

This work is on a Creative Commons Attribution-ShareAlike 4.0 International (CC BY-SA 4.0) license, <https://creativecommons.org/licenses/by-sa/4.0/>. Access to this work was provided by the University of Maryland, Baltimore County (UMBC) ScholarWorks@UMBC digital repository on the Maryland Shared Open Access (MD-SOAR) platform.

Please provide feedback

Please support the ScholarWorks@UMBC repository by emailing [scholarworks-group@umbc.edu](mailto:scholarworks-group@umbc.edu) and telling us

what having access to this work means to you and why it's important to you. Thank you.

# **Involving Urban Single Low-Income African American Mothers in Genomic Research: Giving Voice to How Place Matters in Health Disparities and Prevention Strategies**

## **Abstract**

This article describes the process of using principles from community-based participatory action research to involve low-income, single, African American mothers on the south side of Chicago in genomic research, including as citizen scientists. The South Chicago Black Mothers' Resiliency Project used a mixed methods design to investigate how the stress of living in neighborhoods with high levels of violence affects mothers' mental and physical health. This article seeks to serve as a model for physicians and scholars interested in successfully involving low-income African American mothers in genomic research, and other health-related activities in ways that are culturally sensitive and transformative. The lives of Black mothers who struggle under interlocking systems of oppression that are often hidden from view of most Americans are at the center of this article. Therefore, we provide extensive information about the procedures used to collect the various types of data, the rationale for our procedures, the setting, the responses of mothers in our sample and methodological challenges. This study also has implications for the current COVID-19 pandemic and the need to train a corps of citizen scientists in health and wellness to avoid future extreme loss of life such as the 106,195 lives lost in the United States as of June 1, 2020.

## **Keywords**

Community-based participatory action research; Citizen scientists; Health disparities; Black mothers; Sociogenomics; Stress; COVID-19

## **Introduction**

Violence in Chicago has been nothing short of alarming for many years. For the past decade, for example, many pundits as well as ordinary citizens have claimed that Chicago is experiencing a violence epidemic, with a death toll in the thousands and casualties mirroring the losses experienced by the U.S. army in the Iraq war over the same period [1]. This observation led some Black Chicagoans to refer to the West and South sides of Chicago as Chiraq (a combination of Chicago and the Iraq war), a term that is said to have been coined by Chicago Rapper King Louis in 2009 (Where Does Chiraq Come From?, n.d.). It also prompted residents in these communities to make demands for interventions on behalf of the government, universities, schools, mental

health agencies, and churches to eradicate the war-like living conditions in their communities [2-6].

The term Chiraq gained widespread attention and usage among Chicagoans when film director and academy award winner Spike Lee released a 2016 movie entitled Chiraq that he filmed in Chicago. Several months after Spike Lee completed filming, Chicago experienced the deadliest September in 13 years with 90 homicides and 129 individuals shot, including a four-month-old infant [7]. Because the violence rivals war zones, use of the term Chiraq by Black residents on the South and West sides of Chicago is indicative of an incredibly stressful lived experience that may have high mental and physical costs. The ramifications of this environment are especially felt by Black mothers raising young children [2,8,9].

In an October 17, 2012, ABC News press release, David Ford discussed a “Hidden America” where parents, many of whom are low-income single African American mothers, are raising children in violent conditions that are “unfathomable to most of the country.” That same year Diane Sawyer of ABC News, described the violence in the “Hidden America” as a “crushing tragic slaughter” because the 419 deaths in Chicago that year were more than the number of U.S. troops killed in Afghanistan [2,10]. Although official national crime reports show a significant decline in the violent crime rate since it peaked in the 1990s [11], the occurrence of homicides and gun shootings remains at an unacceptable level for many Black residents in the West and South sides of Chicago [12,13]. For example, through the first five months of 2020 in Chicago, 1,003 people had been shot, 128 more than the entire year of 2019 [14].

Unfortunately, children figure prominently in these gun violence statistics. One week after performing with her high school’s drill team at President Obama’s January 2013 inauguration; 15-year old Hadiya Pendleton was shot and killed. Less known is that Harper High School, where Hadiya was enrolled, had 29 former or current students shot in 2013: eight of them died from their bullet wounds [15]. Even as Chicagoans shelter-in-place due to COVID 19, children remain at-risk of dying from gun violence. On April 8, 2020, 15-year old Demetrius Hardy was shot and killed [13]. Hardy was one of eight people shot in Chicago in less than an hour. Koval described Chicagoans as experiencing a “blitz” of gun shootings. Such a “blitz” was evident, for example, over the 2020 Memorial Day weekend, when the Chicago Police reported that 10 people were killed and at least 42 people were injured in shootings over the city’s deadliest Memorial Day weekend in years. Notably, three teenagers were among those shot, one of whom, a 16-year old, was fatally wounded [14]. The very next day after the end of the Memorial Day Weekend, 5 more children were shot, including a 5 year-old in a drive-by shooting on Chicago’s Southside [16].

The epidemic (or “blitz”) of gun violence is occurring at precisely the same time that Black Chicagoans are experiencing a COVID-19 pandemic within a pandemic. Blacks represent about 72 percent of the COVID-19 deaths in the city; yet they make up less than one-third of the population [17]. This pandemic within a pandemic is playing out nationally as well. According to May 20, 2020 data from APM Research Labs, the Black COVID-19 death rate is staggering (2.4 times higher) compared to other groups. The death ratios are 1 in 2,000 Black Americans, 1 in

4,300 Asian and Latino Americans, and 1 in 4,700 White Americans. However, in places like Michigan, Kansas, Wisconsin, and Washington, D.C., the Black death rate from COVID is 500 to 700 percent higher than Whites [18,19]. The APM Research Labs further state that “if [groups of color] died of COVID-19 at the same rate as White Americans, about 12,000 Black Americans, 1,300 Latino Americans and 300 Asian Americans would still be alive.”

The goal of this paper is to describe the methods used for a study intended to highlight how the stress of living in neighborhoods with high levels of violence may get “under the skin” to affect how the genes that regulate the immune system and inflammation function. This article explores those factors in the Black mothers’ lives that allow them to become resilient to the stress and how this protection from stress is reflected at the genomic level. We used principles from community-based participatory action research to involve low-income single African American mothers on the South side of Chicago in cutting-edge genomic research. We also used a transformative-emancipatory paradigm and seek to use our research findings to promote social change around poverty and other interlocking inequalities such as race and gender [20,21].

## **Barriers to Blacks’ Participation in Health Research**

Historically, the rates of Black participation in health research in general and genomic research specifically have been low [22,23]. The underrepresentation of African Americans in medical research has failed to be alleviated despite more than two decades of federal initiatives such as the 1993 National Institutes of Health (NIH) Revitalization Act (Pub L 103-43; 42 USC 289a-1), which mandated inclusion of women and minorities in research and researchers’ efforts to boost their participation [24]. The total participation rate for people of color in NIH-sponsored trials remains at less than 18% [24]. The 1999 rates for the Food and Drug Administration’s (FDA) clinical trials are about eight percent [25]. Despite having the highest rates of cancer mortality, African Americans represent less than 10 percent of the samples involved in prevention and treatment trials at the National Cancer Institute [26]. In genomic studies, 92 percent of the US Genomewide Association Study (GWAS) participants were white and only three percent were African Americans [27].

Scholars identify the mistrust associated with the tainted history of medical research involving African Americans as a barrier to their recruitment into medical experiments. The history of medical and research abuse of African Americans dates back to antebellum times when slaves were forcefully subjected to cruel medical experiment and demonstrations [28]. The most infamous of the abuses endured by African Americans in the name of medical research was the government-run Tuskegee syphilis experiment, which followed six hundred African American men (four hundred of them infected with syphilis) for 40 years from 1932 to 1972 [29-31]. The study was abusive and violated ethical standards primarily because researchers knowingly failed to treat patients appropriately after the 1940s validation of penicillin as an effective cure for syphilis.

During the same time as the Tuskegee experiment, physicians at Johns Hopkins Hospital engaged in another major breakdown in medical ethics that involved an African American woman named Henrietta Lacks [32]. Ms. Lacks was born in Roanoke, Virginia in 1920. Her mother died in childbirth when she was four, and she went to live with her grandfather in a cabin where her ancestors lived as slaves on the former plantation. In January 1951, at the age of 31, Ms. Lacks was diagnosed with cervical cancer. She died in October that same year, leaving behind five children.

During treatment for her cancer, doctors at Hopkins removed two cervical samples without telling her or obtaining her consent. When doctors discovered that, unlike previously harvested tissue that died after a few days, Ms. Lacks's cells survived indefinitely, they took advantage of the cells' longevity and created a specific cell line called "HeLa" that revolutionized biomedical research. In 1955, scientists also cloned Ms. Lacks' cells.

Scientists have reproduced 50 million metric tons of "HeLa" cells and generated over 10,000 patents [32,33]. Ms. Lacks cells are associated with many breakthroughs in science: the polio vaccine, understanding sensitivity to drugs stronger than aspirin, understanding how our cells work, gene mapping, and medications to treat Parkinson's disease, AIDS, cancer, herpes, leukemia, influenza, hemophilia, etc. [32]. While the "HeLa" cells helped to advance science and save lives, scientists engaged in several ethical violations and abuses that further feelings of distrust in the African American community, including the lack of informed consent. Also, until recently, the Lacks family did not benefit financially from any of the patents or other activities [32,33].

Despite these past abuses, some researchers are successful in enrolling African Americans in genomic research. Spruill wanted to better understand why higher percentages of Gullah-speaking African Americans developed type 2 diabetes early in life and with significant complications [34]. Spruill describes the creation of a DNA registry to look for diabetes-specific alleles or markers. One of the reasons her research was so successful is because she used community-based participatory research (CBPR) practices that included sensitivity to the community's cultural and ethnic background. The research team included a local citizen advisory committee which provided health screenings and jobs for residents in the project. Their efforts resulted in the recruitment of 1,230 people for genomic research, which was well above their goal of 615.

## **Creating a Paradigm Shift: Combining Biological, Psychological and Sociological Frameworks**

### **The Promise of Sociogenomics Research**

Previously, life scientists often tried to explain social behavior by invoking a simple DNA-based genetic inheritance model. This model was a barrier for social scientists and humanists because it was viewed as deterministic and failed to provide a mechanism for how humans are affected by their experiences and environments. In contrast, the sociogenomics perspective, pioneered by

Robinson [35] highlights the dynamic nature of the genome and how environmental factors can influence patterns of RNA abundance (“gene expression”) to reflect an individuals’ current environmental context, environmental history and status of gene-regulatory systems and behavior [36]. Because scientists know how many of our genes are related to basic biological processes, detecting increases and decreases in gene expression can be used to derive insights into health and disease.

Recent developments in both the social and life sciences bring us to a critical point, where a deep synthesis can finally be attempted to bridge the life science, behavioral sciences, social science, and humanist perspectives on health, psychological functioning and social behavior. The conditions for this synthesis are two-fold: new conceptual insights about the dynamic genome and technical advances providing greater access to the genome. Genomic data can help researchers understand the role of socioeconomic factors and social determinants of health (e.g., unsafe housing, poor quality housing, lack of access to employment, etc.) in increasing the risk of disease due to higher levels of exposure to stress [37]. After increased understanding about how social inequality creates negative health consequences, we will build off of the research results and work with community residents to create outreach and educational programs that address their immediate psychosocial challenges, resiliency, and their need for larger structural changes.

### **Role Strain and Adaptation Framework**

Social Psychologist Phillip Bowman [38] argues that when studying the lives of marginalized groups, it is important to use an integrative social psychological approach that identifies cultural resources that appear to mediate the consequences of persistent structural constraints [39,40]. An example of an integrative social psychological approach is his role strain and adaptation model, which argues that structural constraints often limit an individuals’ ability to accomplish developmental goals (e.g., student, worker, provider, etc.) throughout the life course. In addition, challenges during one developmental stage (e.g., student) may negatively affect the next stage in the life course (e.g., worker or parent).

Therefore, it is important to examine the multilevel racerelated risks faced by marginalized individuals that range from oppression in society to personal vulnerabilities. As part of this examination, Bowman [38] argues that scholars should “further clarify specific sociocultural factors that reinforce a sense of mastery, psychological well-being, and resilient outcomes” (p. 302). As a society, it is important to consider the level of social investments that we make in individuals as they transition into various roles and the positive consequences of those investments [41,42]. A focus on mastery, psychological well-being and resilience in marginalized individuals, such as Black women, mandates that their lived experiences are at the core of the analysis. In addition, we utilize a Black feminist framework. Therefore, the final framework used by the researchers is Black feminist thought.

### **Black Feminist Framework**

The Black mothers' project engages Black feminist thought as a methodology or philosophical framework that structures our fundamental assumptions [43]. We engage Black feminist thought in the following ways: we center Black women's lived experiences and provide "fresh insights on the prevailing concepts, paradigms, and epistemologies" (p. 221) [44]. In this context, "lived experiences" is used to describe the first-hand accounts, impressions, and everyday experiences of living as a member of a marginalized and oppressed group (e.g., low-income, Black women). Moreover, the concept addresses the disparity of perception between Black women's actual day-to-day concrete experiences and the larger society's impressions, perceptions, assumptions, stereotypes, misconceptions, and misrepresentations of their lives. When researching and writing about Black women's lives, it is incumbent that researchers present a holistic description and analysis of their lives and experiences within a framework that captures their everyday concrete experiences, the historical context and social structures that their lives are embedded in, and the strategies they use to pursue their goals and enhance their lives [21,45,46].

These fresh insights develop as a result of examining larger social patterns and interlocking systems of oppression such as race, class, and gender and the "new ways of knowing" that are uncovered. "New ways of knowing" include critical social theory that both (1) explains the workings of social structures in the lives of low-income Black women in racially segregated neighborhoods with high levels of violence and (2) demonstrates commitment to social justice [44].

When examining the resiliency demonstrated by African American women despite adversity at the individual, community, and societal level, scholars identify protective mechanisms such as spirituality, cultural resources, and social networks [44,47,48]. In the past, these protective factors enabled African American women to thrive, maintain personal well-being, and engage in collective action such as the Civil Rights Movement, the modern Women's Movement, the Welfare Rights Movement, the fight for desegregated housing, and other sociopolitical campaigns for a just society [48-51].

Today, African American women are once again facing the deep problems of social inequality, including racially segregated neighborhoods with limited economic resources and extreme levels of gun violence that will challenge their resiliency. New knowledge regarding stress resiliency in low-income African American single mothers may unlock novel pathways to eradicate health disparities. These novel pathways may reveal culturally-based resiliency practices that African American mothers have used for decades, centuries even, to thrive and maintain their overall well-being even as they encounter daily psychological and physical threats in U.S. society [40,48]. Our goal for this Black feminist, humanist and collaborative approach was to create a paradigmatic shift in how Black women, especially poor and single black mothers are viewed and researched, especially in the context of genomic research. We provide a Black feminist framework using CBPAR principles to understand these women as self-defined, self-reliant individuals confronting race, gender, class, sexuality and other oppressions in their everyday lives.

## **Reflexive Research**

Using the concept of lived experiences within a Black feminist framework is not without its challenges. The research team must be careful to use the perspectives of the mothers themselves instead of imposing their perspectives and those of others on the subjects. Another challenge to feminist research by and about Black women, and other women of color, has to do with the inherent tensions between objectivity and subjectivity. Because the research is intentionally personal and collaborative and because it has as one of its goals to deconstruct and provide a corrective to mainstream male and White female-centered research and theories, it is subjective in that several of the authors are Black women. However, it is also objective in that Black women's experiences are explained both in terms of what they say about their lived experiences and the historical interlocking forces of oppression that shape their lives [21,46]. Sociologist Howard Becker long ago addressed the role of values in sociological research and the tensions between objectivity and subjectivity in our research [52]. According to Becker, while we can never avoid taking sides, we can impartially use research methods so that the findings and the beliefs we hold can be proved or disproved. In this context, using innovative research methods and a strength-based approach, we created the South Chicago Black Mothers' Resiliency Project.

## **The South Chicago Black Mothers' Resiliency Project**

### **Community-based Participatory Action Research (CBPAR) and Citizen/Community Science**

The goal of researchers in this Black feminist, interdisciplinary and CBPAR project is to contribute to a better understanding of the role interlocking oppressions (e.g., past policies that created racially segregated neighborhoods with concentrated poverty, poor access to health care, and high levels of violence) play in creating chronic stress that gets "under the skin" to affect the health and well-being of Black mothers in neighborhoods with high levels of violence.

The Black mothers' project consists of three phases: (1) exploratory focus groups, (2) mixed methods data collection, and (3) education and community change (Table 1). This project engaged key principles of a CBPAR research design as described by Israel and colleagues [53]. We view CBPAR as a "philosophy, process and an outcome" [54]. Key components of the CBPAR approach include starting with a topic identified by the community as important and then drawing on the knowledge and strengths of both researchers and members of the community to inform actions for social change that improve the community in areas of health, decreases in violence, and environmental justice [55]. Other principles include (1) integrating the knowledge with community change efforts, (2) a mutual transfer of power, capacity, skills and knowledge, (3) an ecological and strength-based approach, and (4) dissemination of findings [53]. Although partnerships with community agencies were not established initially, we developed them in phase three of the project. Phase three will also involve closer collaborations with a larger number of community residents as citizen scientists.

We define citizen/community scientists as ordinary individuals (especially from marginalized groups) working with scientists to create new knowledge. Darlene Cavalier and Eric Kennedy [56], authors of 'The Rightful Place of Science: Citizen Science' define citizen scientists as "members of the general public who are participating in scientific-research not as guinea pigs or funders but by, conducting experiments, making observations, collecting data, and engaging their minds. This allows them opportunities to perform tasks beyond the reach of today's best computers. They believe that research and discovery should be accessible and useful" (p. vi). The goal is, for community members (youth and adults) to ask new questions and jointly create a new scientific culture, and environments for innovating discoveries. Key gaps in knowledge exist because the voices of the marginalized are often absent due to their lack of proximity to higher education and institutions like the University of Illinois at Urbana-Champaign [57].

We believe that it is critical to identify and draw upon the existing strengths of Black mothers in communities experiencing high levels of violence and involve them throughout the process (e.g., identifying the problem, data collection, data analysis, writing manuscripts, designing, implementing, and evaluating the intervention; and training the next generation of scholars to combine biological and sociological frameworks). Unlike traditional research methods which often end once the data are collected, analyzed and published, in CBPAR the project continues by sharing and using the data to transform community interventions and practices/policies around the social problems of persistent poverty, racism sexism, exposure to neighborhood violence, chronic stress, and health inequalities [54].

CBPAR and citizen science are viewed as a mechanism to promote social justice by reducing racial disparities in health because it includes those who are most concerned with the disparities: those who suffer from them. Involving community members provides valuable community-based knowledge, reduces the inequality and distance between researchers and participants, and builds in accountability on the part of the researcher. CBPAR also accounts for cultural distinctions and norms that traditional research often ignores. Therefore, we explicitly incorporated a Black feminist methodological framework. The strength of CBPAR is the ability to empower the community for social action in their interest, and this must be a central element of any project seeking to utilize this approach [53].

We not only sought to bring the everyday lived experiences of the mothers in this project to the forefront, but also took seriously our ethical obligations to the women we studied. Ethical considerations and responsibilities concerning research practice, design, protection of the research participants, disposition of data and framing of the research results are particularly important in the case where the research subjects have limited access over how knowledge (their knowledge in particular) is presented and represented. These ethical considerations are also important considering the past abuses of Black individuals in health research [32].

### **Interdisciplinary Research Team**

All eight of the researchers conducting the focus groups and interviews during phase one and phase two of the Black mothers' project were Black women with the exception of one Latina undergraduate student. At the time of the study, the Principal Investigator (Co-PI) was an African American woman professor of Sociology, African American Studies, Urban and Regional Planning, and Social Work with an affiliate appointment at the Institute for Genomic Biology. The PI has extensive experience conducting research on race, class, and gender using qualitative, quantitative, and mixed methods. She has also published in the area of mental health and coping [40,58]. Other research staff conducting the focus groups and interviews included: an African American woman Emerita Professor in Sociology, African and African American Studies and Women and Gender Studies who has written eight editions of a textbook on marriages and families [59], a MSW Social Worker, two Social Work graduate students with mental health training, one Sociology graduate student with experience as a mental health professional working with individuals with severe mental disorders and conducting mental health trainings, an undergraduate Social Work student, and an undergraduate Sociology student.

One of the PI's is a biologist who has taken an experimental approach to exploring the dynamic nature of the genome and social life by using honey bees as his model [35,36]. Another PI is a biostatistician and uses advances in statistics and molecular biology to integrate genomics and social behavior at the cellular, individual and population levels [60,61]. The final PI is a psychologist whose research focuses on the meaning and scope of the trait of conscientiousness (i.e., propensity to follow social norms and to make plans for goals) and its relationship to the health and other life course outcomes [41,42]. The interdisciplinary team provided expertise in quantitative, qualitative and genomic data.

## **Six Phases of the Black Mothers' Project**

At the core of our approach is the use of mixed methods. This project utilizes a transformative-emancipatory worldview in which the multiplicities and variability in one's construction of reality is extended to include critical and Black feminist theories that critique existing inequalities and promote social change [20,21]. This worldview or paradigm creates a theoretical and methodological bridge through which social, behavioral and biological sciences and the humanities can be integrated to address a social problem.

The overall design of the project is a modified two-phase exploratory design. During phase one, the research team used focus groups to better understand the phenomenon of living in communities with high levels of violence. We used insights from the participants' stories to develop questions for the survey and interview and examine cultural resiliency by using the Africultural Coping Systems Inventory [62]. The second phase of the project employed a multilevel triangulation mixed methods design. We used qualitative and quantitative methods, giving equal weight to both (QUAL + QUANT), to examine Black mothers' lived experiences with the phenomenon of violence at a community, family, individual and genomic level.

## **Phase One: Focus Groups-Documenting the “Hidden America”**

Phase one of the project consisted of two focus groups (July 2012 and March 2013) where we explored the phenomenon of raising children in neighborhoods with high levels of violence. The goals of both focus groups were to involve the community in the planning and design of the Black mothers’ project and subsequent intervention. In addition, the research team felt that it was important to document the “Hidden America” [4].

The focus group questions focused on understanding if community violence was an important issue to the entire community and the scope of the issue. Therefore, the first focus group included women (average age of 45 years), men (average age of 47 years) and children (average age of 13 years). Focus group facilitators asked the following questions: Is violence something that you think about in this neighborhood? What things do you do to stay safe? Have you or your children witnessed community violence? Have you been a victim of community violence? We asked the mothers about their children: How often would you say that your children are exposed to violence? The themes that emerged included families’ focus on brokering educational pathways for their children as a way to achieve social mobility and to move out of neighborhoods with high levels of violence. Parents wanted their children to (1) get a quality education (including instruction in math and science), (2) be exposed to a broad range of individuals (class and race) outside of their segregated communities who could help with future goals (i.e., social capital), and (3) have access to information about college scholarships and how to apply to college.

Once we confirmed that violence was an important issue, we conducted the second focus group with just African American women to get feedback on and ideas about survey and interview questions for phase two of the project. The second focus group consisted of eleven African American mothers with two of the mothers in their late teens and early twenties and the other mothers ranging in age from around mid-thirties to early fifties. We focused on women in this focus group because we also explored their interest in participating in a genomics project and their reactions to recruitment materials that discussed giving blood as part of genomic research. The second focus group questions included: What do you feel about the level of safety in your neighborhood? How does living in this neighborhood affect you and your children emotionally? If so, how do you cope? What do you think about participating in a project that asks you to give some of your blood to see how the genes that regulate your immune system are working? The themes that emerged included the chronic fear and stress that takes up a significant amount of their physical and emotional energy. Their coping mechanisms consisted of spirituality but also a practice of trying to train their minds not to focus on the violence in their neighborhoods, even when it directly affected them, because they could not control it. The women also stated that they would be willing to participate in a genomic project that asked them to provide blood samples. They appeared to be very interested in such a project because they believed that it would be helpful to Black women like them who are under a lot of stress.

## Phase Two-Exploring How Stress Gets “Under the Skin”

During phase two of the project, we sought to understand how the stress of living in neighborhoods with high levels of violence gets “under the skin” to affect mental and physical health. On a structural level, we sought to understand how structural inequality (e.g., poverty, Black racially segregated neighborhoods, raising children with limited resources) may be the unnatural causes of chronic illness and eventually death [9]. To answer these grand challenge questions, we used a mixed methods multilevel triangulation design [43]. The goal of a triangulation design is to take advantage of the strengths of qualitative (in-depth information about lived experiences, theory building, etc.) and quantitative data (larger samples, generalizations, etc.). We collected the qualitative (interviews and field notes) and quantitative (surveys) data concurrently. We took a multilevel approach that includes obtaining genomic information, individual psychosocial data, and family and community processes (Figure 1).

A total of N=95 low-income Black women agreed to participate in the Black Mothers’ project. There are at least two grandmothers who are raising their grandchildren. On average, there are two children in the home. The average age of the mothers is 34 years. Thirty percent of the mothers did not finish high school, and another 30 percent completed high school. Twenty nine percent of mothers attended a vocational school or junior college and eight percent of them graduated. About 10 percent of the sample reported some higher education and three percent have a Bachelor’s degree. Twenty-two percent are taking courses. Before approaching mothers to participate in the project, the researchers carefully selected a site that was consistent with our project’s focus on women.

### Selecting the Site

When selecting a site for the project, the researchers deliberately chose a location that was women-centered and allowed the participants to feel safe and comfortable. It was also important that the location was in close proximity to the neighborhoods where the participants lived but also safe. That was a challenge due to the high levels of violence. The YWCA location was chosen because it offered four private rooms for the interviews and had noise machines to ensure that the participants’ conversations remained private. The location had space and toys for the participants’ children to play with while the mothers were being interviewed. In addition, the YWCA also had a kitchen with tables and chairs which allowed mothers to sit comfortably while eating. Another important factor was that it had a guard at the front door during the times the research was conducted.

The YWCA’s mission of eliminating racism and empowering women coincided with the research project’s transformative goals. The YWCA has a 139-year history of providing services to the women in Chicago. The research team was also interested in a potential collaboration with the YWCA to provide additional support services for the Black mothers due to their vulnerable status as low-income Black women. One example of the collaboration that took place involved a mother who came to the YWCA to participate in the project after a domestic violence incident. Her eye

was black, and her lip was swollen. Research staff took her to the YWCA staff who immediately provided domestic abuse counseling. All of the participants received a folder with support services (e.g., domestic abuse counseling, economic empowerment, mental health counseling, etc.) available at the YWCA and other places in their communities.

### **Recruiting Participants**

Research suggests that there are significant challenges in recruiting and retaining low-income participants of color in health research [22,23]. These challenges include but are not limited to lack of transportation, lack of trust in the researcher or institution conducting the research, and the belief that the participant will be hurt or exploited by the researcher [24]. However, the literature suggests that Black individuals are willing to participate in health research if certain mechanisms are in place such as Black researchers and staff, monetary compensation for their time and expertise, and a connection to the disease/condition being studied [5,63].

To address these recruitment issues, we assembled a research team that included Black academics, social workers and social work students specializing in mental health, and individuals from the community to help recruit, interview, and engage with the participants [64]. As a way of providing jobs to community members and being consistent with principles of CBPAR, we hired a Black male production specialist who played a vital role in creating a public service advertisement for the project that was aired on the radio in Chicago and shared on Facebook and Twitter. He also spent three weeks handing out flyers at bus stops, laundromats, preschools, churches, and the local community college. Many of the initial participants spoke about a “nice Black man who gave them a flyer and told them about the project.”

For two months, we recruited mothers into the project and collected data (including the blood samples). We recruited single low-income Black mothers (and a few grandmothers) who were raising children under the age of 18 years of age in neighborhoods with high levels of violence on the Southside of Chicago. We excluded mothers with cardiac disease, cancer, respiratory conditions, auto-immune disorders, diabetes, or obesity because these health conditions could possibly influence our ability to measure transcriptomic patterns of immune cells.

Data collection was conducted on Fridays (9 AM-4 PM) and Saturdays (10 AM-3:30 PM). During the first few weeks, about six women enrolled in the project each week. The numbers increased gradually. However, by weeks seven and eight, word of mouth spread about the project and the YWCA was filled to capacity with Black mothers. Some of the mothers had to wait outside in the cold because there was not enough space inside. We estimated about 50 mothers on the first day of week seven. We could not collect data from everyone, so we created a waiting list for the next day. The next day, those on the waiting list returned and additional mothers which resulted in a completely full YWCA again. Again we created a waiting list for the following week and had to end the project early because we did not have enough funding to pay all the women who were interested and to analyze their genomic data. The mothers were disappointed and asked to be

notified if we conducted other studies. At least 80 percent of all the mothers requested to be contacted in the future for other paid research studies.

When we reflected on the intense interest in the project, we believed three factors played a role: \$40 stipend, food provided and the desire to understand how stress gets “under the skin” to affect their health. One factor appeared to be the \$40 stipend cash that the women received. The \$40 stipend was approved by the University of Illinois IRB for the amount of time given (120 minutes) and participants’ contribution to the study (i.e., interview, survey, and RNA sample). There were discussions about higher stipend amounts which will be explored in future studies.

All of the women were low-income and about 80 percent of our sample was unemployed, indicating they were living on the economic edge. The mothers often expressed how much the \$40 stipends were going to help them meet some basic, but urgent, need such as buying diapers, medicine, paying cell phone bills, carfare, and purchasing food. They often talked about giving some portion of the stipend to others in their networks. During the interviews, often the first two questions asked by the mothers were “Are you hiring? Do you know about any jobs?”

Another factor that the participants overwhelmingly commented on was the healthy lunch provided for them as they engaged in the project. We understood the importance of providing food as participants provided blood samples, particularly mothers who maybe anemic, in accordance with standard blood donation practices [65]. Each participant was provided an option of fresh fruit, a veggie or turkey sandwich, cheese and crackers, water or 100% juice. More than 80% of the participants commented that this was the only meal that they would have that day. We were deeply saddened by the high level of hunger and food insecurity expressed by our participants. We also knew of mothers who skipped meals to ensure their children were able to eat the available scarce food. We responded to the mothers’ food insecurity in a manner consistent with CBPAR and added humus and nuts to the food provided. When involving low-income African American women in genomic research, it is important to include healthy snacks or meals.

The third factor that appeared to drive interest in the research appeared to be the nature of the project and its goal to examine, through their stories, how the stress they experienced on a daily basis may affect their emotions and physical health. Most of the women stated that they heard about the project from their neighbors and girlfriends. One woman stated, “My girlfriend said that I could come here, and they would pay me \$40 to talk about my life.” When informed that there was a blood component to the project, she laughed and said, “She didn’t say nothing about giving blood.” Like all of the women in the project, she agreed to provide a blood sample.

Many of the women were intrigued by the genomic research and had informal hypotheses about what we would find. They believed the chronic stress they experienced was taking a toll on their health and described chronic headaches, migraines, backaches, stomach aches, hair loss, an inability to sleep for days, decreased sexual appetite, etc. The interviewers listened actively to the mothers and without judgment. Many of the mothers’ thanked us for creating a space for them to discuss the pressures they have as low-income single Black mothers who are raising children in

unsafe environments. One mother, pseudonym is Jillian, waited for the PI to finish her other interviews to tell her what many other mothers also communicated. Jillian stated:

I just wanna thank you for taking the time out to see about people. And you know Black women in the area, just the poor area, [and] just women period. Thank you so much for taking the time out and to get to know people to see what's going on in neighborhoods and you know see what you guys can do to help out [and] to better the community. So I really thank you [for] tak[ing] the time out...If we had more people like you to see what they can do to try to make the world be a better place. I really thank you so much... And I thank you so much for just doing this. The littlest things do matter... (Co-PI: I think [to myself] oh you are trying to change the neighborhood. You [are] trying to change policy. Can you do it? But it's very heartwarming to hear that [the little things matter].) You do. You do. The little things make a difference, people don't even understand that, but you keep doing what you doing. You got a good heart...and I thank you.

In line with the CBPAR principle of having community members participate in all aspects of the research, we asked Jillian to be a co-author on this paper and to write about her experiences as a participant in the project. She agreed to participate but felt that her writing skills were out of date because she had not written a paper in many years. We stated that we would help her write her section of the paper. In the end, Jillian decided not to be a coauthor. However, we do have two other community members as coauthors on this paper, the phlebotomist, and the project recruiter.

## Multilevel Data Procedures

**Providing Food:** We provided food, and many of the mothers discussed being hungry and asked if they could take food home. Two of the mothers who came with their children stated that they had not eaten. It became clear quickly that many of the low-income mothers and their children were experiencing food insecurity, meaning they did not have access to enough food for healthy, active living [66]. If they were able to buy food, they reported income short falls that affected other areas of their lives such as paying rent, gas for their cars, diapers, and electric and heating bills [67].

**Obtaining Informed Consent:** Research staff read the IRB consent forms and provided details about the project as the mothers read along with them. The mothers were instructed that they would be provided \$40 for their time, expertise, information about their lived experiences and blood samples. They were told that as human subjects, their information would be confidential and that they had the right to withdraw from the project at any time or skip questions that they did not want to answer and still receive the \$40. We made it clear that they did not have to give blood to receive the \$40 because we did not want their low-income status and the need for money to drive their decision to give blood. We also mentioned that a trained expert would draw about one teaspoon (5 ML) of blood to measure how stress may be affecting their general health by looking at how the genes that regulate their immune system, and inflammation may be functioning. We emphasized that we would not use the blood sample to diagnose them with a medical condition.

At least eight times when obtaining consent, mothers either mentioned the Tuskegee Syphilis experiment or stated that they were concerned that we would do something more with their blood sample than what was stated on the consent form. We acknowledged the past abuse of African Americans in medical research and explained what we were doing and to whom they could speak if they had concerns. Also, a few of the mothers asked for confirmation that they did not have to give blood to get the \$40. We told them they were correct. In the end, all of the mothers who signed the consent did agree to give blood.

We also engaged participants in conversations about how genomic research is beneficial for the global society and that women of color can use genomic information to get a better understanding of their bodies and how stress may “get under their skin” to affect their health. As the prior research suggests [5,63], when the mothers understood that the goal of the research was to improve Black women’s health, they became more interested in genomic research and that felt that they could make a difference by being a part of the project.

**Collecting the Blood:** The Principal Investigator, project manager, and phlebotomists had to take part in a training that involved understanding biosafety, the safe handling of human cells and the transportation of infectious substances. Based on CBPAR principles, we wanted to hire certified phlebotomists from the community as a way of providing jobs and developing trust regarding collecting blood samples [34] Hiring community members proved challenging but successful in the end. We hired four phlebotomists, and three of them lived in the community. The certified phlebotomist from the community that collected the majority (93 percent) of the blood samples was also trained as a certified nursing assistant. She had four years of experience using sterile procedures to draw blood at a major research university hospital.

At least five of the mothers were willing to give blood but were afraid of needles. Research staff was able to talk them through it by distracting them with engaging conversations about their lives/hobbies and shielding the needle from view. When it was over, the mothers would often say, “that wasn’t bad.” Although all of the 95 women interviewed agreed to give blood samples, we were only able to obtain blood samples for  $n=73$  of them (or 77 percent). Research staff was unable to obtain blood samples from  $n=22$  women, even after several attempts, mostly due to small and rolling veins or the inability to find a “good” vein.

The major phlebotomist for the project stated that many of the mothers asked her how she got the job with the project. They also asked her if the project was hiring. The mothers appeared to view the phlebotomist as someone they could ask about employment resources.

**Administering Surveys:** The mothers also completed four scales psychosocial scales: The Patient Health Questionnaire, PHQ-9) [68], Africultural Coping Systems Inventory [62], the Chronic Stress Scale [69] and the PTSD Checklist (PCL-Civilian) [70]; They also completed a 15-page paper and pencil survey which included demographic and social support information, child and adult trauma, neighborhood safety, and stress and coping. Midway through data collection, several issues repeatedly came up in the interviews and were added to the survey. For instance, some of the women discussed smoking cigarettes as a coping mechanism. Only one or two of the women

reported smoking marijuana. During the interviews, the mothers also mentioned knowing very large numbers of individuals who were shot and/or killed. Therefore, we added new questions about the numbers of individuals that they knew who were shot and/or killed ever. Only 27 of the mothers were asked these new questions. The 27 mothers reported knowing, on average, 22 individuals who were shot (median is 11 with a range of 0-60 individuals) and 12 individuals, on average, who were killed (median is 7 with a range of 0-102). This was an example of researcher bias and a lack of understanding of what it means to live a lifetime in neighborhoods with high levels of violence because we did not expect such large numbers.

**In-depth Interviews:** Recognizing the Black mothers' humanity as part of our Black feminist methodology eliminated the false dichotomy between the knower and the known, the researcher and the informant. Consistent with CBPAR, the mothers described their lived experiences within the context of a partnership. On average the interviews lasted one hour and included questions about the Black mothers' neighborhoods; roles as mothers, workers and partners; stress and mental and physical health. The mothers were engaged during the interviews and spoke frankly about their lives and dreams/desires. Many of them were dealing with untenable situations and yet were kind, friendly, and determined to take care of themselves and their families. Themes related to protective factors included spirituality, meaning, and a faith and belief in a God that intervenes in their lives with protection and resources, family and friends, and their children. However, just as revealing during the interviews was the mothers' vulnerability, exhaustion, sicknesses, disappointments, sadness, and fear for themselves and their children. Though some mothers in challenging situations blamed themselves for their current conditions, others articulated what it meant to be a Black low-income woman and how some doors were closed due to those identities. Mothers also talked about the lack of access to mental health resources.

Interviewers listened to heartbreaking stories about gun violence and deaths of children and adults from weeping mothers, aunts, friends, and grandmothers. They tried to maintain composure but at times cried with the mothers as they cried. As the interviewers sat and listened to the women's stories about their lived experience with violence, poverty and stress, it became clear that they needed to maintain their emotional well-being.

### **Interviewers Reactions and Self-Care**

The interviewers came together at the end of the day to talk about the participants' stories that may have brought up research bias and/or unexpected findings. In addition, the interviewers discussed the emotional costs of bearing witness to how societal failures negatively affect the everyday lives and health of lowincome Black women and their children [71]. As a way to practice self-care, the interviewers had an advanced doctoral student in counseling psychology talk with about compassion fatigue and self-care.

As researchers, it was difficult to bear witness to many of the Black mothers' stories who were living at the intersection of race, violence, health disparities, underemployment, unemployment, endure extreme and chronic stress as they struggled to cope with their circumstances. The

overwhelming majority of the mothers talked about trying to shield their children from experiences of poverty, food insecurity, gun violence, etc. but being unsuccessful in many of the cases. In several cases, the mothers' children were killed – the ultimate inability to protect them. The premature deaths of children and adults due to gun violence also reflect one of the ultimate failures of U.S. society

The same Black mothers at the margins of society also taught the researchers many lessons about vulnerability and daring greatly [72]. As Jullian, who was mentioned earlier stated, “The little things make a difference. People don’t even understand that.” Motivated by Jullian’s words not to discount how “little things” can have a big impact, the researchers began to develop a research, community education, and outreach program that grew out of the mother’s stories of despair, use of cultural resources to remain resilient and hopes for the future. The mothers were quite interested and vocal about wanting jobs and school opportunities to better their lives and the lives of their children. They already had the aspirations but lacked the knowledge and/or resources to follow through on their dreams. The mothers’ desires for decreased stress, better health, living-wage jobs, and quality schooling for their children that includes college attendance inspired the research team to develop the DREAM (Developing Responses to Poverty through Education and Meaning) program. DREAM represents a unique partnership between community members, community organizations, extension educators, university faculty, and funders that has the potential to transform individuals, communities and society around issues of race, gender, and poverty [49].

### **Phase Three-DREAM (Developing Responses to Poverty through Education and Meaning)**

The third phase of the South Chicago Black Mothers’ Resiliency Project began in February 2014 concluded in May 2016 (Table 1). This phase of the DREAM program involved developing an innovative interdisciplinary program of research, community education and outreach designed to provide educational, financial and cultural resources that the mothers indicated would collaterally benefit their day-to-day lives on the Southside of Chicago. We developed the program but were unable to secure funding to implement it.

At the individual level, the goal of DREAM includes providing activities and resources to decrease the negative consequences of social inequality (e.g., stress reduction, health prevention, access to scholarships at major universities, etc.). However, DREAM also has structural-level goals that include creating social change around issues of racial, gender and economic marginalization. See Figure 2 for the DREAM components, pathways, and expected outcomes.

A guiding principle of DREAM is, whenever possible, to create change-oriented programs that can be sustained by the mothers, daughters, and extension educators who take the research from the academy to the community. The research team began to lay the foundation for DREAM by securing commitments from Cook County Extension Illinois educators to work on programming and impact assessment. The team also received support from several social service agencies that serve hundreds of families and provide a range of family-focused social services. Financial institutions and religious leaders also agreed to be community partners.

The development of the DREAM program was based on cutting-edge research and interventions to increase resiliency and coping skills from scholars, scientists, and engineers representing 33 UIUC departments/units. The research program involved using state-of-the-art genomics to explore how aspects of neighborhoods with high levels of violence get “under the skin” to affect health and wellness. We proposed to track changes in gene expression as one way of testing whether and how our interventions help to ameliorate the long-term effects of stress.

The outreach and education program involved mothers and daughters (ages 8-12 years of age) and consisted of courses, workshops, and mental health interventions that promote health, resiliency, financial wellness, and transformative parenting by building on the cultural resources of the mothers and daughters. We planned to develop an artist co-operative that taught participants how to use their artistic talents to engage in entrepreneurship.

A Black feminist book club was designed to 1) highlight the achievements of Black girls and women and 2) study past strategies and social movements for insights about how to create current social change. The program included participants identifying two “dreams” that they have for themselves and the future of their neighborhoods. We planned to help participants achieve their DREAMS by soliciting resources from corporate sponsors, foundation grants, meetings with legislators, etc. Participants’ stories, pictures, essays, and poems related to their DREAMs were to be stored in a big data archive to add to the knowledge about Black women’s lived experience, especially their resistance and resiliency

Mothers and daughters were scheduled to participate in a Genomics for™ You course specifically designed to inform communities of color about the new science of genomics and how it can be used to understand the effects of living in neighborhoods with high levels of violence on health and well-being. To create a concrete pathway for careers in genomics and other fields, participants would collect and analyze genomic data in partnership with the researchers (citizen scientists). It was our hope to have participants receive mentoring and scholarships to universities and become a new generation of interdisciplinary scholars. Such unprecedented access to universities fulfills the land-grant mission of the state of Illinois’ university system. Faculty and eminent female Black scientists and engineers from across the country were identified to give workshops and discuss their career stories in the Black Girls Empowered and Educated in STEM (BEES) program.

The program was created to celebrate large and small steps to achieving the Black mothers’ and daughters’ DREAMs at an annual banquet attended by faculty, the community, community partners and legislators. Through the use of CBPAR (citizen/ community science), education, and mentorship, we hope to inspire the daughters and mothers to “DREAM” of many possible futures, including careers in academia and industry where they produce scholarship and research, and engage in activism, that transforms their neighborhoods and addresses social inequality in the larger U.S. society.

Though the program was not funded, a 2016 TEDxUIUC talk described the program and the desired DREAM campus to promote health and wellness. The “daring greatly” DREAM was to

have a campus of four buildings on the South side of Chicago in a low-income neighborhood with high levels of violence [72].

The first building would house the Fannie Lou Hammer “Sick and Tired of Being Sick and Tired” Health and Wellness Center. The second building would house the Maya Angelou “And Still I Rise a Phenomenal Woman” Arts Center. The third building would house the Harriett Tubman “I have a right to death or liberty” Restoration Center, and the final building would hold the Shirley Chisholm “Our Country Needs Women’s Idealism and Determination” Policy Institute. These names of the buildings listed are tentative because the actual names of the buildings will be determined in consultation with community members.

#### **Phase Four-Citizen Science: How Gun Violence Affects Public Life & Public Health Sensor Study**

Phase four is the period where the project examined working with community members as citizen scientists in a study that examined how gun violence affected public life and public health (Table 2). Specifically, the study examined the physiological effects of exposure to nearby gun crimes such as shootings and other forms of stress. For one month, Black mothers wore biosensors on their wrists to measure their heart rates and physical movements around the city were recorded by their smartphone’s GPS. Researchers collected real-time crime data from the city of Chicago, using 911 calls administrative data that record the specific time and location of gunshot activity. In addition, the research team also collected subjective measures of crime events (e.g. text describing stressful events, photos, audio recordings, etc.). These data will be used to assess the feasibility of detecting the short- and long-term impact of nearby gun crimes on the health and well-being of African American mothers.

The final product was the development of an exhibit titled “How Gun Violence Affects Public Life and Public Health.” The exhibit was held in the same community where the data was collected. Study participants (citizen/community scientists) helped us to collect the data and then create the exhibit using unique visualizations of the complex data. During the exhibit, various tools were presented to empower African American mothers to communicate how exposure to community violence affects their collective health and organize around changes in health policy and public policy more broadly

#### **Phase Five: STEM Illinois Communiversy Think & Do Tank & Wellness Center**

Phase five of the project involves providing greater access to STEM skills and opportunities to communities in Chicago and Urbana-Champaign. Echoing its land-grant mission, the university is answering that call by establishing STEM Illinois with a coalition of local partners to engage with K-12 and college students. STEM Illinois will build upon an eco-system of science, technology, engineering, and mathematics that inspires youth from diverse backgrounds and learning styles to explore STEM education and career opportunities. Following COVID-19 public health guidelines about group gatherings, STEM Illinois will include a STEM Fest and nine STEM Saturdays, which are monthly handson STEM-based activities for children and their parents.

Additional STEM Illinois components include a Communiversity Think and Do Tank, which provides opportunities for community members to discuss challenges facing the STEM pipeline and possible solutions. A Communiversity Wellness Center will provide the UrbanaChampaign community with a respite space, access to premed pathways (and other health careers), and stress reduction activities (e.g., meditation, dance and art). The wellness center is a smaller version of the DREAM campus discussed in phase three. Art and cultural artifacts produced by faculty, staff, students, community members and artists-in-residence are on display at the Community & University Art Gallery. The new initiative will also include Ghetto Genius Street College and the Hip Hop Xpress Double Dutch Boom Bus where young people with interests in electrical and mechanical engineering, graphic art, coding, robotics, sound engineering, and sound design can innovate with technology and culturally grounded music. The Chicagobased component of STEM Illinois is the Chicago Pre-College Science and Engineering Program (ChiS&E). ChiS&E will offer an intensive Saturday program to foster accelerated learning in science and mathematics for first and second graders. STEM Illinois hopes to develop a replicable model that can be scaled up across the state and the country.

### **Phase Six - STEM Pathway Program and Citizen Scientists**

Phase six of the project involves funding from the National Science Foundation for the pathway program, STEM Illinois: The Land-Grant Model of Outreach and Education to Nurture Future Underrepresented Computer Scientists. The program will train 50 to 100 students from underrepresented backgrounds (and who may be at risk of dropping out of school) in computer science. Students will participate in weekly computer science activities that include a maker lab competition. The competition will be hosted by the recently created Designing Resiliency and Well-being Health Maker Lab node. Students will use data science to solve real-world problems, such as, using GIS to identify vulnerable groups during the COVID-19 pandemic.

The goal is to increase the number of marginalized students majoring in Computer Science and Information Technology at the University of Illinois and around the country. We will also plan to provide students with unprecedented access to computer science internships and jobs at large companies such as State Farm, American Association of Retired Persons (AARP) and Microsoft. We also hope to have students apply to the Carle Illinois College of Medicine which requires medical students to complete data science projects. Our goal is to develop healthcare providers at the intersection of technology and discovery who are deeply embedded in communities of color. For other scholars and community groups interested in conducting research that addresses issues of citizen/ community science, health research and social justice, the final section of this article outlines some of our main challenges and lessons learned.

## **Social Justice Research**

### **Main Challenges**

One of the major challenges of the project was the overwhelming interest in participation by the mothers. The unexpectedly large number of interested mothers caused us to end the project early because we did not have the financial resources to pay them stipends or to pay for the genomic analysis of their blood. We put the mothers' names on a waiting list, but they were clearly disappointed that they were not able to be a part of the project.

Another major challenge was the difficulty securing funding during phase three for the holistic DREAM Black mothers' project. We wrote grants to national funding agencies and private foundations. Unfortunately, none of the grants received funding.

A final challenge involves the time-intensive nature of creating community partnerships from multiple sectors such as finance, faith-based, education, and health. However, the DREAM program continues to expand the range of partnerships, and many agencies are interested in the program. We recently started working with African American architects who will organize what we are tentatively calling a "revolutionary charrette." During the charrette, architects, community residents and other community partners will come together to create a rendering or drawing of the four buildings on the DREAM campus. It is our long-term goal to obtain funding for space, or a donation of space, that will house the innovative DREAM community program.

### **Lessons Learned**

The research team identified several critical lessons that were learned throughout all three phases of the project. First, the mothers' low-income status often meant that they experienced food insecurity. Serving a variety of healthy food during data collection provided the mothers and their children with a meal that did not have to be paid for out of their tight budget. Future studies may want to include healthy snacks or meals in their research budgets to address potential food insecurity issues experienced by the low-income families in their sample.

In addition to food insecurity, mothers reported experiencing more violence than the researchers anticipated. The researchers witnessed first-hand the depth and breadth of the realities of the intersections of race, class and gender and the related consequences. This significant underestimation of the violence by scholars studying this subject for several years highlights the need to document the "Hidden America" where residents are exposed to high levels of violence that are "unfathomable to most of the country" [4]. In addition, future studies should have a mental health worker as part of the team to support participants and the research staff.

In terms of coping, a surprising finding was when the mothers talked about the need for "tunnel vision" and to focus on what they "can control." They also talked about "digesting" what they experienced and how they "move[d] on" as a way to avoid mental distress. Future studies should examine the relationship between this type of coping and the idea of the strong Black woman. Is the ability to focus your mind on what you "can control" and "digest" the exposure to violence a strength, like being mindful, that allows them to avoid rumination and mental distress [73]? Do these actions indicate avoidance, pushing down their feelings, and emotional suppression [73]?

Also, in terms of coping, future studies should also include questions about smoking and the various ways that it might relieve stress for participants. For instance, do participants feel that smoking is a time to take a break from stressful daily activities? Is there something soothing about taking deep breaths while inhaling? This is an important area because of the various health issues associated with smoking cigarettes such as cancer.

Contrary to some stereotypes about single Black mothers, the participants in our sample were informed about and wanted to participate in a project about their mental and physical health. The mothers displayed an interest in the genomic component of the project, despite being aware of and asking questions about past abuses in health research. Their interest, in part, their experiences with what seems to be the physical consequences of stress that they personally experienced: loss of hair, headaches, migraines, backaches, loss of sexual appetite, etc. Jullian's message that the "little things make a difference" suggests that individual-level activities, such as talking to other women about their lives, can have a positive impact on stress on mental health. Therefore, when designing community, education and research programs based on the needs of the community, it is important to consider goals that have more immediate individual-level benefits and longer-term structural-level outcomes.

### **Implications for COVID-19**

This study has implications for the current COVID-19 pandemic and the need to train a corps of citizen scientists in health and wellness to minimize as much as possible extreme future death rates such as the 106,195 lives lost in the U.S. as of June 1, 2020 [74,75]. During Governor Cuomo's March 28, 2020, COVID-19 update he stated; that the U.S. Army Corp of Engineers and the National Guard working in New York for about a week, converted the Javitz Convention Center into a 1,000+ bed temporary field hospital to treat patients during the pandemic. The deployment of the Army Corp of Engineers to create a temporary hospital was a critical step in preparing for the rapidly changing health context of the pandemic. We argue that another critical step in addressing the pandemic is to create a Corps of citizen scientists to document the impact of the COVID-19 and to share their health and well-being tools in real-time.

This corps of citizen scientists would provide critical epidemiological and public health insights about the spread and impact of COVID-19. It is also important to train the general public (including citizen/community scientists) about the human body, its systems (e.g., respiratory and immune) and what research suggest can promote health and well-being. An example of a recent shift in the public and medical world's perception about health and wellness is the Robert Wood Johnson Foundation's (RWJF) culture of health movement [76]. RWJF moved the country from just prioritizing health interventions to preventing health conditions. Just as the use of personal protective equipment (e.g., gloves and masks) is now a part of the American culture, understanding the immune system and how viruses operate must also be readily accessible knowledge. Public awareness campaigns may be a simple tool to create a highly health literate and healthier COVID-

19 population. Informal classes at PTA meetings, gyms, churches, etc. can also ensure that we save as many lives as possible, especially for those experiencing a pandemic within a pandemic.

## Conclusion

The need for economic and mental and physical health resources for Black women living in the “Hidden America” where they and their children are exposed to high levels of violence is at a watershed moment. The goal of this project was to involve single low-income Black mothers in genomic research that may provide insights into how living in neighborhoods with high levels of crime might get “under their skin” to affect their mental and physical health. We used tenets from CBPAR to include community members in all aspects of the research to date: identifying violence and hunger as issues, working as paid research staff, asking them to co-author a manuscript, and using insights from their lived experience to develop the DREAM program.

Our research methods demonstrate that by addressing culturally sensitive issues such as past abuses in health research and connecting the research directly to the lived experiences of Black women, enrollment and participation can be greatly enhanced. A major benefit of the project’s methodological approach is that it also provided insights into the transformative nature of the Black mothers’ resistance and resilience. For example, many of the mothers viewed their participation in this project as a pathway to new possibilities, resources and opportunities that could enrich their lives.

A year after Hadiya Pendleton’s murder, her parents [3] wrote an article for the Chicago Tribune newspaper stating the urgent need for policy makers and community members to end gun violence: If we have the courage to wake up every day knowing our daughter is gone, then we demand the courage of our elected leaders to do everything in their power to end gun violence. We are not alone in this fight. We are joined by millions of people who want to keep their communities safe. We will tell our stories and do everything we can to ensure our country’s leaders know why this is so important.

A critical goal of this Black feminist and CBPAR project is to tell the stories of low-income Black mothers living in neighborhoods with high levels of crime and violence as a way of documenting the “Hidden America” in an effort to ensure that such communities and experiences are no longer “hidden” and to let policy makers, politicians and others know why paying attention to individual and structural change is critical for all of our wellbeing. As Hadiya Pendleton’s parent point out, these mothers are not alone. They are joined by millions of U.S. citizens and others in the global community who demand safe communities for children and adults. During the COVID-19 pandemic, the demands also include unbiased access to life saving care such as ventilators despite pre-existing co-morbid conditions [77-84].

## Acknowledgements

We would like to thank Nicole Brown, Claire Rittschof, Nelida Garcia, Laura Reed, Samia Miles, Artesha Williams, Mercedes Gonzalez, Idessa Butler, Maria Valgoi, Sara Olles, Anna Marshall, Lou Turner, Lashuna Mallett, Rochester Bailey, Bobbie Wren and Phillip Bowman for their assistance with this paper. We are grateful to the University of Illinois at Urbana-Champaign Provost's Social and Behavioral Science Research Committee for funding the initial Social Behavioral and Systems Biology Health and Wellness Brown Bag Series that later became the Sociogenomics Group. We would like to thank the Sociogenomics Group for their assistance. We received funding from the Research Board at the University of Illinois, Urbana-Champaign and the Richard and Margaret Romano Professorial Scholarship.

## References

1. Chi Raq by Will Robson-Scott.
2. Bauder D (2012) ABC special shines light on Chicago violence. CNBC.
3. Cowley-Pendleton C, Pendleton N (2014) Hadiya's parents address gun violence. Chicago Tribune.
4. Ford D (2012) Hidden America: Don't shoot, I want to grow up. ABC News.
5. Sweeney GW (2006) Desperation in the air in Englewood: Rally attracts big names, more pleas to end violence there. Chicago Sun-Times.
6. Tatum AW (2015) Writing Through the Labyrinth of Fears. Journal of Adolescent & Adult Literacy 58: 536-540.
7. Chachkevitch A, Bowean L, Gorner J (2015) Deadliest September in Chicago in 13 years.
8. Cole SW (2010) Elevating the perspective on human stress genomics. Psychoneuroendocrinology 35: 955-962.
9. Adleman L (2008) Unnatural causes: Is inequality making us sick? California Newsreel. (Production).
10. Dahlberg LL, Mercy JA (2009) History of violence as a public health issue. American Medical Association Journal of Ethics 11: 167-172.
11. Gramlich J (2019) 5 facts about crime in the U.S. Pew Research Center, Fact Tank, News in the Numbers. Washington, D.C.
12. Bogira S (2015) Weekend shootings and recent homicide stats give Garcia an issue to exploit. Reader.

13. Koval A (2020) Slain 15-Year-Old Boy Becomes City's 8th Person Shot in Just Under an Hour Wednesday. WGN 9 News.
14. Chicago Tribune (2020) In Chicago, 1,003 people have been shot this year. That is 128 more than 2019.
15. Obama M (2013) Michelle Obama: "Hadiya Pendelton was Me and I Was Her".
16. D'Onofrio J (2020) 5-year-old girl, 2 teenagers injured in drive-by shooting in Wentworth Gardens on South Side, police say. Eyewitness News.
17. Perrett C (2020) Black people account for 72% of COVID-19 Deaths in Chicago while making up less than a third of city's population, Mayor Says.
18. APM Research Lab (2020) The Color of Coronavirus: COVID-19 Deaths by Race and Ethnicity in the U.S.
19. Strings S (2020) It's not obesity. Its slavery: We know why COVID-19 is killing so many Black people. New York Times.
20. Mendenhall R, Harwood S, Williams L, Franklin K, Turner L, et al. (2011) Rethinking 21st century urban transformations: Race and the ecology of violence. Submitted to the National Science Foundation.
21. Collins PH (1998) Fighting words: Black women and the fight for justice. Minneapolis, MN: University of Minnesota Press.
22. Bolen S, Tilburt J, Baffi C, Gary TL, Powe N, et al. (2006) Defining "success" in recruitment of underrepresented populations to cancer clinical trials. Cancer 106: 1197-1204.
23. Ford JG, Howerton MW, Lai GY, Gary TL, Bolen S, et al. (2008) Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. Cancer 112: 228-242.
24. George S, Duran N, Norris K (2014) A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health 104: e16-e31.
25. Evelyn B, Toigo T, Banks D, Pohl D, Gray K, et al. (2001) Participation of racial/ethnic groups in clinical trials and race-related labeling: a review of new molecular entities approved 1995-1999. J Natl Med Assoc 93: 18S-24S.
26. Owens OL, Jackson DD, Thomas TL, Friedman DB, Hébert JR (2013) African American men's and women's perceptions of clinical trials research: Focusing on prostate cancer among a high-risk population in the South. J Health Care Poor Underserved 24: 1784-1800.

27. Haga SB (2010) Impact of limited population diversity of genome-wide association studies. *Genet Med* 12: 81-84.
28. Savitt TL (1982) The use of blacks for medical experimentation and demonstration in the Old South. *J South Hist* 48: 331-348.
29. Gamble VN (1997) Under the shadow of Tuskegee: African Americans and health care. *Am J Public Health* 87: 1773-1778.
30. Jones JH (2000) *Bad Blood: The Tuskegee Syphilis Experiment, New and Expanded Edition*: New York, NY: Free Press.
31. Solomon M (1985) The rhetoric of dehumanization, an analysis of medical reports of the Tuskegee syphilis project experiment. *Western Journal of Speech Communication* 49: 233-247.
32. Skloot R, Turpin B (2010) *The immortal life of Henrietta Lacks*. New York: Crown Publishers.
33. Margonelli L (2010) *Eternal Life*. New York Times.
34. Spruill I (2004) Project Sugar: A recruitment model for successful African-American participation in health research. *J Natl Black Nurses Assoc* 15: 48-53.
35. Robinson GE (2004) Genomics. Beyond nature and nurture. *Science* 304: 397-399.
36. Robinson GE, Grozinger CM, Whitfield C (2005) Sociogenomics: social life in molecular terms. *Nat Rev Genet* 6: 257-270.
37. Shields AE, Crown WH (2012) Looking to the future: incorporating genomic information into disparities research to reduce measurement error and selection bias. *Health Serv Res* 47: 1387-1410.
38. Bowman P, Bowman PJ (2013) A Strengths-based social psychological approach to resiliency: Cultural diversity, ecological and life span issues. In: S. Prince-Embury (Ed.), *Resilience in children, adolescents, and adults: Translating research into practice* (pp. 299- 324). New York, NY: Springer.
39. Henderson L, Scott B, Mendenhall R (2016) The "Hidden America": The Ripple Effects Black Women and Families Face When Living with and Responding to Structural Inequality and Violence *Issues in Race & Society: An Interdisciplinary Global Journal* 4: 9-35.
40. Mendenhall R, Bowman PJ, Zhang L (2013) Single black mothers' role strain and adaptation across the life course. *Journal of African American Studies* 17: 74-98.
41. Roberts BW, Kuncel NR, Shiner R, Caspi A, Goldberg LR (2007) The power of personality the comparative validity of personality traits, socioeconomic status, and cognitive ability for predicting important life outcomes. *Perspect Psychol Sci* 2: 313-345.

42. Lodi-Smith J, Jackson J, Bogg T, Walton K, Wood D, et al. (2010) Mechanisms of health: Education and health-related behaviours partially mediate the relationship between conscientiousness and self-reported physical health. *Psychol Health* 25: 305-319.
43. Creswell JW, Clark VLP (2007) *Designing and conducting mixed methods research*. California: Sage Publications, Inc.
44. Collins PH (1990) *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*. New York, NY: Routledge.
45. Elder GH (1998) The life course as development theory. *Child Development* 69: 1-12.
46. Mills CW (1959) *The Sociological Imagination*. London: Oxford University Press.
47. Harris D (2011) *Black feminist politics from Kennedy to Obama*. New York: Palgrave Macmillan.
48. Hine DC, Brown EB, Terborg-Penn R (1993) *Black women in America: An Historical Encyclopedia*. Carlson Publishers.
49. Mendenhall R (2010) The political economy of black housing: From the housing crisis of the great migrations to the subprime mortgage crisis. *The Black Scholar* 40: 20-37.
50. Brewer RM (2003) Black radical theory and practice: Gender, race, and class. *Socialism and Democracy* 17: 109-122.
51. Williams RY (2004) *The politics of public housing: Black women's struggles against urban inequality*. New York, NY: Oxford University Press.
52. Becker HS (1967) Whose side are we on? *Social Problems* 14: 239-247.
53. Israel BA, Schulz AJ, Parker EA, Becker AB (1998) Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health* 19: 173-202.
54. Fals-Borda O, Rahman MA (1991). *Action and knowledge: Breaking the monopoly with participatory research*. New York: Apex.
55. Minkler M, Blackwell AG, Thompson M, Tamir H (2003) Community-based participatory action research: Implications for public health funding. *Am J Public Health* 93: 1210-1213.
56. Cavalier D, Kennedy EB (2014) *The rightful place of science: Citizen science*. AZ: Arizona State University.
57. Brown NM, Mendenhall R, Black ML, Van Moer M, Zerai A, et al. (2016) Mechanized margin to digitized center: Black feminism's contributions to combatting erasure within the digital humanities. *International Journal of Humanities and Arts Computing* 10: 110-125.

58. Perry DM, Tabb KM, Mendenhall R (2015) Examining the Effects of Urban Neighborhoods on the Mental Health of African American Male Adolescents: A Qualitative Systematic Review. *Journal of Negro Education* 84: 254-268.
59. Schwartz MA, Scott BM (2013) *Marriages and families: Diversity and Change*. Upper Saddle River, NJ: Pearson Prentice Hall.
60. Ko Y, Zhai C, Rodriguez-Zas S (2009) Inference of gene pathways using mixture Bayesian networks. *BMC Syst Biol* 3: 54.
61. Sen Sarma M, Rodriguez-Zas SL, Hong F, Zhong S, Robinson GE (2009) Transcriptomic profiling of central nervous system regions in three species of honey bee during dance communication behavior. *PLoS One* 4: e6408.
62. Utsey SO, Adams EP, Bolden M (2000) Development and initial validation of the Africultural Coping Systems Inventory. *Journal of Black Psychology* 26: 194-215.
63. Lang R, Kelkar VA, Byrd JR, Edwards CL, Pericak-Vance M, et al. (2013) African American participation in health-related research studies: indicators for effective recruitment. *J Public Health Manag Pract* 19: 110-118.
64. Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC (1997) Why are African Americans under-represented in medical research studies? Impediments to participation. *Ethn Health* 2: 31-45.
65. Carter Bloodcare (2014) What to do after you donate.
66. Coleman-Jensen A, Nord M, Andrews M, Carlson S (2011) Household food security in the United States in 2010. USDA-ERS Economic Research Report.
67. Frank DA, Casey PH, Black MM, Rose-Jacobs R, Chilton M, et al. (2010) Cumulative hardship and wellness of low-income, young children: multisite surveillance study. *Pediatrics* 125: e1115-e1123.
68. Kroenke K, Spitzer RL (2002) The PHQ-9: a new depression diagnostic and severity measure. *Psychiatric Annals* 32: 1-7.
69. Consensus Measures for Phenotypes and Exposures (2011) Psychosocial measures for PhenX toolkit.
70. National Center for PTSD (2015) PTSD Checklist for DSM-5 (PCL-5).
71. Lispsky LV, Burk C (2009) *Trauma stewardship: An everyday guide to caring for self while caring for others*. San Francisco, CA: Berrett-Koehler Publishers, Inc.
72. Brown B (2012) *Daring greatly: How the courage to be vulnerable transforms the way we live, love, parent, and lead*: Penguin.

73. Woods-Giscombé CL, Black AR (2010) Mind-Body Interventions to Reduce Risk for Health Disparities Related to Stress and Strength among African American Women: The Potential of Mindfulness-Based Stress Reduction, Loving-Kindness, and the NTU Therapeutic Framework. *Complement Health Pract Rev* 15: 115-131.
74. New York Times (2020) An Incalculable Loss.
75. Worldometer (2020) United States Corona Cases.
76. Robert Wood Johnson Foundation (2020) Building a Culture of Health.
77. Baker M, Fink S (2020) At the top of the Covid-19 curve, how do hospitals decide who gets treatment? *New York Times*.
78. Fink S (2020) The hardest questions doctors may face: Who will be saved? Who won't? *New York Times*.
79. Black AR, Woods-Giscombé CL (2012) Applying the stress and 'strength' hypothesis to Black women's breast cancer screening delays. *Stress Health* 28: 389-396.
80. Mendenhall R (2018) The medicalization of poverty in the lives of low-income Black mothers and children. *J Law Med Ethics* 46: 644-650.
81. Mendenhall R, Henderson L, Scott R (2017) African American mothers' parenting in the midst of violence and fear: Finding meaning and transcendence.
82. Evans SY, Bell K, Burton NK, Blount LG (2017) *Black Women's Mental Health: Balancing Strength and Vulnerability*. New York, NY: Sunny Press.
83. Mendenhall R (2009) Families in the Gautreaux Housing Mobility Program: Perceptions and responses to the US political economy. *The Review of Black Political Economy* 36: 197-226.
84. Miller J (2006) *Medical apartheid: The dark history of medical experimentation on Black Americans from colonial times to the present*.