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Community-Engaged Approaches to Address the Ethical Concerns of Maternal Mental Health Disparities Research

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Abstract

Participatory research approaches have brought to the forefront the ethical obligations that researchers have towards underserved communities. We describe how a community-academic partnership used community-based participatory research principles and structure to develop a human subjects research protocol and to address the ethical concerns community stakeholders had regarding maternal mental health research with Black women.

Keywords

Community-based participatory research; maternal mental health; ethics; disparities; perinatal mood and anxiety disorders

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Historically, it is undeniable that some researchers in the United States engaged in unethical research practices involving low-income and racial/ethnic minority communities. In a different but related vein, we note that much public health and biomedical research has failed to involve participants from the communities where it occurs in meaningful ways.¹ Both these broad facts have contributed to a negative perception of research in many low-income and racial/ethnic minority communities.² Low-income and racial/ethnic minority communities are regularly asked by researchers to give consent to research that is conducted in and about their communities; however, they are rarely invited to provide meaningful input about the research that is undertaken, which can benefit the research process and results.³

Community-based participatory research (CBPR) approaches have shown promise as powerful research tools for understanding and addressing health inequities. At the root of CBPR is an ethical proposition requiring reciprocity between those directly affected by the phenomena being studied and researchers seeking to learn from and about these same communities.^{4,5} The principles of the Belmont report—respect for persons, beneficence, and justice—surface again in the ideology of CBPR, ensuring that research conducted is useful for, and respectful of, the communities that are both partners and participants in it.⁶ These participatory approaches allow researchers to focus on problems that affect whole communities and advocate for community well-being.⁴⁻⁶

Our CBPR process was iterative and included processes of research, reflection, and action. With CBPR principles in mind, we had two research objectives: a) to learn about maternal mental health in our local communities by creating and engaging with our CBPR partnership, and b) to translate the data gathered into action (practice and policy) that address perinatal mood and anxiety disorders (PMADs) among a low-income, urban Black population with distinctive needs. The long-term goal of this study is developing a locally, culturally responsive intervention to integrate mental health prevention and promotion into maternal mental health services in community-based settings. Findings from the study will provide us with baseline data to inform science, practice, and policy. This manuscript highlights the process we used to develop the human subject protocol and describes the ethical concerns stakeholders expressed regarding maternal mental health research. This study was approved by the Morehouse School of Medicine Institutional Review Board.

Background of Research Partner Communities

The research partner communities that engaged with the CBPR partnership were located in South Atlanta and are majority African American (88%), have an average household income of \$23,243, a 21% unemployment rate, 38% poverty rate, and ranked the lowest on a constellation of neighborhood health and quality of life factors compared with other parts of Atlanta.^{7,8} For example, there is 12 years or greater difference in life expectancy among neighborhoods within a few miles in Atlanta. Those living in the South Atlanta neighborhoods, which are predominantly Black, fare worse when compared with those who live in affluent, mainly White North Atlanta neighborhoods.^{9,10} Nonetheless, these communities are resilient, with families who have been rooted there for decades and who take collective action to ensure that their neighborhoods are thriving places of opportunity.

Additionally, community-based organizations with long-standing ties to the neighborhoods and residents provided social, health, and advocacy services and are a part of the CBPR partnership.

CBPR Partnership: The Atlanta Healthy Start-Community Action Network (AHSI-CAN)—Yes we CAN!

The Atlanta Healthy Start-Community Action Network (AHSI-CAN) partners work collaboratively to develop community solution strategies that address the social determinants related to maternal and child health. Partners represented on the AHSI-CAN are diverse, with individuals and agencies representing local and state government entities, early childhood centers, hospitals, community-based agencies, academic institutions, health care centers, workforce development agencies, local business, behavioral health agencies, and the like. Over the years, the AHSI-CAN has evolved from an information-sharing advisory group to a dynamic network of committed partners that use the Collective Impact (CI) approach to achieve sustainable change.¹¹ The group chose CI as a model because of its design to address complex problems across sectors.

Using this framework, the AHSI-CAN underwent a series of planning sessions to ensure that all partners had a shared vision for change, that there was a common understanding of the problem, that there was developed trust among partners, and a joint approach to solving it through agreed-upon actions. In 2016, the AHSI-CAN agreed to focus on strategies to address maternal mental health. Each AHSI-CAN member brought expertise, was aware of the prevalence and severity of PMADs in the communities they served, and recognized the inadequacy of existing care. The CI model was also used to have conversations to discuss ethical concerns related to the research.¹¹ See Box 1.

In September 2018, with receipt of pilot funding sponsored by the Detroit Community-Academic Urban Research Center, CBPR Partnership Academy, the study, “Using Community Engaged Approaches to Integrate Mental Health into Community-Based Maternal Health Services” began.¹² The project used a multiple Principal Investigator (PI) model with one academic PI and the other, an executive director of a local, community-based non-profit.

Community-Engaged Processes in the Development of the Human Subjects Protocol

Given that CBPR requires a significant level of community member participation with the objectives of community improvement and social change, the ethical practice of CBPR required us to be vigilant about the way the partnership was developed, implemented, and sustained. As such, AHSI-CAN partners were engaged throughout the process, including the Institutional Review Board (IRB) application, informed consent protocols, subject enrollment, research questions and objectives, research design, and implementation. Each AHSI-CAN partner involved in the research went through a community training on IRB and completed Collaborative Institutional Training Initiative (CITI) training. It was important for

community partners to understand the IRB process involved in the research project. We wanted community partners to understand that the IRB is a protective mechanism that community partners can use if they understand it and are part of the process of designing the research. The AHSI-CAN community training included increasing the AHSI-CAN partners' awareness of various aspects of research studies and their benefits and implications, with a focus on ethics. Although maternal mental health was chosen for research, the AHSI-CAN had ethical concerns related to the research. Community conversations were conducted to explore the ethical implications of the needs identified by the AHSI-CAN on maternal mental health research. AHSI-CAN expressed that this process had to take place because of distrust of research in the community, stigmatization of mental health, and concerns related to research with pregnant women. Our community partners were clear that the human subject issues were addressed, and they can promote the research project with greater confidence.

Community consent.

Before the research was conducted, AHSI-CAN partners determined that it was important to share the study with the broader community from which the study would recruit and enroll participants. Partners of AHSI-CAN disclosed what the research study planned to do and negotiated with them concerns they had about the study. The AHSI-CAN felt it was the research team's ethical obligation to disclose since, although they serve the community, they still may not represent the range of community concerns. The community's main concern was that once research results came in, they would not be shared with the community. They wanted to ensure that the results were reflective of the concerns of community members. Additionally, community members were apprehensive about the dissemination and release of sensitive and unflattering data.¹³⁻¹⁵ They were concerned that research results may negatively portray the community, further stigmatizing their communities. They feared that data and other information from the study could lead to prejudice against those who suffer from mental health in their communities. Community members wanted AHSI-CAN to focus on the strengths and resilience of the communities rather than report on their deficits. They also requested that the research team consider the potential impact to the community if data were released prematurely or in an insensitive manner. The CBPR partnership acknowledged community members' concerns and ensured that research findings would be disseminated with community members to gather input and feedback and in order to confirm some points apparent in the data.

Concern for safety of the fetus.

Although the study was not a clinical trial and would not cause harm to the fetus, community members expressed concerns for fetal well-being. They feared that if the research created anxiety for the mother, it could in turn affect the fetus. The research team explained that the research was not a clinical trial and that the social behavioral research being conducted would be considered minimal risk. The term "minimal risk" was defined to the community as risk that is not greater than the fetal risk associated with the risks that healthy pregnant women ordinarily encounter in daily life and/or the risk fetuses encounter during routine prenatal tests of healthy women with healthy fetuses.¹⁶ This led to a concern that not all women who participate would be healthy or may already have high-risk

pregnancies. There was also a discussion of the fact that what may be considered *ordinarily encountered* for some women may not be the same for this population who already struggle with food security, violence in their communities, and lack of access to health care. Community members indicated that the women in their community encountered more barriers to services than women in more affluent communities.

Maternal risk.

Community members expressed apprehension for the women's mental well-being if they participated in the study. Many worried that some of the questions about their mental health challenges or regarding their past might trigger an emotional response. They wanted the study team to commit to providing support or referrals to women to ensure that they received the assistance they needed. The AHSI-CAN reassured community members that these types of situations were thought of and that procedures were going to be put in place to provide mental health support as well as to link women to care if they so desired. Partners in AHSI-CAN who provide mental health services and other types of services committed to deliver those social and emotional support services.

Some community members mentioned that some women might believe that if they participated and self-reported any type of mental health concern, they would be institutionalized, or their children would be taken away. They had concerns about confidentiality of information they shared, and if there were a breach, they wondered what would happen to them and their families. Partners of AHSI-CAN noted that these are the same concerns and fears women had when it comes to accessing mental health care. Community members pointed out that there was still fear, suspicion, and distrust of researchers, especially with sensitive topics. However, because some community members and community-serving organizations were a part of the research team, these fears were eased.

Informed consent.

A primary concern was the informed consent process. The AHSI-CAN as well as community members described informed consent as lengthy, burdensome, and complex. The AHSI-CAN noted that other studies they participated in or partnered with had issues with their informed consent process. Often, they felt that researchers neglected or did not know enough about the community to ensure that their informed consent forms and processes were culturally and contextually relevant. Even with a clearly written consent form and a relatively well-educated population, many research participants inadequately comprehend basic characteristics of the research studies they participate in. The AHSI-CAN believed that taking time to get this process right would make a difference and was an ethical obligation of the research team. Partners of AHSI-CAN felt attention should be paid to comprehension of community participants. The AHSI-CAN modified consent forms by condensing them (i.e., making shorter sentences), revising content for readability (6th grade reading level), and making the fonts larger. In the future, the AHSI-CAN will be adding infographics to the form. The improved consent forms will be based on a model developed by Heerman et al. and on principles of effective low health-literacy communication techniques.¹⁷

Most of the efforts of the AHSI-CAN were dedicated to training of study staff and interacting with the community. The AHSI-CAN developed an orientation for study staff and AHSI-CAN partners on informed consent procedures. In this training, information was provided about the population of interest (low-income women of color), PMADs, working with pregnant women, and cues on how to read the individual's body language and facial expressions. The training consisted of didactic methods, hypothetical scenarios, role-playing, and the teach-back method. The latter method checks understanding by asking participants to state, in their own words, what they understand from the informed consent before continuing with the process. Although evidence for the effectiveness of the teach-back method for the informed consent process is lacking, its efficacy in medical practice settings permits its inclusion.¹⁸ Information for the training was supported by the literature,^{17,19-21} experiences of AHSI-CAN partners, and the populations involved. The AHSI-CAN believed that the modified informed consents were necessary, but more relevant was having trained study team members who spent time with individual study participants. This process built rapport and trust with study participants. Additionally, the issues of privacy and confidentiality were emphasized in ongoing discussions and how this should be recognized when AHSI-CAN partners and study staff recruit women and during data collection.

IRB application process.

After considering ethical concerns expressed by the community, the AHSI-CAN collaboratively developed study procedures, informed consent, eligibility criteria, and study instruments. The academic partner drafted a protocol with questions based on science and literature; other AHSI-CAN partners developed protocols based on local priorities, concerns, and experiences. Academic partners refined the instruments, with drafts reviewed by AHSI-CAN. Completion of the IRB took place in an iterative process of discussion and revision. Approval of the IRB was obtained through the lead academic partner's institution.

Conclusion

Traditional IRB forms and processes operate within a traditional research framework focused on individuals, not communities.¹⁵ Failure to consider a CBPR approach to the IRB process may inadvertently make communities vulnerable to exploitation and unethical processes in research studies.¹⁵ Maternal mental health, a stigmatized and sensitive topic, involves a segment of a population that is often neglected in research.²² Approaches based on CBPR allowed the AHSI-CAN to create a democratic research process that was inclusive and accommodated a variety of community realities. A CBPR process was relevant and necessary to ensure that research with populations that are already stigmatized was conducted in a way that was respectful and created trust between researchers and communities. Such approaches allowed the AHSI-CAN to create procedures and policies that considered concerns and needs of communities. It created a safe space and community dialogue on ethical concerns related to the research study to shape the IRB process and direction of the research. The processes described here should allow others engaged in CBPR processes to consider ethical implications in partnership with communities.

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Box 1.**COMMUNITY ACTION NETWORK (CAN) COLLECTIVE IMPACT FRAMEWORK****Common Agenda:**

To improve maternal and child health outcomes.

Impact Focus Areas:

Breastfeeding, Early Learning Literacy and Maternal Mental Health* (*Primary Impact Area).

Shared Measurement:

The CAN Partners worked collectively during CAN meetings to develop and implement a shared measurement tool which allows the group to track progress toward shared goals, coordination and collaboration, learn and course correct our actions.

Continuous Communication:

The CAN has a method of continuous communication which includes: group discussions, one-on-one meetings, emails and telephone contact. This method provides a platform for CAN Partners to address concerns and ideas. As a result, members trust each other and know that their interests are equally valued and protected.

Mutually reinforcing activities:

Partnering organizations conduct mutually reinforcing activities aligned with our common agenda and impact focus areas to achieve collective impact. Additionally, all meetings include team-building activities to help us learn more about one another and build trust. Building trust within the partnership is the most important objective in developing quality relationships, and the success of each interaction rests on the depth of trust developed in these exchanges.

Backbone Supporting Organization:

CBWW and MSM serves as the organizations dedicated to coordinating the various dimensions and collaborators involved in the initiative.