfold.¹² The troubled historical context of research done without consent, coupled with ongoing health-care disparities rooted in racism among Black people,¹ fuels Black individuals' caution regarding health-care advice and participation in clinical trials.¹³ This history of abuse affirms the concern many Black people have about the value and efficacy of public and mental health research. Negative reactions and accompanying hesitancy among some Black people to be vaccinated against SARS-CoV-2

during the COVID-19 pandemic reflects the reluctance Black people have in trusting medical research and the advice of health-care professionals.¹⁴ However, such concerns and reluctance can be mitigated by authentic engagement using CBPR.

Effective CBPR with Black communities means understanding that the research laboratory is everywhere that Black people are found (across different geographical regions and socioeconomic status levels, including people with lived experience of mental illness, and among diverse Black cultures and ethnicities). Effective CBPR approaches acknowledge the diversity of the Black experience and dispel the myth that Black people are reluctant to engage and ill-equipped to trust the research process.

To encourage authentic engagement, several frameworks can be used. Breland-Noble and colleagues created a model for optimal conduct of CBPR with Black people after working with underserved and marginalized Black communities in Chicago.¹⁵ The model, known as the Seven Field Principles of Community Psychiatry,¹⁶ is rooted in the theory of triadic influence,¹⁷ which centers two key principles in health promotion: what causes health behaviors; and how to promote health-enhancing behaviors (eg, daily exercise) and deter health distracting behaviors (eg, smoking cigarettes). The Seven Field Principles include rebuilding the village, providing access to health care, increasing connectedness, increasing social skills, re-establishing the adult protective shield, increasing self-esteem, and minimizing trauma.^{16,18}

The Seven Field Principles of Community Psychiatry approach assumes that positive behavior change is supported via person-centered, collaborative approaches and has demonstrated effectiveness in improving behavioral health outcomes in Black adolescents.¹⁵ A US-based non-profit research organization focused on reducing health disparities in young people of African descent and young people of color, called The African American Knowledge Optimized for Mindfully-Healthy Adolescents (AAKOMA) Project, uses the Seven Field Principles through blending community science with traditional approaches to clinical, psychiatric, and behavioral science (eg, clinical trials).¹⁹ Specifically, traditional practices of using standardized research measures and randomly assigning participants into experimental and control groups for comparison are still observed, but they are enhanced with culturally fluent practices grounded in socio-behavioral norms important to Black people. For example, The AAKOMA Project researchers train community partners in the fundamentals of mixed methods approaches to research via a full-day workshop led by traditional academics. The purpose of this training is to rebuild the village (one of the Seven Field Principles). However, the phrase it takes a village to raise a child encapsulates a broader community-oriented approach that can be applied to

mental health and wellbeing, which aligns with the Seven Field Principles emphasis on holistic care and addressing social determinants of mental health. The notion of rebuilding a village suggests the need for collective effort and community involvement in promoting positive mental health outcomes. This approach recognizes that individuals are influenced by their social environment, and that community support plays a crucial role in fostering resilience and wellbeing by capacity building within the community and building equity into the research process overall. The AAKOMA Project researchers (who are not a part of the traditional academy) provide community members with training in understanding Institutional Review Board history and current practices, budgeting for research activities, understanding study participant randomisation, and selecting culturally relevant outcome measures, so that they are better equipped not only as consumers of research, but also to lead and co-lead research long after the initial research is completed. Through these practices, The AAKOMA Project provides a model for community empowerment, resulting in tangible outcomes, such as co-authored publications and opportunities for community leaders to co-present in historically valued clinical research settings, such as hospital Grand Rounds.²⁰

Carrying out collaborative research with Black people (as opposed to Black people's involvement in research being historically restricted to a participant) reframes research so that it seeks to empower communities and educate academicians. This framing is radical, unapologetic, and can yield promising results. For example, one study from The AAKOMA Project serves as a catalyst for change, striving to create a more equitable and inclusive mental health landscape for people of African descent in America.¹⁹ By embracing cultural competence, community partnerships, education, advocacy, and peer support, the project aims to empower individuals, strengthen communities, and address the mental health needs of marginalized populations. In this study by The AAKOMA Project, the one year retention rate for study participants was 88%.¹⁹ This rate is substantially higher than the retention rates of Black people in larger and well funded behavioral and psychiatric clinical trials (eg, retention rates of 30–60%).^{21,22}

In another CBPR project for adults, Bellamy and colleagues, in partnership with recovery support specialists, built a program that reduced recidivism of formerly incarcerated Black people with severe mental illness and substance use disorders by focusing on their sociocultural needs when they re-enter communities.^{23,24} The program provides opportunities for people with lived experience to lead, and it does not dictate the best approach to recovery for citizens returning to the community after being incarcerated; instead, it works collaboratively to inform their care and builds a

personalized service plan for each participant.²⁴ A fundamental principle of this work is that formerly incarcerated Black people exist within systems that must be held accountable to reduce recidivism among returning citizens to the community.

In addition to the Seven Fields Principles, Jan Fook's research framework²⁵ questions how the profession of social work needs to evolve to meet the needs of all people, rather than only those of the dominant White society. This framework can be useful in guiding the process of integrating patient preference into mental health research and treatment. The framework and associated questions therein are intended to guide community psychiatrists and other mental health professionals in their approach to understanding and addressing mental health concerns within general community settings. Fook poses the question "What is happening here?" to allow the provider to delve more into the social and cultural contexts that might be affecting behavior.²⁵ This question encourages community psychiatrists to delve beyond individual diagnoses and symptoms, and to explore the broader social, cultural, and environmental factors that contribute to mental health issues within a specific community. Additional questions in her framework are posed to emphasize the importance of cultural humility and self-reflection when conducting CBPR, and the need for researchers to be aware of their own biases and assumptions to ensure that research is inclusive and culturally sensitive.

Best practices of CBPR, regardless of the race or ethnicity of the provider, seek to understand and must respect and value the habits, skills, and styles of the community members and see them as co-researchers participating in the study project. This is where Black scientists are uniquely poised to advocate and teach other scientists how to adhere to the central tenet of CBPR—a partnership to research that equitably involves community members, key stakeholders (such as Black people with addiction), researchers, and others in all aspects of the research process.^{9,10} When Black people are leaders in science, they can in turn empower research partners that look like them and develop more leaders, so that the data generated and the conclusions drawn are informed by community representation.²⁶

Culturally informed research in faith settings collaboratively led by Black Scientists

Understanding of how to implement better research questions, methods, and definitions of knowledge in research is expanding. This expansion challenges previous beliefs and corrects some of the unethical methods and historical biases associated with research done among Black people and other oppressed communities. Integrating research into faith settings has been shown to be helpful for addressing psychological distress in Black communities.²⁷ As such, the church

holds great cultural significance in the Black community, as a highly relevant institution dedicated to health promotion and social equity. Black churches have been successfully involved in research studies targeting stigmatized issues, such as depression among Black men²⁷ and HIV care.²⁸ Many Black churches are enthusiastic about expanding their ministry to address the physical and mental health of their members.

There is a rich legacy of Black churches partnering with community members to improve the outcomes for Black people afflicted by poverty, ill health, and institutionalized racism. Mollica and colleagues²⁹ noted that: "...the clergy has been identified as a major community mental health resource...certain parish-based clergy, especially the Black clergy, have functioned as a major mental health resource to communities with limited access to professional mental health care". Building upon the tradition of improving mental health in partnership with Black clergy, in the next section we provide examples of CBPR projects in Black churches.

First Corinthian Baptist Church, a predominately Black church in Harlem, provides mental health treatment, addiction, and supportive counseling services to members of their community.^{30,31} Furthermore, faith-based mental health promotion has resulted in resources for faith communities in Black areas, such as Patient-Centered Outcomes Research Institute funding awarded to studies with pastors who are co-principal investigators and Black faith community members. Therefore, when the First Corinthian Baptist Church was approached to serve as a study site in a community-based project investigating the best approaches to encourage Black people with alcohol and other substance use disorders into treatment, there was an immediate knowing and understanding of the legacy in which this project could exist.³²

The Addiction Treatment in the Black Community (ATBC) project, a randomized controlled trial funded by the NIH, uses an evidence-based intervention known as Computer Based Treatment for Cognitive Behavior Treatment (CBT4CBT), which has been shown to reduce the use of many substances independently and in conjunction with traditional addiction treatment.³²⁻³⁴

ATBC is one of the few randomized controlled trials funded by the NIH and led by Black scientists.³

In ATBC, CBT4CBT is combined with a spiritual component provided by Church-based health advisers to improve the cultural acceptability of the intervention.³² Participants with substance use disorders are invited to engage voluntarily in an opening and closing period of non-sectarian meditation. These sessions are led by members of the congregation who have received education in substance use disorders and training regarding how best to relate to Black people with alcohol use disorder and other substance use disorders (figure). The pilot project component of ATBC was conducted to establish acceptability and feasibility of providing substance use treatment in the Black church;³² this led to the ongoing randomized clinical trial, in which treatment in the Black church is compared with traditional substance use treatment in a clinical setting. In the pilot, participants noted the hospitality of the church environment and the non-judgmental attitude of those assisting them (church-based health advisers) to be acceptable and conducive to promoting engagement in treatment.³² The spiritual component of the CBT4CBT approach to treatment for substance use disorders reflects the bringing together of religion, spirituality, mental health care, and primary health care in the professions of psychiatry, psychology, and social work.^{35,36} Church-based health advisers also learned more about substance use disorders, treatment options, and the power and importance of compassion in the care of those coping with alcohol use disorder and other substance use disorders.

Another example of faith-based organizations involved in Black mental health research is The Jordan Wellness Collaborative, a research program solely focused on equitably involving Black and other racially and ethnically minoritized people in all aspects of the research process. The work builds on the research and outcomes of The AAKOMA Project and conducts studies with Black faith communities to democratize and decolonize research, and empower Black people to take control of their mental health.

Greetings and welcome to Dixwell Church	Research assistants	Participants	Spiritual session (conducted by CHAs)	Participants	CHAs will engage in prayer with any participant who requests	Session ends
Participants are welcomed by CHAs	RAs will collect urine samples and conduct EtOH breathalysers	Participants will get a snack and sit with computer tablets	CHAs will open with affirmation that God hears prayer, then participants will read Bible passages before, finally, listening to the song of the day for strengthening your prayer life	Participants will complete CBT4CBT module on computer tablet and complete CBT4CBT workbook	Participants and CHAs engage in prayer at participant's request	Participant's session comes to an end

Figure: Overview of addiction treatment as part of the Black community protocol at Dixwell Church

CBT4CBT=Computer Based Treatment for Cognitive Behavior Treatment. CHA=Church-based health advisor. EtOH=ethanol alcohol. RA=research assistant.

The Jordan Wellness Collaborative builds on the enthusiasm of church leaders and is well placed to improve mental health outcomes for church parishioners and community members alike. The Collaborative received NIH funding to conduct clinical trials to provide data focused on Black adults, to understand which mental health treatments work best. The Collaborative is leading a trial that compares treatment of substance use disorder in Black churches with standardized addiction care in the community, to determine the best option for Black adults with alcohol use disorder and other substance use disorders (NCT04580810). The Jordan Wellness Collaborative model builds on a long history of Black people working to help their communities, even if there has not been adequate funding to support the initiatives and projects of Black researchers. The premise of this group is to empower Black communities as research collaborators via faith-based mental health promotion. It is important to highlight that the NIH-funded research studies conducted by the Jordan Wellness Collaborative (NCT04580810, NCT05260047, and NCT05776316) are rooted in understanding the unique experiences of Black people to improve outcomes. However, members of the Collaborative (researchers, citizen scientists, people with lived experience of mental health and substance use disorders, community members, academicians, and staff) also show the need to support more NIH-funded researchers. Overall, the faith-based mental health promotion approach posits that employing and partnering with the community of interest is crucial to finding long-term solutions to the issues affecting Black people.^{27,28}

Conclusion

Black scientists are best poised to advocate and teach others how CBPR can be used as a tool to promote Black mental health equity, due to their shared experiences and cultural background with the communities of interest. As members of communities that are disproportionately impacted by health inequities and systemic racism, Black scientists are better equipped to understand the needs and perspectives of Black communities. Black scientists are also more likely to have established relationships with community leaders and organizations, or can more easily establish these relationships, which can facilitate the research process and enhance community engagement.

Additionally, Black scientists might be better equipped to navigate the power dynamics and potential mistrust between academic institutions and Black communities. By centering the experiences and needs of communities, Black scientists can teach other scientists and community members how CBPR can contribute to more culturally responsive and equitable research that can ultimately improve health outcomes for marginalized populations.

Taken together, a contextual and cultural framework for doing CBPR with Black people includes personal self-awareness and the conscious use of the professional self,³⁷ tenets that are applicable across mental health research and services. Being aware of one's own value system and biases as a researcher and then intentionally addressing those biases and including the persons of interest in the research itself, is one method to promote mental health equity for Black people.

All Black people should understand the benefits of participation in research studies, and the utility of the study for their families, community, society, and mental health research practice. This approach and attitude can help to minimize the potential for mental health research to further oppressive social systems, and it can provide culturally informed mental health services to oppressed communities, which move away from the legacy of suspicion, mistrust, fear, and anger around previous mental health research and treatment in the Black community. CBPR is truly a tool to expand our knowledge, methods, and repertoires of skills needed to effectively assist marginalized communities and wider communities as a whole.

Contributors

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Declaration of interests

AJ is the Principal Investigator of the Jordan Wellness Collaborative (JWC) at NYU Langone. All other authors declare no competing interests.

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