# More Than a Statistic: a Qualitative Study of COVID-19 Treatment and Prevention Optimization for Black Americans



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# INTRODUCTION

Coronavirus disease 2019 (COVID-19) magnifies the disproportionate burden of cardiovascular disease, diabetes, and other chronic diseases Black Americans face due to structural racism, psychosocial stress, and socioeconomic status.<sup>1, 2</sup> To monitor the progression of COVID-19 which has increased incidence in Black communities, US regional programs began implementing surveillance and strategies to increase testing and reduce spread among vulnerable populations in April 2020.<sup>1, 3</sup> Yet, Black populations are generally less likely to participate in research, largely due to cultural barriers to recruitment and low representation in educational and healthcare institutions. 4 Community-based methods and partnerships with underrepresented populations can increase trust and study participation; accordingly, we sought to understand potential barriers specific to COVID-19 treatment and prevention in Black Americans using focus groups.<sup>4</sup>

# **METHODS**

Self-identified Black American residents aged 30-60 years with regular access to primary care (parent study requirement) were recruited nationally using Craigslist and ResearchMatch advertisements. Focus groups were conducted remotely via Webex from April to May 2020. Study design and interview analysis followed the Consolidated Criteria for Reporting Qualitative Studies (COREQ) (see Table 1 for interview guide)<sup>5</sup>. Online focus groups were each an hour long with a maximum of five participants and 2–3 facilitators. Interviews were recorded with video and audio, transcribed verbatim, and de-identified. Using grounded theory, patterns within the data were analyzed and identified through inductive thematic analysis; recruitment continued until thematic saturation was reached; an inter-coder reliability analysis was performed using percent agreement between raters. Participants provided verbal informed consent per OHSU IRB exemption guidelines.

#### Prior presentations N/A

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# **RESULTS**

Eight focus groups engaged 29 participants (22 women) aged  $40 \pm 8$  years (mean  $\pm$  SD). Regarding optimized treatments for and prevention of COVID-19 among Black Americans, three major themes emerged: patient autonomy, holism, and structural racism. Secondary codes were not used in analysis as inter-coder reliability was found to be in  $\geq 95\%$  agreement. The data that support the findings of this study are available on request from the corresponding author NPB. Table 2 lists themes and representative quotes.

**Patient Autonomy.** Over 73% of participants emphasized accountability for one's own health, described by some as a method for mitigating pervasive historical and personal disadvantages regarding health access due to their Black heritage and identities. Participants placed the onus largely on individuals to reduce risk factors for disease and slow COVID-19 infection.

**Holism.** Eighty-three percent of participants viewed medications for diseases disproportionally affecting Black Americans as a last option, often because of unwanted side effects, and preferred holistic approaches including supplements and lifestyle changes.

Structural Racism. Considering COVID-19 infection and death rates among Black Americans, many participants questioned how their race, and not pre-existing conditions, could heighten their risk. Participants held two predominate beliefs about COVID-19's disproportionate effect on Black Americans despite underlying conditions: (1) implicit bias within health care, and (2) apathy among individuals, possibly influenced by misinformed administration of policies regarding social distancing and subsequent reopening in predominantly Black neighborhoods. Participants also believed that infrastructure and finances limiting one's ability to stay home or socially distance contributed to disproportionate infection rates. Participants generally preferred health initiatives that recruit according to structural or socioeconomic variables contributing to disparity, instead of initiatives that recruit by racial demographics.

#### Table 1 Interview Guide for Eight Online Focus Groups

Prepared question

- 1. Briefly describe a typical appointment with your primary care provider.
- 2. Discuss the relationship between you and your primary care provider.
  3. When you have an appointment, how are recommendations or other health information conveyed to you?
- 4. What are some health conditions that you think Black Americans are the most at risk of developing?
- 5. Imagine that your primary care provider offered a new treatment or drug designed solely for Black Americans. How would you respond? 6. If your primary care provider offered you a holistic plan to treat, for example, high blood pressure, including drugs, physical activity, and nutrition, would you be receptive to this? Why or why not? 7. What are your concerns in the prevention and care of COVID-19?

#### DISCUSSION

Emergent themes in our focus groups suggest that community involvement at the outset is critical for proper needs assessments, as well as in subsequent design and implementation of any new approaches aimed at assessing or reducing unfair burden of morbidity and mortality due to conditions disproportionately affecting Black Americans. For example, COVID-19 transmission surveillance programs that oversample Black communities may face barriers to optimizing outreach if (1) race, isolated from lifestyle or acknowledgement of personal health accountability, is a criterion in sampling or study design; or (2) established community rapport is lacking or overlooked in program design, perhaps prevented through the involvement of community liaisons. Black Americans would likely benefit more from initiatives that emphasize patient autonomy and provide tools for addressing socioeconomic or pathologic risk factors relevant to health outcomes. Potential study limitations include generalizability to populations lacking health coverage. Overall,

Table 2 Frequency and Representative Quotes for Identified Themes

Theme (frequency)*		Participant quote	Gender	Session	Location
Autonomy (91)		Participant #21: I'm all about asking the questions. You can ask my mom, I guess I've been asking questions since I learned how to talk. But again, based on the great relationship that I have with my PCP we kind of have a flow. So, she knows to expect questions from me. And because she's so wonderful and is able to provide rationale for things. She takes the time to explain things to me, as opposed to "here's this resource. Here's this holistic plan, follow it up, I'll see you in three months." That's not going to do anything for me. I'm just going to chuck that somewhere in the passenger seat of my car, and keep things moving.	W	4	Buffalo, NY
		Participant #20: I think, being Black in America, you have to be aware that the system will treat you differently You have to put in the extra mile to take care of yourself because it's not a given that these institutions are here to treat you or prioritize you. So, it's best to be on your A-game so that if you do need to rely on an institution, or someone other than yourself, you know, you can be in the best possible condition to do that. And, hopefully, they'll hold their end of the deal and their oath to, you know, treat people equally, but, you know, it's humans and life.	M	5	Los Angeles, CA
Holism (105)		Participant #13: I feel like I'm being selfish because, you know, I, like, many of you, I—I read and, you know, hear so many stories of generations of various diseases and they say it's hereditarybut from a selfish standpoint, I feel like I have defied all of the odds of the prevalence of the diseases in my family because of, as the previous caller said, the choices I choose to make with regards to eating right, and diet and exercise.	W	3	Pasadena, MD
		Participant #27: Like my mother for example: she uses blood pressure pills and has high blood pressure and she's constantly getting on <i>me</i> about it. And I tell her, "Mother, you don't need to worry about that because my diet and my lifestyle is completely different than yours."	M	7	Columbus, OH
Structural racism (153)	Disparity (51)	Participant #4: I think that one of the coronavirusat risk populations were people with diabetes and so I was wonderingif the African American population is more at risk for diabetes, does that mean that the African American population is more at risk for coronavirus or being differently affected?	W	1	Portland, OR
	Implicit bias (11)	Participant #23: I've been seeing a lot of news reports of African American women, saying they're showing all these symptoms.  And healthcare workers are like "oh, no. Maybe it's a panic attack, or maybe it's a—" Come on now. We need someone to believe us, don't just say "give me some ibuprofen and send me home." Give me testing, and give me resources that are available, because it's a twofold right? Because A) are the hospitals and clinics even open to serve the community? And B) when you go in there, are you paid attention to or told you just have the flu?	W	4	La Mesa, CA
	Apathy (9)	Participant #29:It's the opposite of what you're being told because my understanding is Blacks don't really catch [COVID-19] as much as—it's more so the older generationsI think a lot of it is propaganda and the government having their hands in it to, [try to] fear-base certain demographics such as the Black community. But the Black communitythey're gonna take their own approach at this and listen to their own common sense.	W	7	Stone Mountain, GA

<sup>\*</sup>Frequency was calculated as the total number of thematic endorsements of a particular code by an interviewee in any number of interviews

findings highlight the importance of understanding community concerns about the orchestration of optimized treatments for COVID-19 among Black Americans, and underscore the health benefits of building community trust through early research involvement.

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#### Compliance with Ethical Standards:

**Conflict of Interest:** The authors declare that they do not have a conflict of interest.

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