10-1-2023

Multilevel Community Engagement to Inform a Randomized Clinical Trial

Kirby L. Wycoff

Jabina G. Coleman

Christine M. Santoro

Leah L. Zullig

Niesha Darden

See next page for additional authors

Authors

Kirby L. Wycoff, Jabina G. Coleman, Christine M. Santoro, Leah L. Zullig, Niesha Darden, Porsche M. Holland, Jane F. Cruice, Shukriyyah Mitchell, Michelle Smith, Saleemah J. McNeil, and Sharon J. Herring

Original Research

OPEN

Multilevel Community Engagement to Inform a Randomized Clinical Trial

Kirby L. Wycoff, PsyD, MPH, Jabina G. Coleman, MSW, IBCLC, Christine M. Santoro, MA, CPM, Leah L. Zullig, PhD, MPH, Niesha Darden, CRC, Porsche M. Holland, MS, Jane F. Cruice, RN, MA, Shukriyyah Mitchell, BSN, RN, Michelle Smith, MAHS, Saleemah J. McNeil, MFT, MS, and Sharon J. Herring, MD, MPH

OBJECTIVE: To explore how patients, community-based perinatal support professionals, and health system clinicians and staff perceived facilitators and barriers to implementation of a randomized clinical trial (RCT) designed to optimize Black maternal heart health.

METHODS: This article describes the formative work that we believed needed to occur before the start of the Change of H.E.A.R.T (Here for Equity, Advocacy, Reflection and Transformation) RCT. We used a qualitative, descriptive design and community-based, participatory approach, the latter of which allowed our team to intentionally focus on avoiding harm and equalizing power dynamics throughout the research process. Data were collected between November 2021 and January 2022 through six semistructured focus groups that included attending physicians and midwives (n=7), residents (n=4), nurses (n=6), support staff (n=7), community-based perinatal support professionals (n=6), and patients (n=8).

RESULTS: Four primary themes emerged. The first three themes were present across all groups and included: 1) Trauma in the Community and Health System, 2) Lack of Trust, and 3) Desire to Be Heard and Valued. The fourth theme, Hope and Enthusiasm, was expressed predominantly by patients, community-based perinatal support professionals, residents, and support staff, and less so by the attending physician group.

CONCLUSION: Participants articulated a number of key sentiments regarding facilitators and barriers to implementing Change of H.E.A.R.T. We noted variability in perceptions from different groups. This has important implications for health equity efforts in similarly underresourced health systems where Black birthing people experience the greatest morbidity and mortality.

CLINICAL TRIAL REGISTRATION: ClinicalTrials.gov, NCT05499507.

(Obstet Gynecol 2023;142:929–39)

DOI: 10.1097/AOG.0000000000005344

Cardiovascular disease (CVD) is the leading cause of maternal death in the United States and responsible for nearly 50% of pregnancy-related deaths among Black women.[1] This is three times the rate of White women[2] and is largely preventable.[3] Comprehensive reviews of pregnancy-related deaths demonstrate a fundamental need for multilevel interventions emerging from the lived experience and expertise of Black women that provide support from

From the Department of Counseling and Behavioral Health, College of Health Professions, Thomas Jefferson University, the Maternal Wellness Village, the Program for Maternal Health Equity, Center for Urban Bioethics, the Department of Urban Health and Population Science, and the Department of Internal Medicine, Lewis Katz School of Medicine at Temple University, and the Division of Neonatology, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; and the Department of Urban Health and Population Science, Duke University, Durham, North Carolina.

Research reported in this article was funded through a Patient-Centered Outcomes Research Institute (PCORI) award (AD-2020C3-20906). The statements in this article are solely the responsibility of the authors and do not necessarily represent the views of PCORI, its Board of Governors, or Methodology Committee.

The authors thank the participants in Project HEAR for their wisdom and honesty. Without them, this work would not be possible. The authors also thank coinvestigators and collaborators at Temple Health for their hope and commitment to this work.

The authors' Positionality Statement is available at http://links.lww.com/AOG/D329.

Each author has confirmed compliance with the journal's requirements for authorship.

Corresponding author: Kirby L. Wycoff, PsyD, EdM, MPH, NCSP, Thomas Jefferson University, Philadelphia, PA; kirby.wycoff@jefferson.edu.

Financial Disclosure

The authors did not report any potential conflicts of interest.

ISSN: 0029-7844/23

early pregnancy through the end of the first postpartum year. Interventions should address individual lifestyle behaviors in the context of resilience, family, and relationships, along with community-level factors and institutional barriers, including structural racism.[4] If root causes of racial disparities are not addressed, Black women will continue to die of pregnancy-related CVD.[1]

In response to these inequities, our community–academic partnership developed an 18-month hybrid type 1, pragmatic, randomized clinical trial (RCT), funded in 2021 by the Patient Centered Outcomes Research Institute (NCT05499507). For this RCT, we used a community-driven social ecologic framework. We proposed to compare COH (Change of H.E.A.R.T. [Here for Equity, Advocacy, Reflection and Transformation]), which incorporates evidence-based individual-level interventions (home blood pressure telemonitoring and nutrition and physical activity text messages with resources and tailored feedback)[4–8] and an institutional-level intervention (antiracism training of clinicians and staff and patient feedback to inform respectful care),[9–13] with COH+, which includes COH plus interpersonal support for Black women by Black women (community doula care, mental health services, and lactation support).This RCT aims to evaluate the effect of COH compared with COH+ on blood pressure and body weight changes at 6 weeks and 1 year postpartum in 432 Black women and birthing people at highest risk for perinatal CVD.

Before starting the RCT, we recognized the need to elicit input from diverse patient, community, clinical, and health system collaborators. This was prioritized to ensure that our interventions were conducive to normal clinician workflows and satisfactory to Black birthing people, community-based perinatal support professionals, and health system clinicians and staff. This article describes the formative work that needed to occur before the RCT started. We used a community-based, participatory research approach to explore perceptions of facilitators and barriers to implementation among the communities most affected.

This article has the potential to be useful to others attempting to implement complex interventions in safety-net hospitals and health systems, where broad-based health inequities are most common and continue to persist.[14,15] Not all people who have the capacity for pregnancy identify as women. Terms such as women or mother are used in reference to research that was focused on people who identify as women or in a context where the intersectional and cultural identity of Black women warrants its use.

METHODS

For this study, we used a qualitative, descriptive design and thematic analysis to understand the phenomenon of interest, "perceptions of collaborators."[16] Our study was grounded in community-based participatory research, which is particularly useful in exploring complex health and social issues that have racial and power dynamics involved.[17] We also applied CFIR (Consolidated Framework for Implementation Research), which has been identified as an effective tool to guide the efficient and rigorous analysis of qualitative data through rapid-cycle methods.[18] We used CFIR domains to develop our semi-structured focus group guide (Appendix 1, available online at http://links.lww.com/AOG/D330). This approach uses a priori areas of interest, "to capture the needs of various stakeholders on a timeline that ensured that findings were still relevant when data collection ended."[19]

We used focus groups organized by role in the health care system because our goal was to understand the perspectives of the people serving in each of these roles as they relate to delivery of the future interventions.[20] We organized the focus groups so that each group would be conducted with individuals who held similar titles, roles, or positions to minimize power imbalances and to capture a realistic understanding of participants' perceptions. Appendix 2, available online at http://links.lww.com/AOG/D330, provides additional information on how validity and rigor were established in this study. This research study was approved by the Temple University IRB (protocol 28925).

The setting of this study is Temple University Hospital, which is Temple Health's flagship hospital, the largest safety-net provider in Pennsylvania. Temple University Hospital delivers about 2,300 neonates annually, with more than 90% of birthing people having low incomes (ie, individuals with Medicaid insurance) and nearly half self-identifying as Black. Approximately 2% of Black patients at Temple develop one or more severe maternal morbidities, which is significantly higher than the national average (1.3%).[21] Contemporary and historical structural racism has pervasively affected Temple Hospital and the communities it serves, which contributes to the neighborhood surrounding the hospital experiencing a range of social and health disparities, including high rates of chronic disease, gun violence, food insecurity, poverty, and trauma.

We recruited participants using purposive sampling, through the medical school and hospital, along

with referrals from community partner organizations. Potential participants had to be at least 18 years of age and had to speak and write fluently in English. They also needed to have access to a smartphone, tablet, or computer to participate through Zoom or other virtual platforms. If the participant met all other criteria but did not have access to a device, the research team lent a device and wi-fi hotspot to the participant. Of note, no participants needed to use the research team's devices. The study investigative team contacted the potential participants by phone or email to make them aware of the study. Temple University's IRB waived the requirement to consent in writing. Additional details about the recruitment and consenting process are given in Appendix 3, available online at http://links.lww.com/AOG/D330.

Participants needed to meet the criteria for one of these six collaborator groups: 1) attending physicians and midwives; 2) residents; 3) nurses; 4) support staff, including medical assistants, certified nursing assistants, surgical technicians, and front desk staff or unit clerks; 5) community-based perinatal support professionals, including doulas, lactation consultants, and psychotherapists; and 6) patients. Health system participants included clinicians and support staff who care for and interact with birthing people from pregnancy through the first year postpartum (eg, obstetricians, family practice physicians and nurses, intensive care nursery staff) to fully represent the wide breadth of individuals who interact with birthing families. Additional descriptions of each group are given in Table 1.

Data collection occurred between November 2021 and January 2022. We held six semistructured virtual focus groups with 38 participants. They included attending physicians and midwives (n=7), residents (n=4), nurses (n=6), support staff (n=7), community-based perinatal support professionals (n=6), and patients (n=8), and each was about 2 hours long. The average number of participants per group was six, which is consistent with the methodologic literature suggesting a range of 2–21 participants per focus group.[22] Participants completed a survey with questions about demographics at the start of each group, and we used means and frequencies to summarize these data. Each focus group had two qualitatively trained researchers who served as facilitators. Multiple qualitatively trained team members were out of view of the participants and took notes. Member checking (to assess accuracy) was done iteratively, and participants were invited to follow up with the study team if they had additional insights after the group ended. All Zoom-based groups were audio and video recorded; however, video recordings were deleted immediately after each group. Deidentified audio recordings were downloaded and transcribed for analysis.

This study used a qualitative descriptive design and thematic analysis to understand the phenomena of interest.[16,23,24] To balance the need for identifying actionable findings in a relatively short time frame with the need for achieving scientific rigor, the team used rapid analytic methods. The rapid analytic approach coupled with the use of CFIR was largely a deductive process; however, the open-ended nature of our focus groups allowed the team to uncover more "hidden phenomena" that one may associate with traditional, inductive, qualitative methods.[25]

Our entire research team contributed to the development of our five-step data-analysis process. The multistep process used a systematic, team-based approach that resulted in the identification of commonly occurring themes. A more robust description of our process can be found in Appendix 4, available online at http://links.lww.com/AOG/D330.

RESULTS

The 38 focus group participants self-reported their racial and ethnic identity as follows: 24 (63%) as Black or African American, 10 (26%) as White, one as Hispanic or Latinx, and two as more than one race and ethnicity; one participant chose not to answer. All participants identified their gender as female, which is consistent with the overall population. Mean age was 42 years (range 26–64 years). We report the demographic characteristics of all participants, rather than specific focus groups, to protect their anonymity. Our qualitative analyses revealed four primary themes: 1) Trauma in the Community and Health System, 2) Lack of Trust, 3) Desire to Be Heard and Valued, and 4) Hope and Enthusiasm (Table 2).

In the first theme, Trauma in the Community and Health System, participants across all groups described a significant level of trauma in the community and the health system (Fig. 1). There was a strong belief that pervasive trauma in this health system and surrounding community would affect the uptake of the proposed interventions. Participants acknowledged that the health system has played a role in traumatizing the community and causing harm, through racism and mistreatment among other things, both historically and in the present (Table 3, quotes 1.A–1.C). The trauma in the community and trauma in the health care system are related but in complex, multifaceted, and bidirectional ways. Patients believed that the ongoing and relentless trauma of racism would affect their experience in the health care system,

Table 1. Description of Collaborator Groups

Name of Collaborator Group	Description of Collaborator Group
Physician attendings and midwives	Currently employed by the Departments of Obstetrics and Gynecology and Reproductive Sciences, Family and Community Medicine, Neonatology, or General Internal Medicine within the university-based health care system as an attending physician or certified nurse–midwife
Residents	Currently a resident in the Departments of Obstetrics and Gynecology and Reproductive Sciences or General Internal Medicine within the university-based health care system
Nurses	Currently employed and working as a nurse within the university-based health care system in the Departments of Obstetrics and Gynecology and Reproductive Sciences, Neonatology, or General Internal Medicine; both inpatient and outpatient staff were eligible
Support staff	Medical assistants, certified nursing assistants, surgical technicians, and front desk staff or unit clerks: currently employed working in inpatient or outpatient care in one of these positions in the Departments of Obstetrics and Gynecology and Reproductive Sciences, Family Medicine, Neonatology, or General Internal Medicine within the university-based health care system
Community-based perinatal support professionals	Self-identification as Black or African American along with current or recent work experience as a doula, Internationally Board-Certified Lactation Consultant, Certified Lactation Counselor, or therapist in the North Philadelphia community; at least 1 y of experience was preferred but not required; experience serving Temple patients was preferred but not required
Patients	Current or former patients who have given birth within the health care system or received prenatal care through the health care system as per patient self-report; community members who have given birth in the past and live in geographic proximity to this university-based health care system but chose another area hospital for their care and birth as per stakeholder self-report; self-identification as Black or African American; majority of individuals in this collaborator team have a self-reported history of hypertension, obesity, or both

although the aim of the proposed interventions is to intervene on institutional-level factors. One patient shared, "I want to say it will help…but honestly, I don't think it will. It is our skin color, make us think it won't…People still want to treat Black moms poorly." The relationship between trauma and racism is dynamic and contributes to people feeling dehumanized.

There was also robust awareness that the health system itself, although the perpetrator in causing harm, has also experienced significant trauma. According to clinicians and support staff, they experience vicarious trauma simply from witnessing infant loss, the effects of the coronavirus disease 2019 (COVID-19) pandemic, and gun violence, which then contributes to significant stress and burnout. Clinicians described the trauma of treating gunshot wounds in the same building as attending births and how the trauma of the surrounding community seeps into the fabric of the health system. All collaborator groups echoed this sentiment.

Table 2. Four Primary Themes

Theme	Theme Name	Theme Description
1	Trauma in the Community and Health System	Described as pervasive, chronic, and at times debilitating trauma that permeates the community and health system
2	Lack of Trust	Described as a pervasive mistrust across and between multiple aspects of the health care system and community
3	Desire to Be Heard and Valued	Described as a deep need and desire to be heard and valued, a general sentiment of being devalued assets
4	Hope and Enthusiasm	Described as genuine hope for the future and enthusiasm for the possibilities of the two proposed interventions

Table 3. Theme 1: Trauma in the Community and Health System, Examples

Theme Code Corresponding to Narrative	Stakeholder Group	Quote
1.A	Physician attending	"I was raised knowing that doctors just hysterectomized every Black woman that walked in the door…You better be careful because when you go to the doctor because they are gonna just cut your uterus out…There's a really strong sort of cultural understanding that you are not here to take care of me properly."
1.B	Patient	"They [health care professionals and the health care system] have to stop treating us like because we're Black we're a handicap. Being Black is not a handicap, I'm living in you know, a certain area, you know area [ZIP] code is not a handicap. Having underlying health conditions, that's not certified as a 'handicap' is not a handicap. A lot of times, I can speak personally for myself, I am presumed to be aggressive, because I can properly advocate for myself. You know, I can go to a doctor's office and quote HIPAA law to these people, because I am familiar with the HIPAA law, you know. They have to stop automatically assuming that because you are in a poverty-stricken area, you are an imbecile. Everybody is not undereducated. You have people in my community that I would say have more sense than the college educated doctors, you understand what I'm saying? Doctors also have to be mindful that you are trained to diagnose symptoms, you aren't trained to diagnose ME. We are the professionals when it comes to us because can't nobody tell us about our bodies more than we can."
1.C	Community-based perinatal support professional	"I grew up not too far from Temple. If you ask somebody when you think of Temple, what do you think of? I think of gunshot victims, blood. It's like Temple equals trauma…not just the hospital in itself, but that area."

HIPAA, Health Insurance Portability and Accountability Act.

In light of the prolific trauma described, there was great excitement for the proposed trauma-informed care approach embedded within the RCT. One nurse specifically shared, "I thought that the trauma-informed care approach was so critical. I feel like we can't arm ourselves enough with that approach as caregivers of our patients at Temple. And I think that we all need to be more educated about that from the highest of us down to the lowest of us. Because it [trauma] is in every person that we meet."

In the second theme, Lack of Trust, all participants made it clear that there was pervasive mistrust in the health care system. This emerged both from those external to the system (community-based perinatal support professionals and patients) and from those within the system (clinicians and support staff). This lack of trust is related to a presumed lack of sincerity, authenticity, and transparency coming from the health system. Participants expressed that building trust requires awareness of history and an investment in authentic relationship building, which many reported was lacking. Furthermore, it became clear that without trust, the uptake of any new interventions would be difficult (Table 4, quotes 2.A. and 2.B).

Others discussed the ways in which the history of Black women being ignored in medicine continues to create a deep and ongoing mistrust of clinicians and the health care system. This has largely evolved as a self-protection mechanism in response to systemic and structural racism. For example, one participant highlighted the need for health systems to take accountability for current and historical racism if they want to gain trust (Table 4, quote 2.C). The damage that structural racism causes in both the community and the health care system is pervasive, and this racism sits squarely at the core of the mistrust.

There was further discussion about how a culture of mistrust within a system can seep into the messaging sent to patients. For example, if mistrust is commonplace among clinicians and staff, between the community and clinicians, and between patients and clinicians, is the message to patients that they cannot trust themselves? Several collaborators shared insightful reflections regarding the culture of mistrust and the proposed interventions (Table 4, quotes 2.D. and 2.E).

In the third theme, Desire to Be Heard and Valued, participants in all groups reported feeling unheard, undervalued, and underappreciated. Broadly speaking, it appeared that participants felt

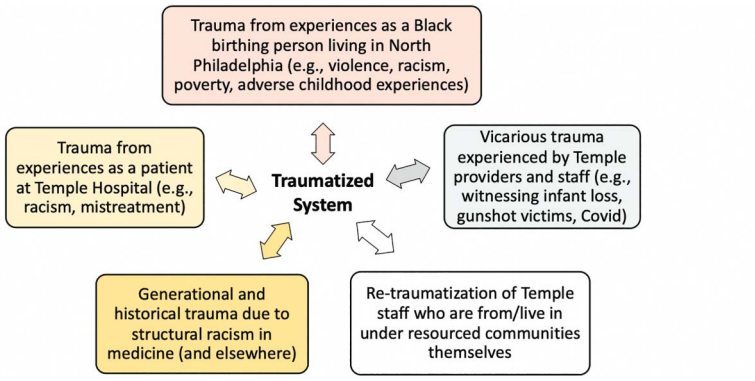

Fig. 1. Complexity of theme 1: traumatized system. Covid, coronavirus disease 2019.

Wycoff. Community-Informed Randomized Trial Design. Obstet Gynecol 2023.

that their voices did not matter and that there was a lack of respect across and between staff, clinicians, patients, and the community. Many felt commoditized and as though they were devalued assets who were largely misunderstood by other collaborator groups.

Many felt that the health care system has done little to amplify and value the diversity and knowledge from staff and patients to improve care. Community members and patients felt like historically, their voices and identity did not matter and have not been heard or valued. One specific patient reflected on how the racism perpetuated by the health system contributed to lack of trust and made her feel dehumanized and unseen (Table 5, quote 3.A).

Table 4. Theme 2: Lack of Trust, Examples

Theme Code Corresponding to Narrative	Stakeholder Group	Quote
2.A	Physician attending	"How well they [patients] respond, depends on how well we build trust. One of the main things that is lacking in terms of the health care relationship between Black women and a [health care] facility, is trust."
2.B	Patient	"I'm so sorry if I sound like that, because…I don't trust, nobody. I don't and I always get a second opinion. I don't trust what doctors say. I tell them they lying…I think this would definitely be a great opportunity, I think it could bring change. I think people will trust…But since we were misled for so long it's so hard to believe that this time."
2.C	Patient	"It will take accountability…But it's hard to break bad habits and they've been doing this stuff for decades…ignoring Black women. If you said I don't feel good, you are alright and then you turn around and bleed to death on the table…I'm so sorry about sounding, like, I do not have any faith in this."
2.D	Midwife	"What we are doing is trying to empower women around their pregnancy experience. I'm thinking that perhaps that will filter into trusting themselves, in life in general. I mean I haven't heard that as a specific goal of the program but that's what I as a Temple [health care professional] think that trusting women in pregnancy and birth is a part of a lifelong intervention…We do so many elective inductions. Is there any chance that we are…systemically robbing people of that inherent trust in their bodies, you know…like we are talking about some really cool interventions here but our practice…automatically assuming induction at 39 weeks…Is there a conflict there?"
2.E	Resident	"I think there is a lot of mistrust. There are historical factors, and personal factors. Patients have experienced racism from our system that affects the way our medical recommendations are perceived. I am hoping that this is a way to build trust. Instead of reiterating that 'I am doctor, holier than thou.'"
2.F	Physician attending	"I find that using phrases like 'so you don't die,' 'so your baby doesn't get stuck,' or 'so you have enough energy to chase your child/children' works really well."

Another patient shared the deep desire to be heard and valued by the system, noting, "Please continue to keep us involved. Give us a seat at the table and get us connected and involved." At the same time, a staff member shared, "We don't have voices. I have to stay in my place, because I need my job." In many cases, collaborators felt excluded from the decision making and described a top-down approach that is often in conflict with real patient-centered care (Table 5, quotes 3.B and 3.E).

There was, in some cases, a sense that patients are seen as a commodity (Table 5, quote 3.C), and there was a sense of widespread dehumanization and a desire for something different. One support staff member noted the need to treat patients as if they were their own family (Table 5, quote 3.D). Clinicians in many ways also shared sentiments of being undervalued and not having the resources that they needed to do their jobs the way they wanted to, while also feeling that these interventions could provide the support that their patients deserve (Table 5, quote 3.F).

The fourth and final theme that emerged was Hope and Enthusiasm for the possible outcomes that could result from the proposed interventions. Despite the difficult discussions related to the three earlier themes, there was also the strong belief that all patients deserve high-quality care, which hopefully the proposed study would bring. There was an "It's about time" sentiment that many patients, community-based perinatal support professionals, residents, and support staff discussed throughout the focus groups. Participants noted that this health care system could be a pioneer in improving maternal health and that this is something that Black birthing people deserve (Table 6, quotes 4.A and 4.B). Another participant shared, "Let this project be the change!" It is interesting that this theme was less present in the attending physicians' and midwives' group, perhaps

Table 5. Theme 3: Desire to Be Heard and Valued, Examples

Theme Code Corresponding to Narrative	Stakeholder Group	Quote
3.A	Patient	"It's hard to break bad habits and they've been doing this stuff for decades…like ignoring Black women. If you say 'I don't feel good,' they say, 'You are alright' and then you turn around and bleed to death on the table…I'm so sorry about sounding like this, but I do not have any faith in this."
3.B	Nurse	"My pet peeve with Temple is…If they're going to implement something, let's say for nursing, you know working nurses, I'm just gonna say…they don't include us. We would love to kind of tell you, how as a nurse…what we think may work, what we think may not work, we want to come to the table…Temple is more like, this is what this it's going to be and you're going to follow it. There's the door."
3.C	Support staff	"Some of us just see them as 'another patient' and just 'move them on.' You know, like, I feel that the staff at Temple makes our patients sometimes feel like they're less than."
3.D	Support staff	"Treat them the way you want to be treated. Treat them the way you want your family to be treated. And I feel that [here] you know, a lot of us, as a staff, lost that."
3.E	Support staff	"I feel like it's stressful because of what I see as a clerk. I'm probably one of the ones who do say stuff. I will say something to a doctor and I will say something to a nurse. Now whether they listen to me and respect me is a whole 'nother situation. But I see when they [patients] walk out. When the patients walk out, and they're frustrated and I see that they're crying and I see that they're saying they never coming back again…it is stressful and it's frustrating, and I want to help them, but I can't."
3.F	Resident	"I think…it will definitely help meet their [patients'] needs. Having extra community health workers that interact with patients is such a benefit…we're stretched so thin on our end, that having extra people that can come in and interact with them and promote "healthy baby, healthy mom"…like getting them access to lactation consultants, like a lot of that stuff, at least my perspective, from the primary care aspect is something that I think we just don't have ready access to. I can give them resources that I Google and print out, but having it implemented in their care and having it as a part of our care team, is a really big benefit to them [patients]."

suggesting that those with the most power and privilege in the system had the least amount of hope.

DISCUSSION

As part of an ongoing Patient-Centered Outcomes Research Institute–funded study (AD-2020C3-20906), our diverse team of researchers conducted a series of focus groups with patients, community-based perinatal support professionals, and health system clinicians and staff in late 2021 and early 2022. Although the aim of these groups was to learn specifically about facilitators and barriers to implementing two proposed interventions for reducing CVD risk factors among Black birthing people, four broad, interconnected themes about their experiences in the health care system emerged.

The most all-encompassing and pervasive theme was Trauma in the Community and Health System (theme 1). The complex and multifaceted cycle of trauma extended across all collaborator groups and created a traumatized system, burdening Black patients, their families and their communities, along with affecting hospital clinicians and staff. In the same way that people are exposed to repetitive and chronic trauma from individual (eg, accidents), interpersonal (eg, abuse, bullying), and sociocultural (eg, racism, poverty) experiences, entire systems can become vulnerable to the effects of trauma and chronic stress.[26] Traumatized systems become more highly reactive and devolve into crisis mode with unmanaged conflict, pervasive mistrust, and exceedingly high levels of burnout.[27] Although often unnamed, this phenomenon is ubiquitous in maternity care,[28,29] especially in hospitals and health systems in under-resourced communities.[30,31]

We contend that the root cause of the trauma is structural and systemic racism. That is, the racism that is deeply and pervasively embedded into systems that perpetuate beliefs, policies, and practices that work to

Table 6. Theme 4: Hope and Enthusiasm, Examples

Theme Code Corresponding to Narrative	Stakeholder Group	Quote
4.A	Community-based perinatal support professional	"One thing I think this [project] allows families to see is that it [high-quality, equitable maternity care] is not a luxury. We deserve it, you know…You don't have to be a certain status in your life to be able to get these things. Because a lot of people feel that doulas are a luxury…'I can't have that because I can't afford it and I don't go to therapy, because it costs a lot, and my job doesn't cover it.' This is game changing, I feel. This actually shows that…this is not a luxury. You do deserve this!"
4.B	Community-based perinatal support professional	"You should be able to walk into any facility and get evidence-based dignified care. That should be the standard and it's not. So hopefully, a program like this is important because people that are within the community surrounding Temple should be able to go there."
4.C	Physician attending	"I think it's a struggle…you know…and it really takes…I mean I think there's research about this, it takes years and years, to sort of to get people to really embrace a new idea even you know changing like a feeding protocol or things like that, and so, but I do feel like it's a struggle."
4.D	Physician attending	"I agree with the excitement about community interventions. I am equally excited about institutional level interventions, particularly since data show that even with many resources [educational, financial, community], Black birthing people still have worse outcomes. And part of this certainly has to do with racism based within the medical institution (both the hospital specifically and the broader medical/health care institution]. Just a small plug for the institutional interventions. I think those will be useful as well."
4.E	Resident	"I saw that graphic [visual of interventions] and I wish I could stare at it forever because these are all of the things that we should have and I think a lot of, I think around the country we should have…I'm just really so excited because I think it's hitting all of the things that we are too spread thin to hit…There's just so much that we can't do and I'm just really excited for others to help with those goals."

condone the unfair treatment and oppression of historically marginalized individuals and communities.[32] Although the entire system is affected by this systemic and structural racism, it causes disproportionately greater harm to Black patients and Black community members, clinicians, and staff.

Health systems, like this one, are particularly susceptible to secondary or vicarious trauma, which may present as chronic stress, fatigue, and burnout. Secondary trauma is tightly linked to employee absenteeism, staff turnover, and depression, along with a host of negative patient outcomes, including high rates of mistreatment and low service utilization.[26] Temple and organizations that serve and employ people living in underresourced environments with exceedingly high rates of trauma, including institutional racism, are often described as being in a "state of chronic crisis" and become traumatized themselves. In parallel, the organization develops its own pattern of trauma symptoms that are reflected in policies and practices, perpetuating a cycle of traumatic stress.[4,27] It was clear that we had to consider this phenomenon in our work. However, fully resolving or fixing these problems, which are hundreds of years in the making and linked to insidious social forces such as structural racism, cannot be the prerequisite for taking action and beginning to make changes.

Closely linked to theme 1 was theme 2 (Lack of Trust) and theme 3 (Desire to Be Heard and Valued). There was a lack of trust, and participants felt undervalued and unheard, contributing to ongoing experiences of trauma. Despite this, certain groups of participants did have Hope and Enthusiasm (theme 4) that things could be different. All four themes are reflexive and interconnected and provided increased understanding for our research team to consider as we moved to subsequent rounds of focus groups and the RCT.

The findings from this formative work made us re-examine how to move forward with the project. We were able to augment our approach to respond to some aspects of what we learned and identify others that would need to be addressed in later research with additional funding. Perhaps most important, our team came to understand the deep and pervasive presence of trauma. Our team had to become more trauma informed and healing centered in our actual interactions with, and expectations of, the health care system and the community. Evidence based models (eg, Sanctuary[4,27]) may be needed to move from a traumatized system to a healing-centered system.[33] Otherwise, well-intentioned intervention efforts may perpetuate problematic dynamics.

In addition to our big-picture lens shifting, we recognized the need to refine and adapt specific elements of our proposed interventions. Some examples include offering support groups for patients, clinicians, and staff. We are also offering smaller, more intimate settings for antiracism trainings to provide a supportive, brave space and to improve relationships. We are providing action tools that offer specific trauma-informed language for key patient, clinician, and staff interactions. We have expanded the scope of the texting component of the intervention to include ways for patients to ask for additional support or community-based referrals. We are also establishing opportunities for patients, clinicians, and staff to share their stories to build hope and connection and to offer a pathway for patients to document their care experiences to inform future institutional-level programming.

Our findings should be interpreted in the context of the following limitations. Our findings at Temple may not be generalizable to other settings. However, the challenges experienced and described in these focus groups are common to many large, underresourced health systems serving historically marginalized and minoritized communities. Regardless of the specific city or hospital, structural racism is a root cause of perinatal health inequities.[25,34,35] Data that emerged from this project speak to clear issues that are relevant to other safety-net institutions attempting to implement complex interventions in places where health inequities are most pronounced. Additional limitations include the tight timeline that accompanies large-scale implementation efforts. Funding mechanisms largely align with traditional RCTs that are not seeking to implement institutional-level interventions. There can be a lack of understanding of the necessary time and resources to make system-level changes in large, complex health care systems. The timeline of the overarching project required that we move efficiently with this early, formative research. Although this yielded valuable and actionable information, it left little time for reflection and sustained dialog, which is critically important in building relationships and amplifying community voices. The tension of these two realities creates an ongoing challenge for research that authentically seeks to partner with communities while securing and meeting the milestones inherent in large-scale funding.

The findings from this study suggest that there was broad enthusiasm for the two proposed interventions despite concerns about the implementation climate in the health system. Many felt as though the "time is now" for large-scale investment in

addressing maternal health inequities through community-driven interventions. However, there was also recognition that time and resources are needed to shift institutional culture and to support individual and interpersonal healing and repair across the traumatized system. Just as individuals who experience trauma require healing to promote long-term wellness and resiliency, health systems–and the community of clinicians, staff, and patients they serve–need to heal from the trauma of interpersonal, structural, historical, and institutional violence. Making such significant and dynamic shifts in an entire health system cannot be done by any one research team or project alone. However, this project is well positioned to advocate for long-term changes in tandem with implementing timely interventions to address health inequities such as those in cardiovascular health for Black birthing people. In the words of James Baldwin, "Not everything that is faced can be changed, but nothing can be changed until it is faced."[36]

REFERENCES

1. Creanga AA, Syverson C, Seed K, Callaghan WM. Pregnancy-related mortality in the United States, 2011–2013. Obstet Gynecol 2017;130:366–73. doi: 10.1097/aog.0000000000002114
2. Hoyert DL. Maternal mortality rates in the United States, 2020. NCHS Health E-Stats. 2020. doi: 10.15620/cdc:113967
3. Pregnancy and heart disease. ACOG Practice Bulletin No. 212. American College of Obstetricians and Gynecologists. Obstet Gynecol 2019;133:e320–56. doi: 10.1097/AOG.0000000000003243
4. Bloom SL, Sreedhar SY. The Sanctuary model of trauma-informed organizational change. Reclaim Child Youth 2008;17:48–53.
5. Richards D. Incorporating racial equity into trauma-informed care. Accessed April 13, 2022. https://www.chcs.org/resource/incorporating-racial-equity-into-trauma-informed-care/
6. Esaki N, Reddy M, Bishop CT. Next steps: applying a trauma-informed model to create an anti-racist organizational culture. Behav Sci (Basel) 2022;12:41. doi: 10.3390/bs12020041
7. Klassa PJ, Dendrinos S, Penn A, Radke J. Shared decision making: through the patient's eyes. J Perinat Neonatal Nurs 2016;30:228–32. doi: 10.1097/JPN.0000000000000192
8. Germán M, Crawford DE, Dumpert K. Measuring the impact of trauma-informed primary care: are we missing the forest for the trees? Accessed April 5, 2022. https://www.chcs.org/resource/measuring-the-impact-of-trauma-informed-primary-care-are-we-missing-the-forest-for-the-trees/
9. Vedam S, Stoll K, Martin K, Rubashkin N, Partridge S, Thordarson D, et al. The Mother's Autonomy in Decision Making (MADM) scale: patient-led development and psychometric testing of a new instrument to evaluate experience of maternity care. PLoS One 2017;12:e0171804. doi: 10.1371/journal.pone.0171804
10. Vedam S, Stoll K, Taiwo TK, Rubashkin N, Cheyney M, Strauss N, et al. The Giving Voice to Mothers study: inequity and mistreatment during pregnancy and childbirth in the United States. Reprod Health 2019;16:77. doi: 10.1186/s12978-019-0729-2
11. Nuriddin A, Mooney G, White AIR. Reckoning with histories of medical racism and violence in the USA. Lancet 2020;396:949–51. doi: 10.1016/S0140-6736(20)32032-8
12. Howell EA, Egorova N, Balbierz A, Zeitlin J, Hebert PL. Black-White differences in severe maternal morbidity and site of care. Am J Obstet Gynecol 2016;214:122.e1–7. doi: 10.1016/j.ajog.2015.08.019
13. Alio AP, Dillion T, Hartman S, Johnson T, Turner S, Bullock S, et al. A community collaborative for the exploration of local factors affecting Black mothers' experiences with perinatal care. Matern Child Health J 2022;26:751–60. doi: 10.1007/s10995-022-03422-5
14. U.S. Department of Health and Human Services. Healthy women, healthy pregnancies, healthy futures: action plan to improve maternal health in America. Accessed December 5, 2020. https://aspe.hhs.gov/sites/default/files/private/aspe-files/264076/healthy-women-healthy-pregnancies-healthy-future-action-plan_0.pdf
15. Black Mamas Matter Alliance. Setting the standard for holistic care of and for Black women. Accessed May 5, 2020. http://www.blackmamasmatter.org/wp-content/uploads/2018/04/BMMA_BlackPaper_April-2018.pdf
16. Schreier M. Qualitative content analysis in practice. Sage Publications; 2012.
17. Wallerstein N, Duran B. The theoretical, historical and practical roots of CBPR. In: Community-based participatory research for health: advancing social and health equity; 2017. P. 17–29.
18. Keith RE, Crosson JC, O'Malley AS, Cromp D, Taylor EF. Using the Consolidated Framework for Implementation Research (CFIR) to produce actionable findings: a rapid-cycle evaluation approach to improving implementation. Implement Sci 2017;12:15. doi: 10.1186/s13012-017-0550-7
19. Lewinski AA, Crowley MJ, Miller C, Bosworth HB, Jackson GL, Steinhauser K, et al. Applied rapid qualitative analysis to develop a contextually appropriate intervention and increase the likelihood of uptake. Med Care 2021;59(suppl 3):S242–51. doi: 10.1097/mlr.0000000000001553
20. Barbour RS, Schostak J. Interviewing and focus groups. Res Methods Soc Sci 2005;1:41–8.
21. Ozimek JA, Eddins RM, Greene N, Karagyozyan D, Pak S, Wong M, et al. Opportunities for improvement in care among women with severe maternal morbidity. Am J Obstet Gynecol 2016;215:509.e1–6. doi: 10.1016/j.ajog.2016.05.022
22. Onyumba T, Wilson K, Derrick CJ, Mukherjee N, Mukherjee N. The use of focus group discussion methodology: insights from two decades of application in conservation. Methods Ecol Evol 2018;9:20–32. doi: 10.1111/2041-210X.12860
23. Saldaña J. The coding manual for qualitative researchers. Sage Publications Ltd; 2021.
24. Yin RK. Qualitative research from start to finish. Guilford Publications; 2015.
25. Perry MJ, Arrington S, Freisthler MS, Ibe IN, McCray NL, Neumann LM, et al. Pervasive structural racism in environmental epidemiology. Environ Health 2021;20:119. doi: 10.1186/s12940-021-00801-3
26. Loomis B, Epstein K, Dauria EF, Dolce L. Implementing a trauma-informed public health system in San Francisco, California. Health Educ Behav 2019;46:251–9. doi: 10.1177/1090198118806942

27. Bloom SL. Creating, destroying and restoring sanctuary within caregiving organisations. In: Odgers A, editor. From broken attachments to earned security: the role of empathy in therapeutic change. Karnac; 2014.

28. Sakala C, Declercq ER, Turon JM, Corry MP. Listening to mothers in California: a population-based survey of women's childbearing experiences. Accessed April 5, 2022. https://www.chcf.org/wp-content/uploads/2018/09/ListeningMothersCA-FullSurveyReport2018.pdf

29. Reed R, Sharman R, Inglis C. Women's descriptions of childbirth trauma relating to care provider actions and interactions. BMC Pregnancy Childbirth 2017;17:21. doi: 10.1186/s12884-016-1197-0

30. Wang E, Glazer KB, Sofaer S, Balbierz A, Howell EA. Racial and ethnic disparities in severe maternal morbidity: a qualitative study of women's experiences of peripartum care. Womens Health Issues 2021;31:75–81. doi: 10.1016/j.whi.2020.09.002

31. Caring for patients who have experienced trauma. ACOG Committee Opinion No. 825. American College of Obstetricians and Gynecologists. Obstet Gynecol 2021;137:e94–9. doi: 10.1097/AOG.0000000000004326

32. Braveman PA, Arkin E, Proctor D, Kauh T, Holm N. Systemic and structural racism: definitions, examples, health damages, and approaches to dismantling: study examines definitions, examples, health damages, and dismantling systemic and structural racism. Health Aff 2022;41:171–8. doi: 10.1377/hlthaff.2021.01394

33. Ginwright S. The future of healing: shifting from trauma informed care to healing centered engagement. Occas Paper 2018;25:25–32.

34. Yearby R, Clark B, Figueroa JF. Structural racism in historical and modern US health care policy: study examines structural racism in historical and modern US health care policy. Health Aff 2022;41:187–94. doi: 10.1377/hlthaff.2021.01466

35. Scott KA, Britton L, McLemore MR. The ethics of perinatal care for Black women: dismantling the structural racism in "mother blame" narratives. J Perinat Neonatal Nurs 2019;33:108–15. doi: 10.1097/JPN.0000000000000394

36. Baldwin J. As much truth as one can bear. New York Times. January 14, 1962.

Authors' Data Sharing Statement

Will individual participant data be available (including data dictionaries)? *No.*
What data in particular will be shared? *Not applicable.*
What other documents will be available? *Not applicable.*
When will data be available (start and end dates)? *Not applicable.*
By what access criteria will data be shared (including with whom, for what types of analyses, and by what mechanism)? *Not applicable.*

PEER REVIEW HISTORY

Received February 1, 2023. Received in revised form May 1, 2023. Accepted May 11, 2023. Peer reviews and author correspondence are available at http://links.lww.com/AOG/D331.