


The Lived Experience of Being Diagnosed With COVID-19 Among Black Patients: A Qualitative Study

Journal of Patient Experience
Volume 8: 1-9
© The Author(s) 2021
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2374373521996963
journals.sagepub.com/home/jpx


Sainfer Aliyu, PhD¹ , Jasmine L Travers, PhD²,
Allison A Norful, PhD³, Michael Clarke, MBA¹,
and Krista Schroeder, PhD⁴

Abstract

Diagnosis and hospitalization for COVID-19 are disproportionately higher among black persons. The purpose of this study was to explore the lived experience of being diagnosed with COVID-19 among black patients. Semistructured one-on-one interviews with black patients diagnosed with COVID-19 were conducted. Data were analyzed using conventional content analysis and a directed content approach. Fifteen patients participated and 3 themes were identified: Panic amidst a COVID-19 diagnosis, Feeling the repercussion of the diagnosis, and Personal assessment of risks within one's individual environment. Fear of dying, inadequate health benefits, financial issues, and worries about spreading the virus to loved ones were acknowledged by the patients as critical areas of concerns. Majority of the patients looked to God as the ultimate way of surviving COVID-19. However, none of the patients reported receiving support for spiritual needs from health care providers. This is the first study to investigate the lived experience of being diagnosed with COVID-19 among black patients. Our results highlight several factors that put this group at increased risk for COVID-19 and where additional strategies are needed to address these inadequacies. Integrating public health interventions to reduce socioeconomic barriers and integrating spirituality into clinical care could improve patient care delivery.

Keywords

COVID-19, coronavirus, patient experience, black patients, interviews, qualitative studies

Introduction

SARS-CoV-2 virus, which causes COVID-19, is responsible for one of the most significant pandemics to date (1). The spectrum of illness severity ranges from mild (81%) to severe (14%) to critical (5%), with mortality rates of 2.3% in mild cases and as high as 49% in critical cases (2). In the initial 3 months of the outbreak, the United States confirmed almost 2 million COVID-19 cases, deaths surpassed 100 000, and hospitalization at times overwhelmed health care system capacity (3). As the pandemic continues and rapid spread persists, the demand for hospitalizations has risen (4).

Racial and ethnic minorities have been burdened with greater severity of COVID-19, resulting in higher mortality rates (5). In a recent US analysis of COVID-19 mortality rates, blacks represented the highest death rate (23%), followed by Latinos (16.5%), Asians (5%), and American Indian Alaska Native (1%) (6). This overrepresentation of black persons being affected by COVID-19 was also

revealed in our study. In a hospital that treats patients from all demographic groups, our study consists of black patients, although we did not set out to solely include black patients.

Although black individuals are disproportionately exposed to and hospitalized for COVID-19 (5,6), information about their experiences with the virus remains poorly

¹ MedStar Washington Hospital Center, Washington, DC, the United States

² National Clinician Scholars Program, Yale University School of Medicine, New Haven, CT, the United States

³ Columbia University School of Nursing, New York, NY, the United States

⁴ Temple University College of Public Health, Philadelphia, PA, the United States

Corresponding Author:

Sainfer Aliyu, MedStar Washington Hospital Center, 110 Irving St NW, Washington, DC 20010, the United States.
Email: sainfer.e.aliyu@medstar.net.



understood. Early research about other epidemic shows some individuals' experiences of an outbreak may cause them to deny symptoms, decline engagement in social distancing practices, and delay seeking care, thus contributing to poor outcomes and disease transmission (7,8). Existing quantitative COVID-19 studies focus on disease prevalence, clinical presentation, and treatment procedures (4,9–13). Subjective information about black patients' experience with the illness is lacking. Therefore, the aim of this study was to explore the lived experience of being diagnosed with COVID-19 among black patients.

Conceptual Framework

Principles of infectious disease such as causes, transmission, prevention, and control rely heavily on understanding the pathogen and the mode of transmission by which it infects individuals. A classic model for infectious disease causation, Clark's Epidemiologic Triad of Disease, identifies 3 components (agent, host, and environment) necessary to transmit disease and serves as a useful tool to define concepts relevant to COVID-19. The *agent* can be described as the virus that causes the disease, the *host* is the susceptible individual that carries the disease, and the *environment* includes those factors that enable disease transmission (14). In this study, the model was applied to better understand the patients' experience of living with COVID-19, characteristics that increase patients' vulnerability, and their environment that influences disease spread.

Method

Study Design and Setting

We conducted a qualitative study using semistructured one-on-one patient interviews to understand their lived experiences of COVID-19 between March 2020 and April 2020. The study was done at a large tertiary academic hospital center located in a northeastern US city.

Participants

A purposive convenience sampling approach was used to recruit participants. First, the principal investigator (PI), a PhD-prepared nurse collaborated with organizational nursing leadership to seek assistance with identifying COVID-19 patients. Eighty eligible patients were approached regarding participation. Sixty patients declined participation because they were either feeling sick or tired, frustrated with their illness, superstitious, busy, or unfamiliar with research. Of the remaining 20 patients who were available and willing to participate, data saturation was achieved at 15 participants. Participants were included if they were (1) >18 years old, (2) English speaking, and (3) diagnosed with COVID-19. Race was not an inclusion criteria, though all patients identified as black. Patients did not receive an invitation if (1) they were ventilated or (2) they had a documented psychiatric,

cognitive, or physical condition (eg, psychosis, dementia, or debilitation) that would limit the patient's ability to participate in the study at the time of recruitment.

Data Collection

A semistructured interview guide was created and informed by Donabedian's quality framework for evaluation of health care delivery based on structures, processes, and outcomes (15). The questions were open ended and were ordered in a general to specific format on the guide. The research team evaluated the guide for clarity and content. The guide was pilot tested with 2 patients. A demographic questionnaire assessed age, race, gender, date of admission, source of admission, occupation, education, and the number and type of comorbid comorbidities (confirmed through electronic health records).

Procedures

Prior to the start of the interviews, informed consent was obtained. The audio-recorded interviews lasted approximately 20 minutes (in-person or via telephone). Data collection continued until thematic saturation was achieved. Interviews were professionally transcribed, deidentified, and reviewed for accuracy. The institutional review board at [BLINDED] approved the study.

Data Analysis

We followed the Consolidated Criteria for Reporting Qualitative Research 32-item checklist to ensure a standard method for reporting qualitative studies (16). Two researchers analyzed transcripts using conventional content analysis and a directed content approach. First, 2 coders collaboratively drafted a definition of each of the themes based on the Clarks' epidemiologic triad of disease (14). Next, they independently coded the same 3 randomly selected transcripts. The 2 coders met to review discrepancies, develop additional codes, and finalize the initial coding scheme until a κ of 90% or greater was achieved. After final codebook development, the remaining transcripts were independently coded. Weekly team meetings were held to reconcile data. NVivo version 12 qualitative software was used to organize and analyze the data (17). The research team worked together to develop themes that reflected the data emerging within the components of the framework.

Results

Fifteen patients participated from 5 different medical-surgical units, 3 of which were designated COVID-19 units. Table 1 summarizes participant characteristics. All of the patients were black with a mean age of 60 years and equally distributed across genders. Two-thirds of our sample had 3 or more common comorbidities. Patients presented with the following common comorbidities: obesity ($n = 14$),

Table 1. Participant Characteristics.

Characteristic	n (%)
Male gender	8 (53)
Age	
18-30	1 (7)
31-45	4 (26.5)
46-60	3 (20)
61-75	3 (20)
>75	4 (26.5)
Race	
Black	15 (100)
Uninsured	6 (40)
Comorbid conditions	
None	2 (13)
1-3	3 (20)
>3	10 (67)
Highest level of education	
High school diploma	8 (53)
College degree	7 (47)
Employment	
Employed	8 (53)
Retired	6 (40)
Unemployed	1 (7)
Source of admission	
Private home	14 (93)
Nursing home	1 (7)

hypertension (n = 10), diabetes mellitus (n = 7), cardiovascular disease (n = 6), dyslipidemia (n = 6), lung disease (n = 4), and kidney disease (n = 4).

Three themes emerged from our data with the following description: (1) Panic amidst a COVID-19 diagnosis—Patients conveyed fear about their health and described the uncertain and unpredictable nature of the disease (n = 15); (2) Feeling the repercussion of the diagnosis—The patients described their symptoms as unpleasant and bizarre. Others expressed feeling isolated and lonely, and majority shared that they relied on spirituality to cope in a time when there was a feeling of being out of control (n = 13); and (3) Personal assessment of risks within one's individual environment—Many patients shared concerns that their home and work environments were sources of disease exposure. Several patients described a positive experience with the health care system (n = 14). Each theme was cited by at least 13 participants. However, only the most illustrative quotes were presented due to the nature of the study. Exemplar quotes reflecting the lived experience of COVID-19 among black patients are summarized in Table 2.

Theme 1: Panic Amidst a COVID-19 Diagnosis

Subtheme 1: Reacting to the Diagnosis

Patients described high anxiety awaiting test results. Some were fearful about dying, whereas a few remained hopeful.

Despite having suspicions of viral exposure, patients were shocked about their diagnosis. One woman explained,

My sister and my brother have been tested. They both haven't come in yet for the virus. But they've been sick pretty bad. I think worse than me. I know I might get it, but I was shocked when the doctor told me. (P003)

Once given the diagnosis, patients became increasingly worried about dying.

Basically, for me, all this is new. I haven't been admitted in the hospital before. My concern is that I might have pneumonia, so that might danger the situation. But when the doctor told me specifically, it's a little bit different. You just pause a little bit and you think about it. I was more scared about dying and concerned about how I got affected because I feel like I don't have any bad medical history. (P008)

Subtheme 2: The State of Uncertainty

A few patients with serious medical conditions expressed that while they are accustomed to living with a complex medical condition, COVID-19 was different than anything they had experienced.

It was shocking. I couldn't believe it. Where did I get this from? How did I get it? It was just a whole lot of questions that I couldn't answer. The fears—oh, boy. I heard so much about it. I got scared. Am I gonna die? What's going on? What's gonna happen to me? Yeah, just fear. (P003)

Patients also spoke about the disease's novelty, which felt more frightening especially during the early phase of the pandemic. "I was scared just because it's so new. Many people don't know what to expect, and because I have an underlying condition it's even scarier" (P007).

Theme 2: Feeling the Repercussion of the Diagnosis

Subtheme 1: Experiencing COVID-19 Symptoms

Most participants had multiple comorbidities (eg, diabetes mellitus, hypertension, and obesity). There was variability in levels of concerns, particularly among younger patients with no perceived serious health condition. For example, a patient reported,

I wasn't too afraid, because I had been following the coverage pretty closely. And based on my age and health, I didn't have a fear of dying. It was more so just waiting to see when the symptoms would pass. (P001)

However, there was greater apprehension among older patients:

Table 2. Exemplar Quotes Reflecting the Lived Experience of COVID-19 Among Black Patients.

Description of themes	Exemplar quotes
<p>Panic amidst a COVID-19 diagnosis: Patients conveyed fear about their health and described the uncertain and unpredictable nature of the disease.</p>	<p>Patients described feelings about contracting the virus. “The family goes to Florida every year and 2 of them had gotten the virus and the baby. I wondered if I would get it. I thought I was going to die when the doctor told me I had it.” (P009) Older and sicker patients felt it was inevitable that COVID-19 would kill them. “I lost hope, the moment the doctor told me, naturally, I thought I might die.” (P011) Some participants expressed it was difficult to describe COVID-19 symptoms. “For the whole week, I knew something was wrong. The first thing that happened was I got a sharp pierce nerve in my nose and it felt like I was under a swimming pool and chlorine got up my nose. I lost my sense of smell and taste on Monday, and also started having body aches really bad. It woke me up out my sleep. Both hands were cramping so bad. I couldn’t ball a fist and my thighs and my legs. I don’t know how to describe it. The pain was weird.” (P013)</p>
<p>Feeling the repercussion of the diagnosis: The patients described their symptoms as unpleasant and bizarre. Others expressed feeling isolated and lonely, and majority shared that they relied on spirituality to cope in a time when there was a feeling of being out of control.</p>	<p>Few patients had no “classic” COVID-19 signs as described on the news. “I was feeling fine, but my daughter said I was not acting right, she said I wasn’t acting like myself so she called an ambulance. The next thing I knew, the ambulance was outside, and they took me to the hospital and I got admitted.” (P015) “I have lupus. So, on Tuesday I went to my doctor and they saw pleurisy and a little pneumonia and they gave me antibiotics and steroids. And then the next day I walked up the steps and couldn’t catch my breath and that’s when I decided to come to the hospital.” (P007) Patients dug deeper into their faith as a means of coping with the pandemic. One woman described her transcendent experience through discovering a deeper connection with spirituality. “Before I knew I had it, I was fighting tooth and nail. Whatever I was feeling, I was hanging in there. And you can’t let that which you don’t know shake your mental state. Just know that God is still God and let Him have his way. Don’t be discouraged, just hold on because once you find out you have it, you might feel a setback. But that’s okay. God is bigger than COVID. So, don’t stop fighting.” (P010) Emotional fatigue was a common feeling shared by many. Patients shared the health care—provider—patient relationship was valuable to their psychological well-being. “You know, a lot of times with illnesses I know it can be scary but thinking negative isn’t making things better. So, really trying to remain positive, keep hydrated, eat as much as possible, rest, and really take the advice of your caretakers, the doctors and nurses. And, you know, with that all together hopefully you can beat it.” (P007)</p>
<p>“The nurses are very friendly and encouraging. So, yes, as far as that’s concerned, they were pretty helpful.” (P001)</p>	<p>“The nurses are very friendly and encouraging. So, yes, as far as that’s concerned, they were pretty helpful.” (P001)</p>

(continued)

Table 2. (continued)

Description of themes	Exemplar quotes
<p>Personal assessment of risks within one's individual environment: Many patients shared concerns that their home and work environments were sources of disease exposure. Several patients described a positive experience with the health care system.</p>	<p>A few patients believed that they were exposed to COVID-19 while at work. While many had no job security, this was not the case for one of the patients—He expressed gratitude after hearing from his work colleague.</p> <p>“... Right now, my job is on shut down. The closed the building since the 11th because they wanted to have cleaning crews into different offices. I work for a really big company. The HR person tells me that my CEO and the head chief person in HR was concerned and they sent their regards. They just wanted me to know so I did not worry about a thing, just get better and take as much time as I needed. They were just awesome. And my boss, he said, you know we love you, and that just made me feel like I was worth something.” (P013)</p> <p>There was increasing worries among patients with failing health. A woman described her concerns about her church family no longer being able to care for her.</p> <p>“... Well, that makes me feel bad, because I really need help. People from the church usually come over and help me, but with this virus, they can't. Who will help with the food and all. I don't know. I guess I have to do it myself.” (P003)</p> <p>Inadequate protocols and lack of social distancing policies were mentioned as means of spreading the virus in the workplace.</p> <p>“I'm under the impression that I may have gotten infected through my occupation. I think there weren't enough protocols in place initially to prevent the possible transmission. At some point in time I may have been in contact with a coworker or one of the passengers that I frequently pick up—that I may have possibly gotten exposed to the virus.” (P001)</p> <p>“I work in a small office with probably 20 people, so I might have gotten infected there.” (P013)</p> <p>Few patients were dissatisfied with long hospital wait-times. There was a sense of being ignored as well as a feeling of unmet standards of care.</p> <p>“... And late that night, I was having a terrible episode of coughing and chills, and my head was hurting really bad. I kept calling saying I needed another blanket because this thin blanket wasn't keeping me warm. I was shivering. It took a while for the nurse to come, I called more than 3 times, I waited between 45 minutes to an hour.” (P013)</p> <p>Most patients reported a good experience when getting tested for COVID-19. One man described his interaction with the emergency department nurses, including the nurse who performed the test.</p> <p>“They were very good. They get you in there and test you and it's real efficient. So, that's why I'm able to get this treatment done because they did what they had to do and admitted me and started the medication.” (P010)</p>

Because I was having issues with my lungs, I wonder how it would impact my lungs and if I would survive it, if my body was strong enough, and if I'll be able to respond to the medicine to the point where I'll be okay and be able to get discharged. (P006)

Overall, patients described a wide range of symptoms including chills, shortness of breath, headaches, fatigue, weakness, diarrhea, fever, back pain, chest pain, cough, loss of taste, decreased appetite, and loss of smell. Among those, the most commonly reported were cough, shortness of breath, and fatigue. Many conveyed that their entire body felt different. One woman described her experience as “a miserable awful feeling” (P015).

Subtheme 2: It's a Lonely Disease

Because the pandemic limited patient-provider contact and visitors were not allowed, many patients reported social isolation and loneliness. “It seems to get really bad. How I'm going to get better? I don't want to go like this. Laying alone forever” (P006). Patients expressed having limited interactions with clinicians, indicating a desire for more communication: “They barely come into the rooms. It's been a couple nurses and doctors, I barely see them” . . . (P002). And another stated, “The nurses on the unit are kind. I see one, but then it takes hours before I would see another one” (P013). Patients also felt deserted because they were unable to connect face to face with loved ones. “I'm married. I live with my wife and 7-year-old son. Right now, they're at home without me. I miss them. They miss me” (P014). Similarly, COVID-19-related stigma increased loneliness. Many believed as rumors spread about the pandemic, the stigma worsened, and influenced people's attitudes toward them. “I was hesitant to tell my family, when I told my wife, I was treated different a little bit. My wife and kids are scared. When I told her she got mad. She was scared. She was crying” (P004). In contrast to feeling isolated, some patients understood it was necessary to practice social isolation. “It's just quarantine, so I'd rather stay by myself. I can talk to people on the phone. I just want to stay away from people and follow the guidance of what the doctor told me” (P008).

Subtheme 3: Coping With the Diagnosis

Greater emphasis was placed on spirituality amidst the pandemic. Patients emphasized how much they relied on God, prayer, and their faith to get through the difficult times:

I come from a very deep church background. So, I tell you that my spiritual base is amazing. It gives you that uplifting that His will be done. We can just pray, and ask for His grace, and His mercy. I'm a praying woman. If I couldn't get a hold of nobody on the phone, I know I can get a prayer through to my God. Because He's the only power I know that can stop this. (P013)

Additionally, patients were emotionally exhausted and expressed that the staff helped them to mentally cope with COVID-19. Many viewed the relationship as a way to express thoughts and build rapport, especially because loved ones were not permissible at the bedside.

Theme 3: Personal Assessment of Risks Within One's Individual Environment

Subtheme 1: Concerns About Work, Family, and Spreading the Virus

Most patients reported financial ramifications resulting from them contracting COVID-19, especially given many worked in low-paying occupations with no paid time off. “I'm under the impression that I may have gotten infected through my occupation. And obviously right now that I'm hospitalized, I can't work to pay my bills” (P001). Others were less concerned about finances and more focused on recovery. One woman expressed: “I can't work. It's affected me because I don't like being sick. But my work, I ain't even thinking about that. I've been too sick to think about work. All I'm thinking about is healing” (P010).

Majority experienced fear of spreading COVID-19. Concerns mounted because the possibility of death was substantial. “My wife and kids will take care of me. I'm afraid of what might happen if I give it to them” (P004). Anticipation of spreading the virus to older parents was a major concern, one man shared: “I live with my older parents. I've been around them, my parents, especially my father has lots of health problems. I don't want them to catch it” (P002). Equally, patients worried about their own health declining and putting the burden and health risk on others. For instance, a patient explained: “My wife is sick too, she was coughing. I usually care for her, now I can't and she needs to care for me. I care about her if she has to care for me” (P006).

Subtheme 2: Sources of Exposure

Several patients were unsure about their exposure to COVID-19, although they reported being in crowded places where social distancing was challenging.

Well, you know, the closeness around folks. I don't know how I got it. I had to be around people. I came to the hospital a couple of times for doctor appointments, so I guess you have to watch what you're doing. (P005)

On the first thought, one patient recalled contact with church members who had COVID-19.

A lot of people that I go to church with got sick with this virus. I was at a church event with about 250 people. So, it turns out a lot of people that was at that event are sick right now. A few of them tested positive, quite a few. (P013)

Conversely, some were not assured safe working conditions and cited protocols and lack of social distancing as contributing factors for acquiring COVID-19.

Subtheme 3: Dealing With the Health Care System

Most patients were happy with the care provided and expressed a feeling of appreciation for the clinical team. “I had a nurse initially when I was transported to a room upstairs. I can’t remember her name, she is very nice. And the care hasn’t dropped off since” (P001). As patient symptoms evolved, the need for effective communication with health care providers to improve quality of care was eminent. Some patients conveyed they were well-informed about their care, which helped them manage their fear. “They’ve all kept me in the loop . . . monitoring my blood pressure, heart rate, temperature, oxygen and everything. I think so far it’s been great” (P002). Another patient described how communicating with the health care providers kept him composed: “The doctors keep me calm. They talk to me about the corona, they tell me about my illness and what I need to do to not spread it. And the nurse tells me about my medication and stuff” (P004).

Access to COVID-19 testing was described as efficient by many. “It was very quick and simple,” one patient expressed. In contrast, two patients were dissatisfied. For example, a patient reported: “When I came to the hospital first, I started feeling symptoms, my back started aching. I started coughing. And they turned me back. But then the second time I came, they admitted me” (P004). Some patients expressed frustration with hospital overcrowding:

I felt a little overlooked. And I knew that the ER was busy but I was in a lot of pain and I felt like with my gasping I wasn’t prioritized. And since my family couldn’t come, I didn’t have anybody who could advocate for me since I wasn’t able to advocate for myself. I ended up texting my mom to call because they just left me in a room for a while. I was probably in the ER for 5 hours before they decided to admit me but once I got upstairs and was admitted, it was better. (P007)

Discussion

This study provides new information about the black patient’s experiences with COVID-19. Fear of dying from COVID-19 was mainly influenced by age and chronic comorbidities. Consistent with previous literature (18), we found that patients reported high levels of uncertainty. Levels of uncertainty were increased possibly due to the unpredictability and widespread rumors associated the disease. Overall, patients raised questions about their prognosis and the lethality of COVID-19, suggesting education surrounding the course of COVID-19 is needed.

Although not our original intent, our sample included solely black patients, within a hospital that sees patients from all demographics. Further, no questions were asked about

race; nonetheless, race emerged prominently in the data. Nationally, blacks make up 13% of the US population and 33% of COVID-19 cases compared to Hispanics, which makes up 19% of the US population and 8% of COVID-19 cases, and Asians that represent 6% of the US population and 5% of COVID-19 cases. A higher burden of comorbidities is associated with COVID-19, including hypertension, obesity, lung disease, diabetes mellitus, kidney disease, and cardiovascular disease (6,19). Of note, two-thirds of our sample presented with at least 3 chronic comorbidities. Factors unique to black persons including economic and social determinants of health have not been addressed adequately to advance health equity, including related to COVID-19 (20).

Our findings also highlighted the role spirituality played in black patients’ coping with their diagnosis. Consistent with emerging data, outbreaks are associated with increased psychological stress (21). Most patients reported high anxiety. Patients reported that the disease proliferated uncertainty about the future, which was alleviated by religious beliefs and practices. Most identified ongoing spiritual support as a way of coping with physical symptoms, thus having a positive outlook. Religious coping including looking to God for help in stressful times has high importance within the black community (22). No patient reported receiving spiritual support from the health care team. Spiritual care involves serving the whole patient and is a part of cultural competence. Although health care providers have attempted to balance their care by incorporating spirituality into clinical practice, it has been challenging, possibly because spirituality is not a part of formal clinical training. Hence, health care providers may feel incompetent to initiate those discussions (23). Our results support the relevance of developing methods to integrate cultural religious competence into clinical care to improve patients’ psychological well-being.

Historically, congregational cohesiveness is important to the black community. However, during the pandemic, places of large gatherings including churches were abruptly closed (24). Some patients encountered struggles with church closures because their congregation provided food, socialization, and assistance with activities of daily living. Leaders of churches in the black community extend themselves beyond the walls of the church to engage with vulnerable congregation members. Therefore, there exists the potential for health care and public health organizations to partner with faith-based establishments to identify strategies for disease prevention.

We identified broader social determinants of health that may influence COVID-19 transmission among black persons. This included living in homes with multiple individuals and working in densely populated cities where social distancing is challenging. Many patients in this study reported having low-paying jobs without paid time off and several were retired with limited income. Further, several patients lacked health insurance. Being able to effectively manage chronic underlying comorbidities that are common in this group is fundamental to lowering adverse outcomes from

COVID-19. Data demonstrate that black individuals are excessively more likely to be infected and die from COVID-19 (25). However, recommendations to reduce infection rates for COVID-19 such as “stay-at-home” orders may present challenges for black persons, given higher levels of socially disadvantage and reliance on work outside the home to supply their day-to-day income among this population.

Our study has limitations. First, non-English speakers were excluded because the PI is English speaking and translators were not readily available in the midst of the COVID-19 crisis. This limits generalizability of our findings and potentially contributes to the lack of representation among non-English speakers in scientific research. Non-English speakers account for a large proportion of those affected with COVID-19, and language barriers likely put them at higher risks for higher prevalence rates and worsened health outcomes (26). Therefore, additional research focusing on this population is necessary as a first step to reduce health disparities. Second, the interview guide was not adjusted to reflect a dialogue around race as this would likely skew our results. Race remains an important social factor in understanding health disparities and should be explored in future studies. Third, the study was conducted in an urban tertiary academic medical center and may not represent the patients’ experiences of being diagnosed with COVID-19 in other health care settings. Nonetheless, this is the first study examining the lived experience of being diagnosed with COVID-19 among hospitalized black patients. By sharing these unique patient experiences, our study could inform a more contextual approach to future clinical practice.

Conclusion

Our findings suggest that having an understanding of the patients’ lived experience with COVID-19, their susceptibilities, and their related environment could guide improved clinical care. Our results highlight implications for future planning efforts for COVID-19 and similar outbreaks within and outside the hospital setting. First, health care organizations could leverage technology to promote health literacy and share updated information about the pandemic to alleviate panic among patients. Second, because of the health disparities within the black community with a high level of comorbid conditions, enabling cultural appropriate programs focusing on modifiable risk factors such as obesity and hypertension could be beneficial. Third, considering the significance of spirituality on the patients’ psychological well-being, there is an opportunity for health care organizations to partner with community faith-based leaders to support integrating spiritual care into clinical practice. Lastly, socioeconomic gaps including financial struggles, crowded housing, and clustered work spaces increase the risks for COVID-19 exposure. Therefore, public health mitigation strategies that tailor to socioeconomic needs are urgently wanted in underserved communities.


Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Sainfer Aliyu, PhD  <https://orcid.org/0000-0002-9904-1798>

Supplemental Material

Supplemental material for this article is available online

References

1. World Health Organization. WHO announces COVID-19 outbreak of a pandemic. Published 2020. Accessed May 10, 2020. <https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/news/news/2020/3/who-announces-covid-19-outbreak-a-pandemic>
2. Wu Z, McGoogan JM. Characteristics of and important lessons from the coronavirus disease 2019 (COVID-19) outbreak in China summary of a report of 72,314 cases from the Chinese center for disease control and prevention. *JAMA*. 2020;323:1239-1242. doi:10.1001/jama.2020.2648
3. Centers for Disease Control and Prevention. Coronavirus disease 2019 (COVID-19), cases in the U.S. Published 2020. Accessed May 7, 2020. <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html>
4. Young BE, Ong SWX, Kalimuddin S, Low JG, Tan SY, Loh J, et al. Epidemiologic features and clinical course of patients infected with SARS-CoV-2 in Singapore. *JAMA*. 2020;323:1488-94. doi:10.1001/jama.2020.3204
5. Rentsch CT, Kidwai-Khan F, Tate JP, Park LS, King JT Jr, Skanderson M, et al. Covid-19 by race and ethnicity: a national cohort study of 6 million United States veterans. *MedRxiv*. 2020. doi:10.1101/2020.05.12.20099135
6. Sutton P. Centers for Disease Control and Prevention. National Vital Statistics System’s Response to COVID-19. Centers for Disease Control and Prevention; Published 2020. Accessed July 1, 2020. <https://ncvhs.hhs.gov/wp-content/uploads/2020/06/D-Paul-Sutton-June-2020-NVSS-COVID-19-Response-508.pdf>
7. Person B, Sy F, Holton K, Govert B, Liang A. Fear and stigma: the epidemic within the SARS outbreak. *Emerg Infect Dis*. 2004;10:358-63. doi:10.3201/eid1002.030750
8. McQuilkin P, Udhayashankar K, Niescierenko M, Maranda L. Health-care access during the Ebola virus epidemic in Liberia. *Am J Trop Med Hyg*. 2017;97:931-6. doi:10.4269/ajtmh.16-0702
9. Oxley TJ, Mocco S, Majidi S, Kellner CP, Shoirah H, Singh IP, et al. Large-vessel stroke as a presenting feature of Covid-19 in the young. *N Engl J Med*. 2020;382:e60. doi:10.1056/NEJMc2009787
10. Kucharski JA, Russell WT, Diamond C, Liu Y, Edmunds J, Funk S, et al. Early dynamics of transmission and control of

- COVID-19: a mathematical modelling study. *Lancet Infect Dis.* 2020;20:553-8. doi:10.1016/S1473-3099(20)30144-4
11. Diao M, Zhang S, Chen D, Hu W. The novel coronavirus (COVID-19) infection in Hangzhou: an experience to share. *Infect Control Hosp Epidemiol.* 2020;41:1-5. doi:10.1017/ice.2020.62
 12. Bhatraju PK, Ghassemieh BJ, Nichols M, Kim R, Jerome KR, Nalla AK, et al. Covid-19 in critically ill patients in the Seattle region-case series. *N Eng J Med.* 2020;382:2012-22. doi:10.1056/NEJMoa2004500
 13. Cavallo JJ, Donoho DA, Forman HP. Hospital capacity and operations in the coronavirus disease 2019 (COVID-19) pandemic-planning for the Nth patient. *JAMA.* 2020;1:1-2.
 14. Clark EG. Natural history of syphilis and levels of prevention. *Br J Vener Dis.* 1954;30:191-7. doi:10.1136/sti.30.4.191
 15. Donabedian A. The quality of care. how can it be assessed? *JAMA.* 1988;260:1743-8. doi:10.1001/jama.260.12.1743
 16. Tong A, Sainabury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007; 19:349-57. doi:10.1093/intqhc/mzm042
 17. QSR International. (n.d.). NVivo. <http://www.qsrinternational.com>
 18. Hoth KF, Wamboldt FS, Ford DW, Sandhaus RA, Strange C, Bekelman DB, et al. The social environment and illness uncertainty in chronic obstructive pulmonary disease. *Int J Behav Med.* 2015;22:223-32. doi:10.1007/s12529-014-9423-5
 19. Arentz M, Yim E, Klaff L, Lokhandwala S, Riedo FX, Chong M, et al. Characteristics and outcomes of 21 critically ill patients with COVID-19 in Washington State. *JAMA.* 2020; 323:1612-4. doi:10.1001/jama.2020.4326
 20. Feigenbaum JJ, Muller C, Wrigley-Field E. Regional and racial inequality in infectious disease mortality in U.S. cities, 1900-1948. *Demography.* 2019;56:1371-88. doi:10.1007/s13524-019-00789-z
 21. Wang C, Pan R, Wan X, Tan Y, Xu L, Ho CS, et al. Immediate psychological responses and associated factors during the initial stage of the 2019 coronavirus disease (COVID-19) epidemic among the general population in China. *Int J Environ Res Public Health.* 2020;17:1-25. doi:10.3390/ijerph17051729
 22. Holt C, Clark E, Dehnam K, Roth D. Religion and health in African Americans: the role of religious coping. *Am J Health Behav.* 2014;38:190-9. doi:10.5993/AJHB.38.2.4
 23. Isaac KS, Hay JL, Lubetkin EI. Incorporating spirituality in primary care. *J Relig Health.* 2016;55:1065-77. doi:10.1007/s10943-016-0190-2
 24. Wolford B. How did 2 people with COVID-19 infect 35? This church offers dramatic lesson, CDC says. Published 2020. Accessed June 10, 2020. <https://www.miamiherald.com/news/coronavirus/article242847301.html>
 25. Crawford D, Huddleston Q. The black burden of COVID-19. Published 2020. Accessed June 7, 2020. <https://www.dcfpi.org/all/the-black-burden-of-covid-19>
 26. Abdel-Latif M. The enigma of health literacy and COVID-19 pandemic. *Public Health.* 2020;185:95-6. doi:10.1016/j.puhe.2020.06.030

Author Biographies

Sainfer Aliyu is the director of Nursing Research at MedStar Washington hospital Center.

Jasmine L Travers is an assistant professor at New York University Rory Meyers College of Nursing.

Michael Clarke is a senior director of Nursing at MedStar Washington Hospital Center.

Allison A Norful is an assistant professor at Columbia University School of Nursing and jointly appointed at NewYork Presbyterian Hospital.

Schroeder Krista is an assistant professor at Temple University College of Public Health.