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Reconsidering Community-Engaged Research Through a Syndemic Theoretical Framework: Lessons from COVID-19

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ABSTRACT

Background: Community-engaged research is a well-established approach to tackling health disparities in communities of color. However, the devastation caused by COVID-19 calls for a reexamination of the practice of community-engaged research. Syndemic framework characterizes the clustering and synergistic interactions between two or more diseases amid an underlay of social and environmental threats. This framework has been used to explain the disproportionately higher rates of COVID-19 in communities of color and may have utility in guiding future community-engaged research.

Objectives: This paper describes the process by which a syndemic framework was used to generate discussions on lessons learned from COVID-19 and describes the ensuing collaborative writing process that emerged from this discourse.

Methods: This paper was developed by the Community Engagement Working Group (CEWG) of the Jackson Heart Study (JHS), a community-based epidemiologic study focused on cardiovascular disease among African Americans in the Jackson, Mississippi Metropolitan Area. By drawing upon a syndemic framework and lessons from COVID-19, the CEWG identified gaps and opportunities to enhance community-engaged research.

Conclusions: Using syndemic framework as a starting point, the CEWG identified the following as aspects of community-engaged research that may warrant further consideration: 1) the need to examine multiple dimensions and assets of a community, 2) the need to view communities through an intersectionality lens, 3) the need to acknowledge the impact of historical and current trauma on the community, and 4) the need to provide support to community-engaged researchers who may be members of minoritized groups themselves and therefore, experience similar trauma.

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KEYWORDS: Community-Based Participatory Research, Community health partnerships, Community health research, Health disparities, Health promotion, Syndemic frameworks, COVID-19

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Background

Community-engaged research is a process in which research is conducted in partnership with groups that have a shared interest, groups that are affiliated by geographic proximity, or groups that face similar health and social conditions.[1 2] Community-engaged research has been utilized as an approach to addressing conditions such as cardiovascular disease, obesity, cancer, and HIV that disproportionately impact marginalized and minoritized communities. [3, 4] COVID-19 is yet another public health threat that calls attention to the importance of community-engaged research. Studies examining community-engaged approaches in the context of COVID-19 have begun to proliferate.[5] However, conducting research on COVID-19 is complicated given the social, environmental, and political context and clustering in minoritized communities. In communities of color and in the US, COVID-19 was not a singular pandemic. It consisted of a rapidly spreading virus, underlying health conditions, fractured social infrastructures, and a history of inequitable and unjust allocation of resources. These factors converged to wreak havoc on our communities.

Singer proposed the term 'syndemic' to characterize the clustering and synergistic interactions between two or more diseases amid an underlay of social and environmental threats.[6] The clustering and synergistic interactions of diseases, social, environmental, and economic factors yields health outcomes that are worse than either condition alone. In essence, the whole becomes greater than the sum of its parts. As we further develop community-engaged research focused on COVID-19, it is important to see the totality of events surrounding COVID-19 and identify new frameworks that can capture all of its complexities. This paper describes the process by which a syndemic framework was used to generate discussions on experiences and lessons learned from COVID-19 and describe the ensuing collaborative writing process that emerged from this discourse.

The conceptualization of this paper emanates from the work of the Jackson Heart Study (JHS) Community Engagement Working Group (CEWG). The Jackson Heart Study (JHS) is a single-site, community-based epidemiologic investigation of environmental and genetic factors associated with cardiovascular disease among African Americans supported and funded by the National Heart, Lung and Blood Institute (NHLBI) and the National Institute on Minority Health and Health Disparities (NIMHD). In addition, the JHS conducts community education and outreach activities to promote healthy lifestyles and reduce cardiovascular disease risk burden. JHS also supports undergraduate and graduate-level research training programs in order to prepare and encourage students from backgrounds that are underrepresented in biomedicine to pursue research careers.[7] The JHS has a long history of fostering community partnerships to support research, education, and outreach pertaining to cardiovascular disease. [8, 9] Approximately 5,306 participants were recruited from community-based settings in Hinds, Madison, and Rankin counties in the Jackson, Mississippi Metropolitan Area.

In 2019, the JHS Community Engagement Working Group (CEWG) was established in an effort to promote joint collaborations that would contribute to advancing the practice of community-engaged research. Members included representatives from community-based organizations, senior directors and community outreach coordinators from the Mississippi State Department of Health (MSDH), JHS study program staff members, researchers from academic institutions, undergraduate students, and post-doctoral trainees. Over the course of the year, the CEWG held monthly meetings during which trainees presented their research, updates on community outreach was shared, and potential topics for collaborative papers were discussed. A year later, in April 2020, the urgency of COVID-19 caused the CEWG meetings to shift gears from focusing on advancing community-engaged research that specifically addressed

cardiovascular disease prevention to also thinking about the impact of COVID-19 on the practice of conducting community-engaged research.

During this time, the JHS study as a whole also began responding to COVID-19 infections as well as growing social tensions. The Community Engagement Core of the JHS study housed in the Mississippi Department of Health temporarily halted their cardiovascular prevention outreach activities to promote COVID-19 awareness, promote social distancing, promote mask wearing, and disseminate masks and hand sanitizers. The JHS study recruitment team also began to disseminate information about COVID-19 as part of the routine follow up of the cohort. In addition, given the mounting social injustices, the JHS Community Engagement Core sponsored community forums to address community wellness and coping. New surveys were conducted that focused on trust and vaccine hesitancy. Therefore, COVID-19 and its associated events also caused the entire JHS study to shift some of their activities to address COVID-19.

Methods in developing this paper and the role of community partners

The authors represent those members of the CEWG who expressed interest in contributing to manuscript. Individual roles included conceptualizing the goal of the paper, conducting a literature review, outlining key components, writing sections of the manuscript, and reviewing and editing drafts of the manuscript. Community outreach coordinators from the MSDH set the stage for discussions by providing feedback on what they observed in their communities and directed the paper toward experiences during COVID-19. The co-chair and an undergraduate student reviewed the literature and identified frameworks that would help to coalesce the different experiences and lessons learned about COVID-19 that were shared by the CEWG.

The Community Engagement Working Group (CEWG) is one of several working groups of the JHS. Each working group is tasked with addressing a specific subject matter and applying relevant JHS study data in developing manuscripts and mentoring of early investigators. Data from the actual study were not used in this manuscript. However, members of the CEWG included staff and researchers on the JHS study who made sure that the overall goal of the paper aligned with the scientific, training, and outreach goals of JHS.

Representatives from the JHS study team provided an overview and drafted sections on the history and goals of the JHS study. The writing of the manuscript occurred through a series of monthly meetings during which drafts were circulated, reviewed, and discussed. All authors provided approval of the final version.

The content of the manuscript unfolded through these meetings. Notes were taken to document overall discussions and to capture comments that were made by members of the CEWG. These notes were taken by the chair and an undergraduate student. An important aspect of these discussions is that they reflect the evolving social and political context of COVID-19 from the spread of the virus to police brutality and to a focus on equity and access when COVID-19 vaccines became available.

An important goal of the CEWG was to develop a paper that would advance the practice of community-engaged research. As such, an initial focus was on identifying theoretical frameworks that can help anchor subsequent discussions. As stated by a CEWG member, "we need to consider how during COVID-19 people had trouble finding work, communities had problems with social engagement, and there were trust issues (given the political climate)." This comment reflects the complexity of COVID-19 and the factors that converged to exacerbate disparities in communities of color from the perspective of the CEWG. These discussions

combined with a literature review directed the focus of the manuscript toward a syndemic framework that could capture the multiple factors surrounding the COVID-19. [10-13]

A Syndemic theory as a framework to advance community-engaged research

A syndemic has 3 core features: 1) the clustering of two or more diseases within a population; 2) the biological, social, and psychological interaction of those diseases; and 3) the large-scale social forces that precipitate disease clustering.[11] The term syndemic has been used in describing the social and environmental context of HIV such as SAVA, a syndemic characterized by Substance Abuse, Violence, and AIDS.[14] Another syndemic example, VIDDA, characterizes the confluence of Violence, Immigration, Depression, type 2 Diabetes, and Abuse in women of Mexican descent.[15]

A syndemic perspective has also been applied to understanding endemic and contextual factors such as gendered racism, wage inequality, experiences of discrimination in healthcare, and other social stressors that converge to exacerbate disparities in morbidity and mortality of Black women and birthing people. [16] Griffith and colleagues applied syndemics as one perspective in describing how structural racism exacerbates disparities in exposure to COVID-19 among Black men. [17]

A syndemic framework can be applied to understanding the interactions between socioeconomic discrimination and a host of conditions that cluster with cardiovascular disease.[18] In Mississippi where the JHS is conducted, Black residents made up approximately 38% of the population, yet 56% of the COVID cases.[19] Moreover, in these communities, there is a high prevalence rate of hypertension(46.4%), obesity(43.7%), and diabetes (16.0%) [20] These conditions are referred to as pre-existing conditions associated with greater severity of disease. A syndemic perspective adds value to this work by enabling us to focus beyond the mere

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coexistence of conditions and place greater emphasis on the potentiating, synergistic and reinforcing interactions.[13] As an example, interactions between the viral pathogen, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and pre-existing cardiometabolic risks have been described.[21] [22] The vascular inflammation associated with cardiovascular risks may interact synergistically with COVID-19 infection, creating a hyperinflammatory response.[23]

A syndemic framework also calls attention to the influence of structural racism and discriminatory practices on COVID-19 related disparities. Recent studies demonstrate that neighborhoods that were historically redlined had the highest cases of COVID-19.[24] Redlining is the practice of outlining neighborhoods in many communities across the country including in Mississippi, as undesirable based on the race and ethnic composition of residents. This institutionalized practice of residential segregation perpetuates inequities in community disinvestment, economic, educational and employment deprivation.[25] [26] These structural barriers limit access to health care, healthy foods, and optimal settings for physical activity which in turn, contribute to overall poor cardiovascular risk profiles.[27]

Using a syndemic framework as a backdrop, the CEWG focused on discussions about lessons learned from COVID-19 and how these lessons can advance community-engaged research. In doing so, key elements of community-engaged research that may warrant further consideration were identified such as 1) the need to examine multiple dimensions and assets of a community, 2) the need to view communities through an intersectionality lens, 3) the need to acknowledge the impact of historical and current trauma on the community, and 4) the need to broaden the training and support for community-engaged researchers who are part of minoritized groups themselves and therefore may experience historical and current trauma as community members. These elements helped to organize the content of the paper.

There is a need to consider multiple dimensions of a community

As we reflected on lessons learned from COVID-19 within a syndemic framework, members began asking a germane question of 'what is a community?' and as stated by a CEWG member "How do we now define community?" Prior to these discussions, we focused on the Jackson Mississippi Metropolitan area as a geographic community, which is a common tendency of community-engaged research.[28] We realized that a focus solely on the geographical designation of community misses the opportunity to examine interactions and dynamic processes that occur within a community. Understanding the nuanced social interactions within a community has implications for addressing syndemics and for advancing the practice of community-engaged research.

CEWG discussions also focused on the role of community assets such as barbershops, salons, and faith-based organizations and how these organizations mobilized in response to COVID-19. Future studies addressing the economic impact of COVID-19 on community-based organizations may help inform studies that address health disparities while also building capacity for economic development. CEWG members described how in their communities, organizations mobilized to disseminate masks, hand sanitizers, and food. This is important to consider the resourcefulness of communities and to build on collective assets when conducting research. Community-engaged research might also consider new social connections that were developed and how communities mobilized to address their needs.

The CEWG also reflected on the closure of several community business. While many churches transitioned to virtual services, some were closed. One member said, "If the community-organizations we work with are no longer engaged in community activities, how do we then define community-engagement?" This comment emphasized the need for community

engaged-research to closely examine social connections and how disruptions in community interactions may contribute to adverse outcomes.

MacQueen disentangles community into multidimensional core elements that include locus, sharing, joint actions, social ties, and diversity.[29] Adapting similar elements when describing the community may be of value to community-engaged research. This approach may further the understanding of how information is shared and help to characterize the collaborative joint actions that are taken by community members in response to public health disasters such as COVID-19. This information is important to informing the development of tailored syndemic-informed interventions that address multiple dimensions of a community.

There is a need to view communities through an intersectionality lens

As we continued to reflect on COVID-19 within a syndemic framework, discussions on the differential impact of COVID-19 on various members of the community emerged. CWEG members were particularly interested in discussing the impact of COVID-19 on Black men, children, and older adults. This led to a discussion of considering intersectionality when conducting community-engaged research. Intersectionality describes how social identities can interact and overlap in ways that create systems of power and inequality, advantages, and vulnerabilities. This is particularly salient for groups that experience discrimination, marginalization, and oppression. [30, 31]

Variations in vulnerabilities to COVID-19 has been observed based on differences in gender, sexual orientation, gender identity, immigration status, or disability.[32-34] Examples include people living with disabilities experiencing greater challenges when accessing care[35] and some members of the transgender community experiencing higher rates of gender-based violence. [31, 36] The urgent need to rapidly disseminate tailored messages on minimizing risk of

exposure and promoting vaccine uptake to all members of the community must consider the heterogeneity that exists within communities. A one size fits all approach may be less effective.

There is a need to acknowledge the impact of historical and current trauma

A syndemic framework created a platform to discuss the role of racism and COVID-19 disparities. CEWG members discussed the highly publicized murders of Black men and women across the United States in the midst of COVID-19. As one member stated, "Yes, we've come a long way since the bad old days, but the present day is still pretty bad and we have to address this." Another stated "My son is afraid to wear a mask outside for fear of being stopped by the police." Police brutality has a direct emotional and physiological toll on the individuals themselves and their community as a whole. These social stressors can interact with underlying health conditions to increase allostatic load, a marker of impaired physiological function that results from chronic stress. [37] Historical and current trauma create vulnerabilities in communities of color that increase exposure to COVID-19 and create environments that increase the susceptibility to its health and socioeconomic impact.[38] Community-engaged research provides an opportunity to hear from community members about their experiences of stress and violence and raise public health awareness of the deleterious impact of repeated exposure to stress.[39]

One of the members described the need for "community-engaged research to adapt an antiracism perspective." This perspective enables one to recognize the inherent privilege and power differential that exist between academic institutions and members of the community". [40] The importance of antiracism practices such as critical self-reflection on the historical relationship between members of the community and the academic institution were raised. Self-reflection on how personal perceptions and attitudes shape community narratives is important to

developing solution-oriented research questions that empower communities and minimize further marginalization, traumatization or stigmatization. [41]

There is a need to broaden support for the next generation of community-engaged researchers

The CEWG also discussed the importance of applying a trauma-informed lens when supporting and mentoring researchers from backgrounds that are underrepresented in biomedicine who may also face similar traumatic experiences as the communities that they study. As one member noted, "community engaged researchers may have their own concerns that need to be considered especially, those who are in close contact or live in communities that are most impacted by COVID-19." One junior researcher remarked "the impact on communities has been horrible and there is an emotional toll on researchers as professionals and as members of actual communities." CEWG members discussed the need for creating safe spaces for investigators who may come from minoritized communities to share their perspectives. One of the students on the CEWG described the need for 'time outs' just to reflect on what's happening. The complex nature of COVID-19 calls for multidisciplinary and interprofessional team approach to research. Community-engaged researchers may benefit from collaborations with diverse community partners as well as researchers from other disciplines.

Conclusions

Community-engaged research is well-established as an approach to tackling health disparities in communities of color. However, the devastation caused by COVID-19 calls for a renewed look at the practice of community-engaged research. COVID-19 creates an opportunity to reflect and reconsider several aspects of community-engaged research. Through a series of candid discussions about the personal and community impact of COVID-19, the JHS CEWG

identified factors that may need to be reconsidered when conducting community-engaged research. A syndemic framework can provide a holistic foundation for community-engaged researchers to consider the dynamic relationships between social, economic, political conditions, and health.

The application of a syndemic framework provides a holistic perspective on disease and social interactions and can guide the development of community-based interventions. However, with few examples, there is a gap in applying this framework more broadly and many studies maintain focus on one condition.[42] Much of the syndemic-based interventions focus on HIV and co-occurring psychosocial health. Interventions that have been motivated by syndemic framework include a motivational interviewing based HIV prevention intervention addressing both condom use and co-occurring depression, alcohol use, and internalized homophobia.[43] The Partners in Health Clinical Treatment model is another example of syndemic-informed community-based work that aligned treatment plans with the social context in which people lived including the provision of food and housing.[44] A trauma-informed syndemic intervention has been used to address co-occurrence of traumatic stress and stimulant use among women who used cocaine.[45] The Community Champions HIV/AIDS Advocates Mobilization Project (CHAMPS) aimed to reduce HIV related stigma and concurrently tackling stigma related to addiction, homophobia, and mental health. This intervention also addressed underlying social injustice through community capacity building.[46]

A syndemic approach can also be applied to address macrolevel policies.[47] Examples include reforming the justice system to eliminate the embedded structural racism which leads to higher rates of incarceration for Black men. [17, 48] Research focused on reproductive justice is needed to address the greater susceptibility of Black women and birthing people to COVID-19

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due to denied access to a range of resources.[49, 50] Research addressing access to care for frontline workers is critical to addressing structural barriers that contributed to disparate COVID-19 outcomes among food industry and transportation workers. These individuals are more likely to be immigrants and at risk for discrimination especially, if they are undocumented.[51] Expanding health insurance and access to care for vaccines and COVID-19 testing are important policy level factors to consider. An expansion of Medicaid eligibility is important to prevent further decreases in access to health care .[52] These factors reside upstream and if addressed can reduce the disproportionate impact of future public health threats in communities of color.

Applying a syndemic perspective to community-engaged research identifies the need for policies that directly address structural racism. This requires forming partnerships with scholars outside of traditional health and public health disciplines and including other segments of the community, such as legal and justice experts, historians, and traditional healers, who can help to build greater connections through community dialogues. Community-engaged research can be enhanced through development of mechanisms for integrated surveillance that links large data sets that capture real-time data on social trends, emerging social as well as disease threats.[53] As an example, prior to COVID-19 there was an increasing trend in hate crimes. Syndemic-informed data collection and surveillance methods may have anticipated the surge of racism and xenophobia that further flared during COVID-19.[54]

By drawing upon a syndemic framework and the lessons from COVID-19, the CEWG identified gaps and opportunities to enhance community-engaged research. These elements included broadening the conceptualization of a community and considering its multiple dimensions, viewing communities through an intersectionality lens, acknowledging historical trauma, and broadening support for community-engaged researchers from underrepresented

backgrounds. Addressing cardiovascular disease disparities is a major goal of JHS. Cardiovascular disease research can benefit from a more intentional focus on intersectionality. Our prior discussions on cardiovascular research centered on outcomes in different groups based on race, gender, age, disability and other identities. COVID-19 exposed variations in vulnerabilities based on differences in gender, sexual orientation, gender identity, immigration status, or disability.[32-34] This highlights the importance of applying an intersectionality framework. An intersectionality lens can benefit cardiovascular research by considering how the intersection of these factors shape cardiovascular disease practice and outcomes. Syndemic-informed community-engaged research can provide new perspectives on the practice of research and also inform the development of new community-level interventions. The devastating community impact of COVID-19 on communities of color was intertwined with a mutually reinforcing social epidemic. Syndemic frameworks can have benefits beyond COVID-19, enabling researchers to consider the complex interactions between health, social, economic, environmental, and political factors and advance community-engaged research.

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