Experiences With COVID-19

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Background: Millions of Americans have tested positive for COVID-19. The illness has a range of clinical symptoms with varying degrees of symptom severity; there is limited research about the lived experience of having COVID-19.

Objective: The study aim was to understand the lived experience of having COVID-19, provide detail on the length and severity of symptoms as well as coping mechanisms of those with the illness, and identify issues individuals face when accessing healthcare.

Methods: This phenomenological qualitative study included semistructured interviews of 45 people ages 18 years and older living in the United States who tested positive for COVID-19. Inductive content analysis was employed for subjective interpretation of the text through a systematic coding classification to identify themes for analysis and conclusions.

Results: This study details a variety of symptom presentations of individuals who tested positive for COVID-19 as well as mental health concerns related to fear and living with COVID-19.

Discussion: Individuals expressed varying emotions when finding they tested positive for COVID-19. Many conveyed fear of having COVID-19 and indicated it was a traumatic experience. This fear is an important clinical finding that policymakers and providers should consider when treating acute and chronic COVID-19 patients. Finally, many participants, commonly referred to as “long haulers,” experienced ongoing and lingering symptoms highlighting an area in need of further research.

Key Words: COVID-19 • health services accessibility • interviews • qualitative research

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Millions of Americans tested positive for COVID-19 during the pandemic (Centers for Disease Control and Prevention, n.d.). COVID-19 has a range of clinical symptoms, including cough, fever, myalgias, gastrointestinal symptoms, and anosmia. Some affected individuals reported a wide range of clinical symptoms with varying degrees of severity, whereas others reported minimal or no symptoms. COVID-19 infection prevention efforts centered on using personal protective equipment for healthcare workers and the public, in addition to social distancing and testing (Gandhi et al., 2020; Wan et al., 2020). Although publications provided detail regarding COVID-19 symptoms and how these affect the healthcare system, there is limited information found related to the lived experience of being diagnosed with and having COVID-19 and how the symptoms vary from person to person. The purpose of this qualitative study was to (a) increase knowledge of the lived experience of having COVID-19, (b) provide detail on the length and severity of symptoms, (c) learn how people coped and managed with having COVID-19, and (d) identify issues individuals faced in accessing healthcare.

These issues are essential for policymakers and nurses to better understand and assess how individuals deal with COVID-19 sequelae and provide more information when counseling patients with vaccine hesitancy.

METHODS

The study’s primary aim was to explore the lived experience of having COVID-19. Qualitative methods were suitable for this study because of the exploratory nature of the research in identifying perspectives and insights from the experiences of people with COVID-19 (Kingstone et al., 2020). The phenomenological qualitative research included semistructured interviews conducted from December 2020 through February 2021. The Sterling Institutional Review Board reviewed the study and determined it was exempt. All participating individuals were required to provide consent before participating in an interview. They also received information about the purpose of the study verbally and in writing before the interview. Participation was voluntary, and the responses remained anonymous.

The target sample included individuals aged 18 years and older at the time of the interview and who tested positive for COVID-19. All individuals meeting the criteria were interviewed. Inductive content analysis was employed for subjective interpretation of the text through a systematic coding classification to identify themes and reach conclusions (Creswell & Plano Clark, 2011). The coding classification was completed using NVivo qualitative data analysis software (Version 12; QSR International Pty Ltd., 2018); data calculations were completed.
using Excel. The primary author completed the initial theme identification and analysis; the other authors confirmed or amended the findings as appropriate.

Recruitment occurred using various social media sources by posting flyers or a narrative explaining the purpose of the study and how to contact the principal investigator (PI) for an interview. Flyers and study information were e-mailed to organizations and individuals to recruit diverse participants. A total of 50 people expressed interest in participating in the study. Three individuals who experienced COVID-19-like symptoms but did not have a confirmatory test were excluded. Two other individuals contacted the PI for an interview but subsequently withdrew. Both symptomatic and asymptomatic individuals were included to record experiences of testing positive and managing throughout the quarantine phase.

Data Collection and Analysis Procedures

Data were collected by semistructured, open-ended, one- or two-person interviews. The interviews were conducted using virtual software (e.g., Zoom or FaceTime) per the participant's preference; one participant preferred to submit written responses to the interview questions. Interviews were audio-recorded and transcribed verbatim. The transcribed material was analyzed using inductive content analysis to identify common themes (Patton, 2015); the systematic coding classification process helps researchers organize large amounts of text into content categories. This process led to the thematic analysis allowing researchers to focus on meaning across a data set. Data collection continued until all eligible participants were interviewed and thematic saturation was reached. Members of the research team completed interviews, data collection, and analysis. A summary of the study findings was shared with the participants, and their feedback was incorporated into the analysis.

RESULTS

A total of 45 people meeting study criteria were interviewed. The demographics of the participants are presented in Table 1. There was a wide range of responses when participants were asked what it was like to have COVID-19. The responses varied across age groups and by gender, from having no symptoms to something akin to a minor cold to something akin to influenza times 100. It was the worst illness I ever had. I am a healthy person, and it totally brought me down. I would rather go through childbirth than have COVID. (female, 38 years)

I was so tired I could hardly move. I had brain fog and fuzzy thinking. I could not read or make sense of anything. I tried to read for over a week. (female, 75 years)

I was scared I was going to die. It hit so fast. It was like having influenza times 100. It was the worst illness I ever had. I am a healthy person, and it totally brought me down. I would rather go through childbirth than have COVID. (female, 56 years)

I lost my hand–eye coordination. I had to write a check; it was October. I wrote the “1,” I had to think about writing the “0” with the hyphen, then I could not remember the date... I thought it was overblown and just did not buy it; I thought it was just the flu. Then, I got it and I was scared I was going to die. It hit so fast. It was like nothing I have ever had before. (male, 32 years)

I was so careful; I wiped everything down. My family thought I was just the flu. Then, I got it and something felt different; this is like nothing I have ever had. I can’t quite explain. (female, 56 years)

It kind of felt like a pretty bad flu, except for the sense of smell was the difference. It was all whacky. (male, 24 years)

I slept a lot; the first week it seemed like I slept 24 hours per day. I could not eat anything. It feels like something you have three kind of things: bronchitis, the stomach flu, and the flu (influenza) all at once... If I got this again, I don’t think I would live through it. (female participant, 72 years)

This is unreal as to how sick you get. It was like having influenza times 100. It was the worst illness I ever had. I am a healthy person, and it totally brought me down. I would rather go through childbirth than have COVID. (female, 62 years)

TABLE 1. COVID-19 Interview Participant Demographics, n = 45

| Demographics | n = 45 |
|-------------|-------|
| Gender | |
| Male | 18 (40%) |
| Female | 27 (60%) |
| Mean age (years) | 47.53 |
| Age range (years) | 23–75 |
| Age groupings (years) | |
| 18–30 | 11 (24.4%) |
| 31–40 | 7 (16.0%) |
| 41–50 | 2 (4.4%) |
| 51–60 | 15 (33.3%) |
| >60 | 10 (22.2%) |
| Race/ethnicity | n |
| White | 40 (89.0%) |
| Black | 2 (4.4%) |
| Hispanic | 2 (4.4%) |
| Asian Indian | 1 (2.2%) |

have had colds, flu, and pneumonia, this was different. (female, 59 years)
I know for me; the worst part was not the acute illness but the lasting symptoms that came afterwards. The acute part I expected and could just bunker down and ride through it since it was very much like a flu. So, I, like many others, thought after a few days of feeling bad everything would be back to normal again...the acute illness faded away, but the symptoms kept lasting. This is what really bothered me and made me more fearful as COVID went from acute to chronic. (male, 26 years).

**Testing for COVID-19**

The two main reasons individuals decided to seek a COVID-19 test were developing symptoms and being notified of possible exposure. Once individuals began developing symptoms or were exposed, all knew where to go for testing and began their quarantine before obtaining their results. People did not hesitate to seek testing and follow existing public health guidelines. Over half (n = 25, 55.56%) were tested because they were experiencing symptoms, whereas the remaining 20 individuals sought testing postexposure. Although the various media sources provided testing information, some confusion did exist with time frames related to length of quarantine. Several participants noted discrepancies between guidance as defined by the Centers for Disease Control and Prevention and their healthcare providers. One participant discussed the confusion and contradictions related to COVID-19 by stating:

- **Theme 1. Expressing Fear, Being Scared, or Being Surprised (n = 18, 40.0%)**: "I freaked out for 20 minutes. I was really scared. I am diabetic, and I am overweight. But then I thought there is a 99% survival rate."

"Oh my gosh! I have asthma and being in my age group. I thought I would be dead."

"At first, I was a little scared; it is an unpredictable virus."

"I was like, 'oh crap!' And I was also thinking, 'where did I get this?'"

**Theme 2. Not Surprised (n = 15, 33.33%)**: "I was not surprised. I have never been that sick in my whole life."

"I kind of figured I had it living in close proximity with two COVID positive people. I was not surprised."

"I was not surprised because my son had it; I knew I had it."

"I was in the hospital when I got the phone call that I was positive for COVID. By the time I got the phone call, I kind of figured I had it."

**Theme 3. Worried About Infecting Others/Leaving Coworkers Shorthanded (n = 13, 28.89%)**: "I was thinking about if I had been around anyone lately and letting them know."

"I worried about letting my work team down, not having enough staff."

"I was afraid for my coworkers, and then I was afraid for my children and family."

"I am a nurse, and I was devastated because I just worked a 10-day stretch and was worried about all of the people I had come into contact with. I had fear, anxiety, and guilt."

**Theme 4. Angry About Exposure or Isolation Inconvenience (Quarantine; n = 6, 13.33%)**: "I thought, ‘Ahhh! Now I have to quarantine for another 14 days!’"

"It was close to the holiday season, and it meant I could not go out and see family, which is what we were planning on doing."

"I was unhappy with a family member who tested positive and did not wear a mask (around family members)."

**Theme 5. Relieved/Not a Big Deal (n = 5, 11.00%)**: "I was relieved...I have a compromised immune system, and I was so tired, then when I got the positive result, I thought, ‘now I know what this is.’"

"I was pretty ill, and I was going to honestly be disappointed if I did not have it because I wanted to get it over with…. Just knowing I had it was a relief."

"I was kind of relieved to know that I had it...I was running a fever, and I wondered if I had COVID…. What relieved me about it was it was easier to manage with my (college) school. Like trying to get exams moved around and not attending classes in person."

Throughout the interview process, participants talked about the steps they took to prevent infecting others and the initiatives used to identify and notify anyone they had been in contact with during the weeks before testing positive. Many participants indicated that they isolated themselves from other family members living in the same household by living in the...
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just get out of the chair, and it was like this for 5 or 6 days. I could not walk up the stairs.

The lingering effects made it the worst thing I ever had

Many participants (n = 29) could identify where they
had been exposed to COVID-19. Places of exposure included
the workplace, interacting with people who subsequently
tested positive, having a family member or a roommate in
the household who tested positive, or attending an event
where a breakout was subsequently reported (Gandhi et al.,
2020). The remaining 35.56% (n = 16) participants could not
identify where they had been exposed despite being careful,
wearing masks, or washing their hands frequently.

COVID-19 Symptoms

Participants were asked if they experienced commonly recog-
nized COVID-19 symptoms and asked to provide details re-
garding their experiences. Table 2 provides a list of symptoms.

Fatigue Fatigue was the most frequently reported symptom
affecting 93.33% of participants. On average, fatigue lasted for
13.4 days, with some individuals saying that it started as severe
by sleeping more than 16 hours per day and then slowly faded.
Half (n = 22) of the participants reported having 10 days or more
of fatigue, and some reported tiring quickly 6–8 weeks postonset
of symptoms. One participant referred to themselves as a
“long hauler,” who reported feeling fatigued 8 months after
diagnosis. Participants described the fatigue as follows:

“I was extremely fatigued. I have never felt like that before.”
“I felt drained for 10 days, and then it improved over time.”
“I would get up and work for 2 hours, then take a 2-hour
nap. I would have to take a couple of naps throughout the day.
The lingering effects made it the worst thing I ever had. . . This
just lasted and lasted and lasted, and you feel like crap.”
“It was horrible; I felt weak; I could not even walk up
the stairs.”
“I was so tired I could hardly move; I could barely walk
from my living room to the bathroom. It was all I could do to
just get out of the chair, and it was like this for 5 or 6 days.”
“The fatigue was horrible. . . I was so weak I could not even
hold my phone or sit in a chair.”
“I slept 12 hours and woke up exhausted.”

Headache Many participants (n = 35) reported headaches of
varying levels of severity lasting an average of more than 9 days.
The number of days people experienced headaches ranged
from 1 to 35 days, with 12 participants reporting pain for more
than 12 days. The headaches generally started as moderate to
severe and decreased over time. Some participants reported
having a headache in the morning that would go away during
the day and then return in the evening. Most participants re-
ported a frontal headache or a dullness at the top of their
head, described by some as a type of sinus headache. Others
reported pain with specific eye movements. About 51% of those
experiencing a headache described it as severe; a subset of this
group sought medical treatment through their primary care phy-
sician or went to the emergency room (ER) to obtain pain med-
icine. Several participants reported that taking acetaminophen
and ibuprofen did not take the pain away. General comments
participants made about their headaches include the following:

“It hurt to move my eyes.”
“The headaches were bad; they would wake you out of a
dead sleep. I was taking four Motrin at a time, which seemed
to help. . . the first 10 days were really bad, and then, after that,
you started getting less and less.”
“I had it (headache) for 2 days; it felt like I got shot be-
tween the eyes.”
“My headache was severe. I was taking Tylenol extra
strength every 6 hours, and it was not doing much for the head-
ache. I had this for 7 days, and it got better after I went to the
ER, and they gave me steroids and other medications.”
“My headache was on and off. It was at the top of my head.
It felt like someone was hitting me on the top of my head.”
“I had a headache for 2 weeks. I get migraines, and it was
not a migraine; it was more of a tension headache.”
“Oh God, that (headache) was terrible! I had that for 4 or
5 days, and then it went on, but not as strong.”

Loss of Smell (Anosmia) Loss of smell was identified as a
hallmark sign of having COVID-19, with 30 participants
(66.67%) reporting complete loss of smell or having an altered
sense of smell for an average of 8.5 days and a range of 1–
56 days. Three individuals noted that their sense of smell had
not returned at the time of the interview, and two had been
experiencing loss of smell for greater than 60 days. Many par-
cipants reported their sense of smell was lost, and then it
slowly came back. Others said that they lost their sense of
smell, and as it was returning, things smelled differently:

“Things smelled like chemicals.”
“I could smell perfume, but I could not smell bleach.”
“I could smell pleasant odors, but not bad smelling things.”
“I could not smell, then when it came back, it was blunted
for a while.”

Loss of Taste Thirty-one participants lost their sense of taste.
Five participants lost their sense of smell but did not lose or ex-
perience a change in taste. Conversely, five participants lost
their sense of taste but did not lose their sense of smell. One in-
dividual (female, aged 36 years) indicated she lost her sense of
smell for 10 days, and as it was slowly coming back, she then
lost her sense of taste for 14 days. In this case, the two symp-
toms did not overlap. At the time of the study, three participants’
sense of taste returned, but their sense of smell had not.
Loss of taste was described as not being able to taste anything, all food tasted the same, or all food and water had an iron or aluminum metallic taste. Ten participants reported that food or water had a metallic taste and stated, “Food tasted awful.” When the sense of taste began returning, some participants noted enhanced taste sensations with hypersensitivity to sweets. For example, an item such as cookies seemed to have “too much sugar” or “tasted different.” Others reported that certain foods they usually liked tasted very salty. One participant stated, “I could not eat my Thanksgiving turkey; it tasted so salty.” Others reported that even after their sense of taste returns, they find it is still altered or blunted and “seems to come and go.”

**Other Symptoms** The World Health Organization defines a possible case of COVID-19 as a person experiencing fever, cough, shortness of breath, loss of smell, loss of taste, and that
symptom presentations can vary widely. Participants were asked if they developed specific symptoms and were asked if other symptoms had not been discussed. The following is a list of symptoms reported by more than two people: bladder spasms, severe back spasms, oral thrush, excessive thirst, eye inflammation, “brain fog,” burning sinuses, hair loss, and a rash. Four individuals in the greater-than-60-years age group reported hair loss after having COVID-19. One participant indicated that hair loss was extreme, noting they needed to wear a wig for a while until their hair grew back.

In addition to physical symptoms, one of the major issues identified in this study was fear. Many participants expressed fear of knowing they had COVID-19, whereas others expressed fear of getting it again. Some who experienced severe symptoms worried they would not recover if infected for a second time. This is especially concerning with the variants identified in other countries that have made their way to the United States. Many indicated they would get the COVID-19 vaccine if recommended by their doctor after having COVID-19 (Dubey et al., 2020).

**Accessing Healthcare**

For those with mild to moderate symptoms without breathing problems, accessing healthcare via telemedicine was sufficient and a positive experience. Most participants did not seek healthcare after they tested positive. For some who had breathing issues or other acute symptoms, there were reports that it was difficult for them to obtain an in-person doctor’s visit. Although these participants were offered a telemedicine visit, they did not feel this type of visit would be sufficient. A few participants had negative experiences interacting with healthcare staff, who seemed afraid to be near COVID-19-positive patients, whereas others had a positive experience with the healthcare system:

"I felt like a leper...I wanted to make sure I did not have pneumonia... Since I was experiencing those symptoms, they weren't going to let me in. They would do a telemedicine appointment, but they could not listen to my lungs. The person was good but could not do the exam and could not alleviate my concern during the telemedicine visit...I don't like telemedicine as much; I don't feel like it satisfied the needs I came with...my only other recourse was to go to the emergency room to get it checked. It was just unfortunate with COVID; it makes it difficult to get healthcare. After I was discharged from the hospital, I called my doctor's office, and I said that I had been in the hospital with COVID-19 and had pneumonia and needed to get a recheck. They said we can do a televisit. I am like, what is the point? If you are not going to let me come in and listen to my breathing and check me out. What is a televisit going to do for that? You are not going to do a recheck or X-ray? How are you going to do that over the phone? That really annoyed me. Nowadays, if you are sick, you cannot go to the doctor.

I went to the ER and I felt like they treated me differently, they were not customer service friendly, because I had COVID... They were trying to keep their distance. I went to the ER and the staff were awesome. I called my doctor first, who told me to go to the ER as I was dehydrated. She told them I was coming. When I got there, they took me to a private room for COVID patients; they were great. They were awesome. My doctor was wonderful. I got right into the ER on Thanksgiving; staff treated me well. I had a good experience both times. I told them I was COVID positive both times, and they got me right in."

**DISCUSSION**

This study highlights the complexity, presentation, variation, and length of the mental and physical symptoms experienced by individuals of varying ages. The presentation for some symptoms, most notably fatigue, ranged from 1 day to several months.

There is a rising concern in the literature about the long-term effects of COVID-19 and how people suffered once the acute illness abated (Kingstone et al., 2020). The persistence of symptoms for weeks to months is an issue that continues to emerge and was clearly expressed by several study participants (del Rio et al., 2020). Policymakers and healthcare providers need to be aware of this variation and length of symptom experiences by individuals with COVID-19. The study of COVID-19 “long haulers” or long COVID-19 is an area that needs further exploration (Kingstone et al., 2020; Rubin, 2020).

People’s reaction to a positive COVID-19 test resulted in five different themes, which is noteworthy in understanding how people process the effect of a COVID-19 diagnosis. It is essential to highlight that many participants expressed fear after testing positive or after having severe symptoms and were fearful of getting it again. Healthcare practitioners should consider this underlying fear as they provide counseling services or discuss vaccine options (Dubey et al., 2020). Nursing will be vital to helping to identify ongoing mental health issues with persons who had COVID-19 as they may be more willing to discuss their persistent fears with nurses. Access to healthcare varied as healthcare professional responses was great for some, yet others had difficulty accessing primary care. Telemedicine provided access to healthcare, but it was not an adequate healthcare delivery service for those needing in-person assessments and reassurance.

It may be important to develop a process outside ER visits to assess patients with concerns about physical symptoms, particularly with a diagnosis of pneumonia. This follow-up is a central role for nurses when monitoring patient progress. In addition, best practice in COVID-19 treatment is to assess an individual with a confirmed positive COVID-19 test for eligibility for specific COVID-19 treatments such as outpatient infusion of monoclonal antibodies. Many of these patients would have qualified for treatment (Rubin, 2021).
Limitations

Limitations of this qualitative study center on the fact that all measures are self-reported via a virtual format, which may be subject to social desirability bias (Patton, 2015). There was a lack of minority representation in that the sample was 88.89% White. The timing of interviews in respect to the actual COVID-19 diagnosis may have affected responses. However, most interviews occurred within 2–3 months of participant’s positive COVID-19 test; many experienced symptoms that lingered for weeks or months beyond this time frame. More detailed evidence related to long haulers may be elicited if additional follow-up interviews were conducted at longer post-COVID-19 intervals (Rubin, 2020). Although the PI offered an interview to anyone who met the study criteria, a potential limitation is that only people willing to volunteer a half hour of their time for an unpaid interview may have negatively influenced participation. In addition, recruitment occurred through social media, and individuals who do not have access to social media may not have been aware of the study.

Conclusion

This study shows the wide variety of symptoms for those infected with COVID-19. Several people in their 20s and 30s had difficulty fighting the virus and managing its lingering effects, yet there were people over 50 years of age who had little or no symptoms. This stresses the importance of everyone exercising caution and seeking healthcare early when diagnosed and becoming symptomatic. The findings of chronic symptoms underscore the effect that COVID-19 may continue to have upon healthcare long term and the need for continued research to manage these outcomes.

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The study information was submitted to the Sterling Institutional Review Board, which determined that this research study is exempt from institutional review board review.

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