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ORIGINAL RESEARCH

Exploring Barriers to Effective COVID-19 Risk Mitigation, Recovery, and Chronic Disease Self-Management: A Qualitative Multilevel Perspective

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Introduction: Many research activities have focused on SARS-CoV-2 infection and subsequent COVID-19 respiratory illness during the pandemic. However, significant racial inequities emerged months after the COVID-19 pandemic began. The similarity between racial/ ethnic disparities in COVID-19 and those for other diseases raised awareness about the context for risk exposure and healthcare access. The purpose of this study is to examine social and structural determinants of health among COVID-19 survivors, carepartners, and the perspectives of healthcare stakeholders who experienced disruption during the early pandemic.

Material and methods: A purposive sample of interviews (n=9) and focus groups (n=10) were used to collect data regarding knowledge of barriers to effective COVID-19 risk mitigation, recovery, and chronic disease self-management. This included nurses, physicians, COVID-19 survivors and their carepartners, public health, and community leaders connected with the healthcare systems in rural counties of South Carolina.

Results: Five major themes were identified across the subgroups. The themes: The COVID-19 Illness Trajectory Added Major Health Challenges and Stressors, Access to Care Is Lacking, Support is Needed for COVID-19 Survivors and Care Partners, Support Must be Distributed Equitably, and Racism and Structural Issues Affect Stress reflect the strengths, opportunities, and inequities perceived within these groups.

Conclusion: This research is the first qualitative study focused on COVID-19 survivor-carepartner dyads that consider the intersectionality of race/ ethnicity, geography, and health that is known to occur when engaging healthcare systems. The themes illustrate the need for infectious disease prevention at all socioecological levels: structural/ systemic, community, organizational/ institutional, interpersonal, and individual.

Keywords: COVID-19, health equity, rural, African American, chronic disease, dyads

Introduction

Significant racial inequities emerged within months after the COVID-19 pandemic began, and they have persisted, with non-Hispanic Black and Hispanic people being two times more likely to die compared to non-Hispanic White (White) people in the United States (US).[1] Of particular concern was the higher rates of mortality among young Black and Hispanic adults.[2] Over time, additional disparities were noted related to the disproportionate rates of SARS-CoV-2 infection, reduced access to testing, and increased rates of hospitalization among minoritized racial and ethnic groups.[3] The similarity between racial and ethnic disparities in COVID-19 and those reported for other disease risks and outcomes raised national, regional, and local awareness about the overall context for risk exposure and access to healthcare. This

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ongoing pandemic illustrates the poorer healthcare quality that continues to persist among individuals from these communities. In response, many research and clinical activities have focused on SARS-CoV-2 infection and subsequent COVID-19 respiratory illness during the pandemic. However, some have argued that research designed to understand and develop strategies to reduce the racial-ethnic inequities in COVID-19 has been too slow to emerge because of the early focus on mortality.[4]

COVID-19 Racial-Ethnic Health Disparities and the Structural and Social Determinants of Health

US Census data show that there are now more than 127 million survivors of COVID-19, but limited empirical data are available on the implications of surviving COVID-19 and the long-term effects on the health of survivors.[5] Recent estimates indicate that 28% of Americans have had long COVID, with higher proportions impacting multiracial (33%), Hispanic or Latino (32%), or Black Americans (31%). Social determinants of health (SDOH) are complex, influencing health outcomes, defined as

> Conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.[6]

Structural determinants refer to systemic disadvantages that impact a population group. Further, the areas in which healthcare providers and healthcare systems can improve COVID-19 treatment have not yet been identified based on the perspectives and experiences of COVID-19 survivors. More specifically, little is known about the many factors that serve as barriers and facilitators of positive outcomes among those with COVID-19. Additionally, because of the ongoing nature of the pandemic and the need to achieve continued reductions in mortality, few studies have been centered around theoretically sound examinations of COVID-19 outcomes that carefully consider the intersectionality of racial identity, geography (eg, rurality), health, and levels of racism that are known to occur when engaging healthcare systems. These concerns must be explored, particularly when the institutional and structural nature of healthcare systems is known to negatively influence health-related outcomes for some population groups.[7] Accordingly, the purpose of this study is to examine the experiences and social and structural determinants of health (SSDH) of COVID-19 survivors, carepartners, and the perspectives of those healthcare stakeholders who experienced unprecedented disruption during the early pandemic prior to vaccine implementation.

This qualitative study used a community-engaged research approach to recognize and incorporate the perspective and experiences of individuals who had a lived experience with COVID-19 treatment and survivorship. Specifically, key informant interviews and focus groups were conducted to inform needed revisions to a COVID-19 survivorship intervention for a telehealth-enhanced intervention *Integrating Community-based Intervention Under Nurse Guidance with Families* (*iCINGS FAM*).[8] This formative study was designed to elicit stakeholder concerns, priorities, and preferences to tailor the iCINGS FAM intervention to COVID-19 survivors and informal carepartner dyads based upon individual and interpersonal factors (eg, dyads family, friends, peers), community and social environment influences, SSDH assets and/or barriers to illness management.

Methods

Data Collection and Recruitment

A purposive sample of individuals possessing practical knowledge of barriers to effective COVID-19 risk mitigation, recovery, and chronic disease self-management. This included nurses, physicians, COVID-19 survivors and their informal care partners, public health, and community leaders connected with the healthcare systems in rural counties of South Carolina. To ensure the fit of this constructivist/interpretivist research design, we did not force a single analytic approach, which requires strict adherence to the process.[9] Borrowing procedures from different approaches supported a pragmatic, hybrid approach.[10] The primary qualitative methodologist, who is a nurse scientist (LN), has used these methods for two decades in numerous research projects focused on pragmatic practice-based primary and community-based care. The study was approved by the IRB at the [Redacted for Peer Review]. Following a discussion related to the purpose of the study, confidentiality and use of anonymized responses and de-identified direct quotes in publications, informed consent was obtained. All participants provided informed consent. The study was conducted in accordance with the Declaration of Helsinki and local statutory requirements.

Key Informant Interviews (KII) (n= 9) and Focus Groups (FG) (n=10) were used to collect data on associated SSDH ecological (social-environmental) determinants, strategies, and potential barriers to intervention implementation in the context of dyads and pandemic. Semi-structured, in-depth KII (30–60 minutes) were conducted using Microsoft Teams (Microsoft, Redmond, WA) since these interviews occurred during the early pandemic. All KII and FG interviews were led by the principal investigator (GSM). Participants included Black/ African American (AA) adults following COVID-19-associated hospitalization within 2020–2021, informal caregivers (ie, carepartners) of COVID-19 survivors, health-care providers, and community leaders. Consented FG participants completed a socio-demographic questionnaire and the COVID-19 Impact and Stress Survey to capture attitudes and perceptions prior to participating in the FG discussion. KII and FG participants were compensated $25 upon completion of the interviews. FG and KII data were recorded and auto-transcribed in Microsoft Teams.

Qualitative Analyses

The initial Microsoft Teams transcripts were reviewed for accuracy, then professionally transcribed verbatim, removing identifiers that might breach subject confidentiality and editing for corrections by two research assistants. The final transcripts were read for initial content and imported into NVivo 12.0 (Lumivero, Denver, CO). Thematic analysis involves immersion in the data to obtain a sense of the entire data set, open coding, categorizing, abstracting, and developing themes of interest. The transcripts were first reviewed to get an understanding of the data related to the COVID-19 experience for dyads of survivors and care partners, along with key stakeholders, using NVivo as a database and analytic tool. The initial codes were topically focused on the interview questions. As further transcripts were coded, comparisons regarding meanings and theoretical hunches were developed, and the coding was refined and reworded, generating a set of themes from the insights.[11] Initial queries within the NVivo database were used to reflect on the common experiences, perspectives, and needs of the participants. The principal investigator (PI) and qualitative methodologist met several times to review key themes and modified an initial concept map to further discuss with project team members. The key themes were named, and exemplar quotes were pulled out to elaborate the concepts being considered in the final analysis. The project team, including the co-authors of this report, participated in an immersion and crystallization meeting to refine the analysis and come to a consensus about the final themes and their relevance to the project.[11] The NVivo project file was maintained securely accessible to only the PI and the methodologist to provide confidentiality and anonymity for the participants. The COREQ guidelines and checklist ensured the rigor and trustworthiness of the process.[12]

Results

Sample Demographics

The average age of COVID-19 survivors was 54.7 years old, ranging from 22 to 66 years and the average age of care partners was 52.2 years old, ranging from 21 to 72 years (Table 1). Both survivors and care partners were primarily female, 76.5% and 88.9%, respectively. Differences in education were minimal, with both care partners and survivors having a little over one-third with a college degree (eg, associate, bachelor, and master's degrees). Twice as many care partners reported employment as the COVID-19 survivors (61.1% compared with 29.4%), with 29.4% of COVID-19 survivors reporting retirement status compared with only 5.6% of care partners. Public health insurance was most reported among the sample population, with 41.2% of COVID-19 survivors enrolled in Medicare and 22.2% of care partners enrolled in Medicaid. Almost one third (27.8% of care partners reported no chronic health condition, while over one-third (35.3%) of COVID-19 survivors reported at least one chronic health condition. Key stakeholders were primarily female (80%) and Black (80%). Most stakeholders were community leaders (46.7%) with a bachelor's or master's degree (60%). The average number of years served varied greatly between the types of stakeholders (Table 2).

Table 1 Socio-Demographic and Comorbidities of COVID Survivors and Carepartners

	Covid Survivor (n=17)	**Carepartner (n=18)**
Age	Min: 22 Max: 66 Mean: 54.7	Min: 21 Max: 72 Mean: 52.2
Sex	Male: 4 (23.5%) Female: 13 (76.5%)	Male: 2 (11.1%) Female: 16 (88.9%)
Race	Black: 17 (100%) White: 0 (0%)	Black: 17 (94.4%) White: 1 (5.6%)
Highest Education	High school diploma: 6 (35.3%) Some college, no degree: 6 (35.3%) Associate's degree: 1 (5.9%) Bachelor's degree: 2 (11.8%) Master's degree: 2 (11.8%)	High school diploma: 1 (5.6%) Some college, no degree: 5 (27.8%) Associate's degree: 2 (11.1%) Bachelor's degree: 2 (11.1%) Master's degree: 2 (11.1%)
Employment	Disabled: 5 (29.4%) Retired: 5 (29.4%) Employed: 5 (29.4%) Declined/ Other: 2 (11.8%)	Disabled: 3 (16.7%) Retired: 1 (5.6%) Employed: 11 (61.1%) Declined/ Other: 2 (11.1%)
Insurance	Medicaid: 5 (29.4%) Medicare: 7 (41.2%) Private: 6 (35.3%) Declined/ None: 2 (5.9%)	Medicaid: 4 (22.2%) Medicare: 3 (16.7%) Private: 4 (22.2%) Declined/ None: 7 (38.9%)
Comorbidities	One: 6 (35.3%) Two: 3 (17.6%) Three: 4 (23.5%) Five: 2 (11.8%) Six: 1 (5.9%)	None: 5 (27.8%) One: 5 (27.8%) Two: 3 (16.7%) Three: 1 (5.6%) Four: 2 (11.1%) Five: 1 (5.6%) Six: 1 (5.6%)

Table 2 Demographics Characteristics of Stakeholder Participants

	Stakeholder (n=15)
Sex	Male: 3 (20.0%) Female: 12 (80.0%)
Race	Black: 12 (80.0%) White: 3 (20.0%)
Ethnicity	Hispanic: 0 (0%)
Type of Stakeholder	Community Leader: 7 (46.7%) Physician: 2 (13.3%) Public Health Official: 4 (26.7%) Nurse: 2 (13.3%)

(*Continued*)

Table 2 (Continued).

	Stakeholder (n=15)
Highest Education	High school diploma or less: 1 (6.7%) Some college/ Associate degree: 2 (13.4%) Bachelor's/ Master's degree: 9 (60.0%) Doctorate/ Professional degree: 3 (20.0%)
Years as Stakeholder	Community Leader: 29.1 Physician: 35.5 Public Health Official: 10.5 Nurse: 20.5

Themes

Five major themes were identified as part of the interviews and focus groups across the subgroups of survivors, care partners, healthcare stakeholders and community leaders. The themes (*The COVID-19 Illness Trajectory Added Major Health Challenges and Stressors, Access to Care Is Lacking, Support is Needed for COVID-19 Survivors and Care Partners, Support Must be Distributed Equitably, and Racism and Structural Issues Affect Stress*) reflect the burdens, strengths, opportunities, and inequities perceived within these groups. The following subsections elaborate on each theme with examples from the various participants. Additionally, a concept map displays themes, subthemes, and potential intervention strategies to improve health equity within COVID-19 Dyads (Figure 1).

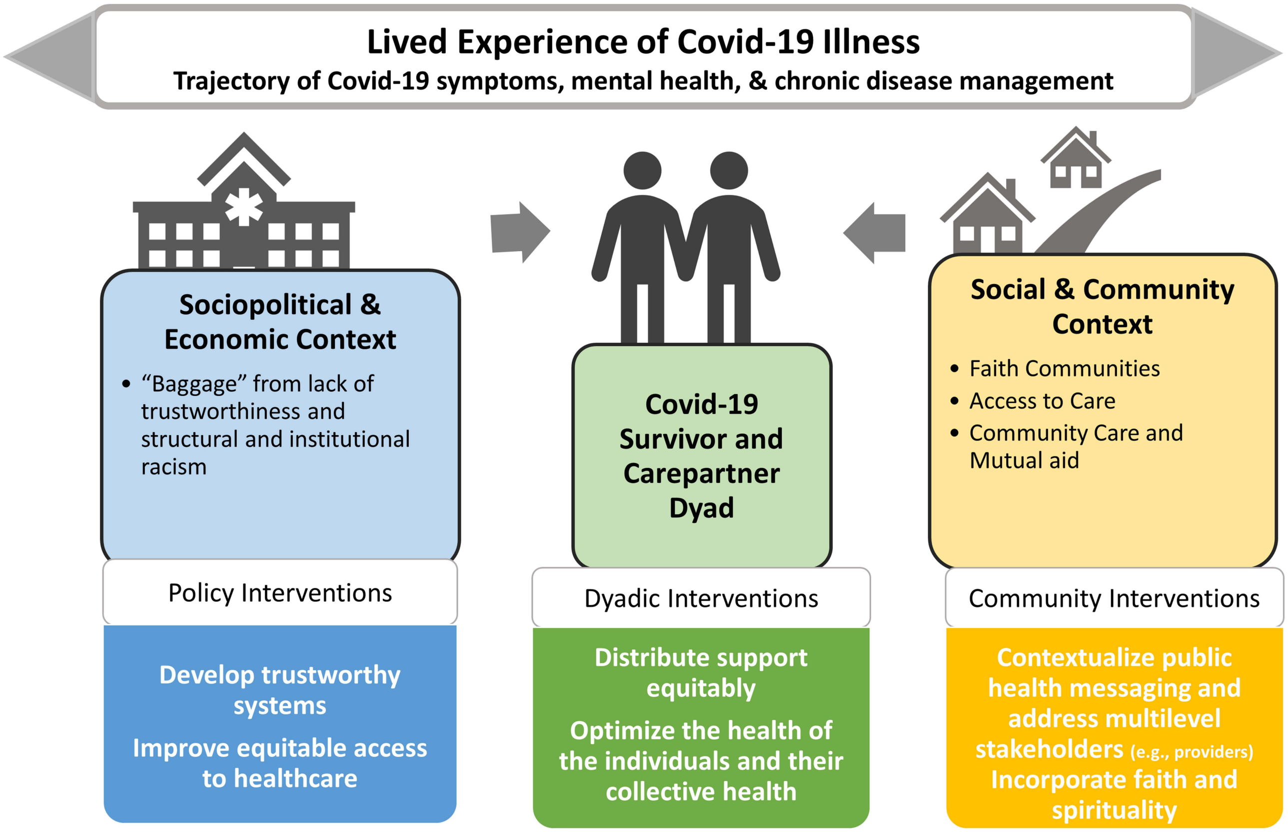

Figure 1 Lived Experience of COVID-19 Illness Concept Map. The concept map displays key themes, subthemes and potential intervening strategies for addressing challenges and health inequities experienced by COVID-19 survivors and their support person(s). The dyad experiences are situated between the sociopolitical and economic climate and social and community context (eg, availability and access to resources and/or a support network).

The COVID Illness Trajectory Added Major Health Challenges and Stressors

This theme encompasses the experiences of the participants from the stage of becoming aware of symptoms, getting to hospital, difficulties taking medications, receiving care at home, and feeling better as steps along the trajectory. A large portion of the discussions included perceptions on the COVID-19 safety protocols needed to protect self, family, and community against a pandemic virus at an early stage. There were new symptoms, health conditions, and mental health concerns that elaborated on the specific illness, related chronic care needs, and the impact these needs were having on mental health. The following quotes below indicate the uncertainty and added health, social and financial challenges that stressed the participants:

> July of 2020, my daughter, who was 48 years old at the time, contracted COVID. She was hospitalized and she was in the hospital for about 3 weeks, and they sent her home. During the next months she was in and out of the hospital four different times. Each time they sent her home and told us that would be the last time. OK. And. She is about to be 50 this weekend, so it's been over a year and a half that she's still here. Still with us, she. She is brain damaged. She is wheelchair bound. She's learning. She's in speech therapy, so she's learning to speak again. (CP06)

> I am the partner of the one that had the COVID. I also had COVID at the same time, but the most stressful part for me was uh, I didn't know how sick he was, and he was in bed, well, when I went upstairs, he was [on] the floor and I was too sick to get him up, so I kept talking to him. I said let me call the Rescue Squad, so we finally did that. Uh, we got into the hospital my daughter went 'cause I had COVID I couldn't go to give insurance cards. Well, she couldn't even get in there, you know, to give his insurance cards, and it was so hard for me to keep up uh, you know, with what was going on with him 'cause he was so sick, he had to be, his heart had to be shocked back into rhythm. He had to go into intensive care. He wasn't put on the ventilator or anything. He didn't have pneumonia [that] I know of. It was so hard for me to get information from the nurses. I would try to call 'cause he was so sick. He had his cell phone with him, but he couldn't answer. He had it either [under him] or what, so it was so hard for me to get any information about him, and that was so stressful on my part. (CP13)

Many individual care partners related their own conditions and that of the COVID-19 survivor impacting them during these times.

> I had to do a lot of my mom's running when she came home, 'cause she was still trying to recover from her knee surgery as well. And uh. I couldn't come in the house because I was also still pregnant and she still didn't want me around, but I'm the one that does everything anyway, so it was just kinda hard being pregnant and being around her and still running for her 'cause we'll do the running together. You know, I'd still get out and do everything else, but it was hard, and it was just like whenever she calls, she couldn't eat, couldn't taste anything (CP2)

A COVID-19 survivor related how the long COVID-19 illness prevented returning to work and added financial stressors. Going through the hassles of applying for disability added stress in addition to the illness.

> But one thing I dealt [with when um], after getting [COVID] is that I couldn't return to work and that, you know really 'cause I would be figuring I had seen other people at my job, you know, [they] was out for two weeks and back at work and it never happened for me. It really, you know, kind of bothered me and I didn't like going through the time it take the, you know, [them to] set me up with my disability and all that and it would, it just was a [stressful] time and then didn't know what to do, didn't have no income coming in it, it just, you know, it flipped me upside down in a way. (CS13)

A home care nurse discussed the additional care burdens that shifted much of the healthcare into the home setting. Nurses in these care settings had to handle situations that were more intense than they were used to.

> I care for your patients who have comorbidities, diabetes, hypertension, heart failure, you know so. Primary care, primary care is everything. So yeah, you get it all from mental health to… it's all primary care. Uhm, so the majority, I can mainly speak too, because with the COVID pandemic, because I worked in the home health setting, so what we saw a lot of times where if they did get hospitalized and came home, the bulk of our referrals that we received was from the hospital because you know they couldn't go to their doctor's office being COVID positive. So, we received all of those referrals and a lot of it was just trying to manage symptoms. Uhm, with, along with the comorbidities, the diabetes so you know, along with their hypertension, so trying and there were a lot of cases, a lot of patients that we had especially the elderly population. There wasn't much else we could do, so our company was a home health company, but it was also a Hospice. So not only did I have to care for the primary care side, I also took care of them from the Hospice side. (KS14)

Access to Care is Lacking

The lack of hospital beds during the early days of the COVID-19 pandemic and the lack of procedures, treatments, and vaccines complicated the care that could be provided during this time. However, as noted within these interviews, there was a general lack of resources within rural counties. Carepartners were especially vocal about this concern.

> I took care of my elderly uncle. He was 79 years old … we had to take him to the emergency room, which is here in Georgetown where I live. Uh, when they kept him in there all day, he was in the emergency room for 24 hours, and then they released him from the emergency room because of the occupancy of the bed, and he had pneumonia in his lungs as well, so that was scary ‘cause we had to really monitor him and check his oxygen level ourselves, so that to me you know, being that we're in a small rural area and you only had limited beds that you can take the patient, so a lot of people to me, I felt like a lot of our African American dies for lack of care. (CP18)

> This is what we need you to do because she takes 10 different kinds of medication, high blood pressure, diabetes. I mean, we just go from one thing to the next thing. This is this, we need you to get where you check, don't let her oxygen go below 90 and they're trying to teach me something in one night. All of this information that you have to do all of this. We don't have room in the hospital, you have to take her home, so that's what we did, and so now we have 5-6 people in a house that we just, she came, like total bed [ridden]. We had everything in the room, gloves to the door, [mask] to the door [mask] in the kitchen, gloves in the kitchen, wherever she called whatever end the house you grab, and you geared up. (CP16)

> … in certain areas are going to be offered certain services quicker than certain other areas, and I've seen that happen. I mean, like in my little [dynamic] area, I'm you might not be familiar like I live in Georgetown County, which is a rural area, but we also have another area that's called Pawleys Island, SC, where the people in Pawleys are probably going to get access to the service quicker than the [rural] area in Georgetown, and that's just how it's been. I mean, that's just like and I do believe that I do believe your dynamics of where you lived determined how fast you're gonna receive certain services as well as your health insurance. (CP13)

Comments from the healthcare providers during our interviews also illustrate the opinion that access to healthcare was lacking, as exemplified in the following comments, including the system-related issues that prevent individuals from receiving needed care or advice efficiently.

> I would say this, the things that would help people with chronic comorbidities, uh, and when they get sick, for whatever reason, but COVID certainly would be the, the issue. If the average person in Walterboro had access to someone that they could interface with in a meaningful way and asked simple questions, I think a lot of people would have been well served by that simple thing, and, and I don't know exactly how you can spread the word. (Provider)

> Don't know why we can't, we give tetanus shots in the ER all the time for a disease that we've, I've only seen once in 42 years of the practice of medicine. Why the hell can't we give flu shots? Why can't we give COVID shots? You know, why can't we set up a system through us, where we know, people are going to show up to administer those hugely needed things that were not. [It] was all about money, I mean, that's the punchline for most of that, the system is broken in so many ways and the people that need what it seems so apparent to you, and I are[n't] getting it and I don't know how to get that. You know, I don't know how to answer all those questions, but I just feel like corporate medicine has not been good to America on this. If you had to step away from the picture a little bit and say what's wrong with America, the whole concept of corporate medicine, in my opinion, would be pretty high on that list. (Provider)

Support is Needed for COVID-19 Survivors and Care Partners

Multiple perspectives about the need for support demonstrated that carepartnering is not an option, and they are not always prepared how to deal with the stress and burdens of being a carepartner and providing such intense support to family members. The comments below illustrate the sentiments of learning to care for themselves.

> We feel obligated to do because that that is our parent, our child. You know, that's a family member. We're obligated, but it in in turn it is extra stress on us, and it wears us down as the caregivers as well. So, you know I was shaking my head ‘cause it's very important, I believe, and what I've learned it is very important to find that time to get yourself. You're well filled back up because you pour out so much with caring for those. (CP3)

> Because I've noticed from for like I said in in the area that I worked in, a lot of people have a lot of health issues that are still surrounding having COVID, and knowing where they can go to get the help that they need is definitely needed. More information as to where they can get certain help from, and definitely a support group where they're able to talk to other people that's actually been through the same thing that they've been through. (CP18)

> I became point of contact for my uncle as well, so at that time, I'm point of contact for my uncle and my aunt, and then that Wednesday, she went in on that Monday, that Wednesday, she had already passed away. Um, that following Saturday, her daughter ended up on in the hospital with [sickle cell] and COVID so it's like, ok at that point, it was every time my phone rang, I was on edge because I now have my cousin and I have my uncle in there and both of them are still fighting, but it's like ok, so every time my phone rang I was on edge. Dealing with the passing of my aunt was also a part of that chaos. So not only am I managing her passing, I'm trying to maintain for my mother. That was her baby sister. I'm trying to maintain for my cousin, which is my aunt's son. I'm trying to maintain for my, his sister, which is the one who was in Florence, and then they transport my uncle to Florence because they say he was going into kidney failure. Uhm, so yeah, I have a lot of, still to this day unanswered questions that nobody could answer … when we sat down and talked about everything and it's just like yeah, nobody was able to say anything, so yeah, it's still some anger and some frustration, but there's not much I can do about it so. (CP09)

The value of support groups was discussed where the carepartners could help to process their feelings and frustrations in caring for their loved ones.

> I think support groups would be good if they can do like hospital based, or community-based support group um just so people can get out that frustration get out the aggravation and Participant [CP11] said something earlier that really that really rang out to me. She said about, we have to remember that the person who is sick, that whatever they're doing, it's nothing against us personally. They can't help that, so we just have to remember to just kind of ignore the part about what they're doing, and just try to do what we can do as far as just assisting and helping. So, I think [a] support group would be good 'cause you get to see other people side of it, you get to see other people's frustration. You just get to kind of let go, and you feel more comfortable talking about it with other people who've been through it. (CP15)

Support Must Be Distributed Equitably and Within the Context of the Population Served

The theme of access to care begins to describe the need for context-specific and sensitive approaches. However, the undertone of inequity compels a broader understanding of how the health systems can help to change these perceptions with deliberate actions. For example, healthcare stakeholders emphasized the need for support to provide care in trustworthy systems. Access should be focused on groups that have been made vulnerable or historically marginalized and under-resourced communities. Specific processes that consider health equity need to address trust, structural, systemic, and institutional racism on health and social outcomes.

> There also were you know, [CMS] sort of had policies around Tele Health, how you could do had Tele health, it had to be done in the doctor's office, and that was the only way it could be done you know, it couldn't be the doctor sitting in their house doing it. We as an insurance company as others did not reimburse it you know, unless it was, we were following [CMS] regulations you know. Uh, and then I think you'll also get down, and zoning maybe some of this kind of sort of situation. I mean, I always say you know, in Cottageville I have PRTC is my only Internet provider. I have no other options that's the only one I have, and you know it's, I have to pay a lot of money if I want good Internet. KS03.

> So policy I think starts when we start looking at policies and start thinking about zoning laws and why some places in rural counties have Charleston, Beaufort talked about y'all um, [Bluffton] they have been able to create an environment of wellness because of zoning laws, so I think we need to think about that too and you know what, I don't think I've know enough about zoning laws to even talk about it anymore, but I was in a meeting and someone was telling me about it, and I think in in these spaces we don't really understand the policies that go into place that creates the disparities and inequities that we are dealing with. I think that we need to like look at that. (KS06)

Educational Messages are Needed

This subtheme regarding support needed referred to information from trusted sources that were needed during the pandemic to maintain health and well-being.

> You did some more education than you ever could imagine about how to keep themselves safe within the home, or if one was negative and you had several positive, OK, how do I keep you negative? How do I keep you from not contracting COVID and literally, educating them lot of times we, we carried supplies like certain supplies so gowns, gloves, masks, things like that, so sometimes I would just give them, they didn't have [some] just, hey, here's a couple, see what you guys can do. You know how to try to keep [the mask] clean. So, a lot of education within those other family members who were in [that] home. If I could do any prescribing [of] things like that for them. (KS13)

> The ones that aren't getting that information [are the] ones on the underbelly of the economy, who, you know, have, maybe very bad living situation, may have no, you know, access to Internet and all that goes with that, but most of them are linked to a welfare system of some sort, somewhere, and you could link almost whatever you wanted [to] that even if it was just to have the movie running when they went to the Social Security Office. (KS12)

Prayer and Beliefs Carry Us Forward

This subtheme reflects an underlying strong faith supporting African American peoples' survival in the face of structural racism and adversity in their lives.

> The commonality I've heard is our faith. And I think because we are people of faith, that's where that's the well we go to the drink from when we are weak. And so, you know, imagine those people who don't have that, you know. And they just keep spiraling and spiraling. At least we know there's a higher power or there's someone else, you know, to call on when we need that break. And some people don't have that, you know, so yeah sometimes you gotta lock yourself in that bathroom and cry. But you come back out stronger. (CP3)

> Talking to you guys have made me feel so much better about everything that I've been going through and literally to like hear different stories from each and every one of you all about what you guys go through that. And the thing having that faith is like has been the biggest thing for us and our family. And to hear that that's something that's in your family makes me feel like, OK, that's something you've got to have is faith and prayer. You said your daughter was supposed to been gone months ago and it's been a year now; that's beyond faith. Like, that's like a testimony right there. It makes you feel good at something and He's showing out. He is showing out for each and every one of us. (CP2)

Racism and Structural Issues in Health Care

Structural racism, which is defined as

> A system in which public policies, institutional practices, cultural representations, and other norms work in various, often reinforcing ways to perpetuate racial group inequity

… has produced long-term stress for the rural communities in this study.[13] We found that participants in this study perceived that healthcare systems do not understand their concerns and are not sensitive to the needs of the African American community.

> I think generally as a people we're distrusting of healthcare. And I mean, in some cases, this rightfully so…Because even when I went…it seemed to me like I got Pfizer. But most of the White people that I talked to got a different one, and I was wondering what's the difference? Why are all the Black people I know getting one and all the White people that I know, given the other one? Is there something to it?. Like I said, they don't really trust healthcare. And you know, I'm an advocate for organ donation. And even when I talked to people about organ donation, it's no, I would never donate, because if I'm a Black person, then I go to the hospital, and they see that I'm an organ donor, they're gonna let me die. And we're the ones that need organs so much more than other people. But like I said, I can understand why we're not trusting the healthcare system. Because we've been beaten, so many beaten down so many times. Used as examples so many times (CP4)

> I would suggest you add trust building Community Trust, and I can't speak for the entire Black race…There is no trust in the government, there is no trust in the hospitals, there's no trust in the [doctors]. You don't have that within the community because of the news outlets and the information that they're sharing and how they're putting it out there. (CP09)

> I feel like in the African American culture, sometimes we take things too lightly, sometimes we kind of withdraw. Like I'll use the vaccine for an example, so sometimes we really have to encourage our people to go ahead and get the vaccine and how it can help them rather than believing in myths. [They were] saying the majority of people that died from it [COVID] was African American. Well, I believe that's because some of us didn't do what we were supposed to do, and I do believe some of us died because we didn't get the correct care that we needed at the time that we had [COVID], we didn't have access to the correct care, so I believe that as well…– CP18

Discussion

The purpose of this study was to better understand multilevel stakeholders' experiences during the COVID-19 pandemic to inform the tailoring of an intervention to address structural and social determinants of health to support dyadic illness management. Our findings illustrate that the disparities experienced by African American communities were magnified during the COVID-19 pandemic, particularly within rural communities. Importantly, our findings illustrate the unique manifestation of persistent racial disparities in access to care, supportive care needs, and racial and ethnic disparities in access to care that existed long before the COVID-19 pandemic.[14,15] Access to care refers to "to the ease with which individuals can obtain needed healthcare".[15,16] During the early stages of the pandemic, access to general care hospital services, surgeries, and other specialty services was reduced due to fear of exposure to the virus.[16] Thus, access to care for those populations who have been made vulnerable was further reduced beyond the disparity that traditionally exists.[16,17] Hospitals had limited capacity to manage patients due to high occupancy rates and increased mortality, which existed before treatment options were available for COVID-19.[17,18] Black people and Hispanic people experienced long wait times during the pandemic, even at US VA Hospitals where access to care is equal.[18,19] Increased barriers to testing for COVID-19 and lower perceived quality of care have also been reported, further complicating the observed access to care disparities in COVID-19.[19–21]

COVID-19 Survivors and Care Partners Support

Consistent with other published research, a need for additional support for COVID survivors and care partners was voiced by all categories of participants: key informants, patients and carepartners.[22–24] The concept of survivorship has been used in the context of COVID-19 because of the severe morbidity and post-infection symptoms associated with some COVID-19 infections.[23] The CDC Household Pulse Survey found a higher prevalence of long COVID associated with multiracial, Hispanic, and African American/Black respondents and people with lower socioeconomic status who lacked the ability to adequately rest after COVID-19 infection.[23,25] Decreased independence with activities of daily living and exacerbation of pre-existing illnesses, or new complications such as renal failure, come with a high physical and emotional cost to survivors and their care partners; many who were not in a caregiving role pre-pandemic.[22,23,26] The challenge of adapting to the role of informal carepartner may partially explain recent research findings of greater emotional distress, including evidence of a trauma-like response, among people who were informal caregivers during the pandemic compared to those who were not.[24,26] A national study conducted in June 2020 found that compared to non-caregivers, caregivers had more adverse mental health symptoms (57.6% vs 21.5%), and mental health symptoms were more common among Black and Hispanic caregivers than White caregivers ((80.2% and 89.4%, respectively, vs 53.4%).[26] In many ways, the survivor and care partner dyad are both adjusting at the same time, and it is important that both perspectives are represented in research and future interventions that aim to provide the needed social and behavioral support.

African American people were among the populations most adversely affected by the COVID-19 pandemic, and the intersectionality of race and racism, economic marginalization, and rurality are key contributors.[1–4] As individuals and communities aim to recover from the pandemic's impact, a focus on distributing support equitably must be a priority. Notably, few informal or formal interventions published since the pandemic focus on carepartners.[24,27,28] Research among rural individuals with chronic lower respiratory disease and their informal caregivers identified a preference for telehealth services to be delivered by telephone rather than internet-based or video conferencing, indicating the importance of considering place-based limitations such as internet access and technology literacy among rural residents.[28] In light of the significant post-COVID symptoms some survivors experience, the development of survivorship care plans may need to be explored. In the oncology literature, survivorship care plans typically include how to manage ongoing symptoms, plans for follow-up, and specific recommendations for health behaviors, but few of these interventions are culturally tailored for ethnic minority survivors.[29] Similar to the racial inequities in COVID-19 infection rates, racial and gender inequities in caregiving are well documented.[30] Data from a 2011 national study indicated that Black and Hispanic caregivers provided approximately 30 hours more caregiving in a month than their White peers, although there was no difference in the percentage of caregivers who were employed.[30] An intersectional and equity-based approach needs to be a central component of interventions, with consideration of tailoring to the unique needs of Black and rural communities.

Persistent Medical Harms Fuel Mistrust and Misinformation

Work by Miller, Gee and Katz (2021) concluded that knowledge of COVID-19 facilitated protective behavior to limit negative pessimistic illness expectations.[31] However, many Americans, regardless of race, were overburdened by large volumes of constantly changing (mis)information that resulted in many individuals having little faith and trust in any information source.[32] This wealth of misinformation during a pandemic is described as “infodemic” misinformation phenomena during the management of disease outbreak.[33] Regarding “infodemic” during the COVID-19 pandemic, Zarocostas noted that “the public health community must help the media to “better understand what they should be looking for, because the media sometimes gets ahead of the evidence”. Culturally tailored and community focused educational strategies and support to identify and mitigate barriers are urgently needed to improve health outcomes. Identified strategies must carefully consider the role(s) that faith, prayer, and rural community context have in the population to ensure culturally acceptable and context-specific interventions are developed.

The perceived lack of understanding and sensitivity by healthcare systems described by participants in this study highlights the history and impact of structural racism and discrimination in healthcare settings among African American people. Previous research has shown that African American people have greater distrust in healthcare providers and healthcare systems.[34,35] Our findings underscore the importance of enhancing the trustworthiness of healthcare systems and providers. The result of this distrust is lower preventive care, including vaccination rates and care-seeking behavior.[36] The implicit bias from providing this data suggests blame, but however, all relevant details are not always shared with providers and can be construed as gaslighting by the healthcare system. More can be done by healthcare leaders to instill trust, by listening better and understanding that there are barriers to access, communication, transportation, technology and affordability.[37]

Limitations

The strength of this research is in the wide range of stakeholders who experienced COVID-19 as patients, carepartners, healthcare providers, and community partners. This research informed an existing framework that focuses on dyads of African Americans who had COVID-19 infections in the earlier stages of the pandemic and their carepartners to strengthen support and identify the social determinants that impact chronic care management. This research is limited in that we only reached individuals in the South Carolina Lowcountry area, whose experience may not be generalizable in other parts of the US. The qualitative analysis of the interviews and focus group was primarily led by one senior qualitative methodologist, but to overcome this concern, regular meetings with the authors and research team occurred to discuss and distill the main themes and areas of emphasis. An extensive audit trail and collaboration cloud in NVivo software enabled the opportunity to closely review all the confirmed themes transcripts, coding, and concept mapping.

Conclusion

This research is the first qualitative study focused on COVID-19 survivor-carepartner dyads that consider the intersectionality of race/ethnicity, geography, health, and levels of racism that are known to occur when engaging healthcare systems. What's more, is the timing of our investigation; we conducted our research during the early pandemic, prior to vaccination implementation. Our community-engaged methodology was timely and informative, guiding much-needed modifications to a COVID-19 survivorship telehealth-enhanced intervention. The themes illustrate the need for infectious disease prevention at all socioecological levels: the structural/ systemic level, the community level, the organizational/ institutional level, interpersonal, and individual levels.[38] The desire for health equity was evident among survivors, carepartners, and healthcare providers, with many expressing similar challenges with access to healthcare. Our work demonstrates the importance of health equity at all levels, especially given the rise in COVID-19 cases and the continued mutation of the virus. It also highlights the need for early pandemic responses that prioritize resources to the most marginalized and rural communities. Often resources reach urban and more affluent populations earlier, even though these populations are more likely to have access to their own resources thereby requiring less immediate support. Additionally, telehealth-enhanced interventions are crucial to managing comorbidities related to COVID-19 and preventing worsening racial/ ethnic health disparities. Additional research is needed that examines the health outcomes and supports of both COVID-19 survivors and their carepartners over the life course, especially those that utilize different technologies.

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