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Original Research

The Lived Experience of COVID-19

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A B S T R A C T

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This qualitative study examined the essence of living with coronavirus disease 2019 (COVID-19). We used a phenomenological research design and interviewed 14 individuals ages 18 and older during the first wave of the COVID-19 pandemic. Data analysis using Colaizzi's method for analysis revealed 2 overarching themes—physical experiences and psychologic/emotional experiences—and 8 subthemes that identify concerns that affect quality of life. The findings provide insights for nurses and health care providers on the experiences of living with COVID-19.

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Introduction

Severe acute respiratory syndrome coronavirus (SARS-CoV-2), also known as coronavirus disease 2019 (COVID-19), was discovered in Wuhan, China, in late 2019. Although the virus resulted in variations of the severity of symptoms, the virus's infectious nature quickly grew into a global pandemic.¹ The number of cases of COVID-19 was on the decline until Fall 2020, when the rate of individuals infected with COVID-19 began to increase with varying degrees of severity after social gatherings associated with the fall and winter holiday season. The COVID-19 infection rate surge resulted in quarantine and mitigation measures to stop the spread. Understanding the experience of individuals infected with COVID-19 who did not require hospitalization is essential for nurses and other health care providers to help those suffering from COVID-19. This study was conducted to understand the experience of individuals infected with COVID-19.

Literature Review

In Spring 2020, the World Health Organization (WHO) declared the novel coronavirus, COVID-19, a global pandemic. Factors leading to the worldwide pandemic included the high infection rate, the lack of understanding of the virus, and the absence of a treatment or a vaccine.² These conditions led to widespread human-to-human transmission.^{3,4} By mid-July 2020, approximately 3.4 million cases had been reported in the United States (US) and the expectation that COVID-19 would rise to the third leading cause of death in the US.⁵ Individuals have experienced long-term sequelae after acute infection with COVID-19, which may lead to debilitating symptoms.

COVID-19 can result in severe disease, including hospitalization, admission to an intensive care unit, and death. Information about symptoms experienced by patients with COVID-19 in the US is limited, especially among patients who were not hospitalized. A symptom profile of 164 symptomatic patients with COVID-19 was conducted from January to April 2020. All the patients in the profile

reported fever, cough, or shortness of breath. A variety of other symptoms were reported, including chills, myalgia, headache, fatigue, and the presence of at least 1 gastrointestinal symptom.⁶ Owing to the virus's mutations and the wide range from mild to severe symptoms, the individuals' experiences with the infection vary.

Design and Methodology

The study qualitative study used a phenomenological approach and Colaizzi's⁷ phenomenological method for descriptive analysis. A semistructured interview was used to interview adults diagnosed with COVID-19 and aged 18 years and older via telephone (due to COVID-19 restrictions), and their responses were transcribed. The researchers asked open-ended questions related to the experience with follow-up questions regarding the information. The interviews lasted 20 minutes to 1 hour. Snowball sampling continued until saturation of data was reached. The snowball technique is appropriate because it enabled the participants to share their lived experiences.

The participants also completed a demographic questionnaire (Table). The only questions asked on the questionnaire were sex and age because the data points may have affected the disease. Confidentiality was maintained by coding all data to protect the anonymity of the participants. Colaizzi's⁷ method was used for data analysis of phenomenological research. A peer debriefer, as described by Lincoln and Guba,⁸ participated in the data analysis to ensure trustworthiness. Verification of the themes by the participants using member checking provided authenticity. The researchers immersed themselves in the data until themes were illuminated.

Data Analysis

Participants reported physical and psychologic/emotional experiences. The physical incidents most commonly reported included extreme fatigue, loss of taste and smell, fever, brain fog, and weight loss. The most widely reported psychologic/emotional

Table
Demographic Questionnaire

Variable	Participants (n) (n = 14)
Sex	
Women	11
Men	3
Age, y	
20-31	1
31-40	1
41-50	3
51-60	2
61-70	7

experiences were feelings of loss of control, fear and worry, isolation, anger, guilt, shame, anxiety, and embarrassment from being diagnosed with COVID-19.

Themes

The data analysis resulted in 2 major themes emerging from the transcribed interviews of 13 nonhospitalized participants with a diagnosis of COVID-19 and 1 person who was hospitalized but not on a ventilator and was interviewed at home. The first major theme focused on physical experiences. The second major theme focused on the psychosocial/emotional experiences.

Physical Experiences

Overwhelming Fatigue

All of the participants reported overwhelming fatigue. The theme clusters concluded:

- “I had extreme fatigue; I was unable to get off the couch. It took all I had to get to the bathroom.”
- “I couldn’t walk five steps without losing my breath and my heart rate going up to 140 beats per minute.”
- “[I had] no energy to do anything.”
- “I needed a cane to stay upright... everything has to be planned.”
- “The fever caused fatigue that was absolutely crippling.”

Loss of the Sense of Taste/Smell

The participants reported loss of smell and subsequent loss of taste. One participant described her experience with the lingering effects:

- “...It could take months for some people to get smell back... there are certain things, like bacon, I can smell bacon being cooked, so now, when I cook, I have to be very careful if I am by the stove to make sure I am there so something doesn’t burn.”
- “I lost about 22 pounds in about 2.5 weeks or so.”

Neurologic/Muscular Symptoms

Participants described an array of neurologic and muscular symptoms. This ranged from body aches to headaches and brain fog.

- “I got excruciating body aches.”
- “The headaches were worse... the body aches... it was like someone was standing on my head.”

- “It was just like the bones were being screwed in the opposite direction... the whole week was torture.”
- “I have brain fog, my mind was a little fogged... I couldn’t think.”

Psychologic/Emotional Experiences

Loss of Control

Loss of control was articulated in terms of fear of the unknown, worry, and isolation. Overall, the participants felt they were at the mercy of COVID-19. Overall experiences with the virus included:

- Fear of the unknown: it lasted 2 months.
- Not having control over what you want to do.
- “...nothing has prepared me for this.”
- “...you are at the mercy of letting the virus run its course.”

Loss of control was also manifest in *fear of the unknown*. Participants described multiple dimensions of fear.

- Fear of the unknown: it lasted 2 months.
- Afraid to go to sleep: “It awful not knowing if and when I would get better. I couldn’t sleep, I don’t know if it was because I was afraid, I would not wake up—when I had a lot of unknowns and we still do not know enough.”
- Fear of long-term sequelae
- Fear of unknown: “all the unknowns... it is very scary. You never know, especially the first couple of days. You are making sure that you are watching yourself making sure that things don’t turn and go in a different direction you don’t need to go to the hospital.”
- “Worried about my job” and “fear of being ostracized from work.”
- “It’s scary being out and about with people not wearing masks—even today people don’t believe that masks work.”
- “It was scary thinking I could have infected my cancer patients and coworkers and cause them to die.”
- “My sister had the same symptoms—and possibly worse—I assume blame for that, but then it’s like you just never know where it came from but me being in the medical field, and then hearing what is going on, it caused them (family) to worry about living in the same house” — “I do my best not to bring it home, I change at work, I wash my hands, I walk around in my own house with a mask on.”

Isolation Also Was Part of Fear

- “Loneliest experience you could ever have—you cannot see anyone—no one can see you.” “There was touch missing—human touch missing.”
- “You’re on your own... very isolating,” “alone when you get told.”
- “It took a toll on me mentally... (I) did not have a ton of support, so that was tough... they (others) did not think it was a real thing.”
- “What has been hard for us as a family is the isolation... This isolation has really taken a toll on all of our mental health.”

Anger

Anger manifest against the disease itself, but also toward others related to COVID-19.

- At husband’s workplace for not following rules.
- “Just get angry knowing that people aren’t listening to what the guidelines are and that we are having another surge in other parts of this country.”
- Lack of compassion from other people: “ ‘sounds like flu’ ... people don’t want to take it seriously.”

Shame/Embarrassed

Participants described the feeling of shame and embarrassment. Several participants described this as having a stigma or being marked related to COVID-19. Therefore, they attempted to hide the diagnosis from their family. They did not want to be put in a category that the virus was fake.

- “Some of my friends thought I had cancer; I didn’t correct them because I didn’t want them to know I had COVID—it’s like a mark around here.”
- “I feel like I am ‘marked’.”
- “Didn’t want to tell neighbors.” “Didn’t want to tell people.”
- “Didn’t want family to find out.”
- “I felt ashamed—did my best to avoid it.”
- “I think there a stigma having it. People think it is fake, like people saying the numbers are fake and this is fake.”
- “I didn’t want people thinking I am ‘faking it’—didn’t put on Facebook—didn’t want to be put in ‘fake’ category.”

Anxiety

The anxiety of having the virus was worse than the physical symptoms of the disease for these participants.

- “I had two moments when I wanted to die.”
- “This took a mental toll on me.”
- “This took a toll on me mentally.”
- “No one prepared me for this.”
- “I didn’t realize how sick I was”
- “...not knowing what was going on.”
- “The anxiety of the whole siege was probably worse than the disease we caught—nothing else we could do but ‘ride it out’.”
- “It’s almost liked a PTSD [posttraumatic stress disorder] kind of effect.”
- “The disease is vile, and it’s evil.”

Essential Structure of Living With COVID-19

The themes identified by the study participants create an essential structure that gives a face to the experiences of people who have experienced COVID-19. As one participant said, “Until you put a face on the disease, it is not real.” The experience of living with COVID-19 creates enduring physical and psychologic health concerns that impact the quality of life.

Discussion

Relating Themes to the Literature

Physical Experiences

Study participants described physical experiences that affected their health and sense of well-being. The experiences included overwhelming fatigue, loss of the senses of taste and smell, and neurologic/muscular issues. The literature supports the experiences reported. Stokes et al⁹ reported 36% of patients experienced myalgia, 43.4% experienced headache, and 10% reported a loss of taste and smell. Other studies reported a greater incidence of changes in taste and smell.^{10,11} Although only 1 patient in this study required hospitalization, the experience of “brain fog” or cognitive symptoms, such as poor memory and poor concentration, were reported.¹² The physical experiences were drivers for psychologic and emotional experiences manifested in the participants.

Psychologic/Emotional Experiences

The psychologic/emotional experiences of the participants often resulted in anger, shame/embarrassment, and anxiety. Participants reported the loss of control, isolation, anger, shame/embarrassment, and stress attributed to feelings of fear. Since the plague and subsequent pandemics, people react in different ways to infectious outbreaks and experience fear. Study participants who self-identified as health care providers described the fear of possibly infecting their patients, coworkers, and family members—this concern added to their anxiety. Posttraumatic stress disorder and depression can result in severe cases of fear and anxiety.¹³

Loss of control. Pandemics often trigger fear and a sense of loss of control, which manifests in different ways and often as a mechanism to be in control. Feelings of uncertainty and loss of control result in buying excess products, such as toilet paper, to gain a sense of control. Because it is perceived that a pandemic such as COVID-19 is a genuine threat and expected to last, steps are taken to gain control.¹⁴ Uncertainty and fear are also heightened when messaging from health officials is mixed and causes confusion.¹⁵ Social isolation and the inability to handle distress escalate the loss of control.¹⁶

Isolation. The literature reveals a connection between the virus and feelings of isolation. Early on in the disease process, isolation was more tolerable, as evidenced by Fuller and Huseth-Zosel.¹⁷ The researchers conducted phone interviews of 76 older adults (ages 70-97 years) during the pandemic’s early weeks. The researchers found resilience as a component of older adults’ ability to cope with the social distancing and isolation required during the early weeks of the pandemic.

As the pandemic persisted, a review of the literature on the mental health impacts of social isolation in older individuals during the COVID pandemic and other epidemics by Tappenden and Tomar¹⁸ documented the increasing social isolation among older adults prevalent in Europe, the US, and China compared with before the onset of the COVID-19 pandemic. Findings suggest that feelings of isolation result in implications for mood changes and sensitivity to a threat, resulting in an increase in cortisol levels and a decline in older adults’ immune function.¹⁸ In addition, researchers explored the lived experience of patients diagnosed with COVID-19 living in isolation in an Australian health care setting.¹⁹ The researchers reported “contextual aspects of their social and physical environment together with their individual resources contributed to the framing of their planning for, and response to, the outbreak and were important mediators in their experience.”^{20(p1445)} The impact of feelings of isolation is significant to the quality of life. In more extensive studies of other viral infections, such as HIV, researchers report an association between social isolation and mortality.²⁰

Anger. The participants described anger both in terms of being angry with the disease and also being angry with others. Anger was also related to COVID-19 in other studies. A recent survey reported fear, anger, and hopelessness as the most frequent traumatic emotional responses in the general public during the first stage of the outbreak of the COVID-19 pandemic.²¹ In a study by Smith et al,²² participants reported arguments, feeling angry, or having “fallen out” with someone because of the COVID-19 pandemic. The feeling of worry about financial difficulty resulting from COVID-19 created anger, particularly in younger participants. Anger over thinking that measures to prevent the spread of the virus were relaxed too early or worry about restrictions being lifted and the increased risk of COVID-19 to self or others attributed to anger.²²

Shame and Embarrassment. Quinn et al²³ explored how the HIV/AIDS epidemic has helped sexual minority men living with or affected by HIV/AIDS and who had lived through the HIV epidemic of the 1980s. The participants related to the life-changing aspect of

the pandemic. Although some of the participants did not recognize a stigma associated with COVID-19, others in the study did notice stigma imposed on those who contracted COVID-19. The participants compared wearing a condom to wearing a mask and their anxiety was compounded by the knowledge that the COVID-19 virus could be spread asymptotically. Some of the study participants found growing evidence of COVID-19 stigma similar to what they had experienced with HIV stigma.²³

Anxiety. Anxiety was expressed in multiple ways by the participants. In a study by Wong et al²⁴ patients reported impairments with self-care and anxiety or depression.¹⁸ Researchers reviewed health records of COVID-19 patients and found an increase in anxiety disorders, insomnia, and dementia. The authors postulate that the survivors of COVID-19 may be at greater risk for psychiatric sequelae.¹⁸ Similarly, in a recent study, 70% of people in Hong Kong expressed anxiety about contracting SARS.²⁵

Implications

People living with COVID-19 report many of the same psychological, emotional, and physical experiences. Although isolation and quarantine measures are mechanisms used for disease control, existing research findings suggest both positive and negative outcomes following such measures.^{26,27} The findings of this study of the lived experience of COVID-19 are consistent with existing literature. These findings indicate that there are negative and unintended psychologic consequences of isolation, fear of the unknown, and lasting physical effects, such as anxiety and depression, documented in the existing literature. Coping with the feelings generated by contracting a highly infectious novel virus and the psychologic effects of isolation, loss of control, and embarrassment can have detrimental effects on patients' coping capacity and self-esteem.²⁶ The physical impact of the novel virus produced overwhelming fatigue and loss of sense of taste and smell, and these neuromuscular effects require understanding and compassion by caregivers.

Caregivers can provide several ways to decrease the long-lasting impact of the virus. This includes assessment of access to space to enable exercise as tolerated, stimuli from the outdoors, and sensory stimuli such as radio, television, and computer access. Virtual visits with significant others can provide emotional support and lessen the experience of isolation.

Nurse practitioners (NPs) can provide resources and ongoing support for individuals diagnosed with COVID-19 and for health care providers caring for individuals infected with COVID-19 and their families. NPs can assist with the development of systems that provide access for patients with COVID-19 or those who have experienced COVID-19 as well access to care for providers giving care and also receiving care as patients diagnosed with COVID-19.²⁸ NPs can implement telehealth as a safe alternative to provide ongoing services to patients diagnosed with COVID-19. These services can include episodic care, mental health counseling, general wellness checks, and education for homebound patients living with COVID-19.²⁹ NPs can provide education regarding the COVID-19 virus to individuals, families, and communities to minimize the negative effect of the virus and improve overall outcomes.

Conclusion

This study took place during the early stages of the COVID-19 pandemic. Recruitment was a challenge because potential participants were often hesitant to be interviewed. Individuals expressed hesitancy in admitting they had been diagnosed with COVID-19 due to their perception of a potential stigma and subsequent embarrassment of the diagnosis. The participants' experiences

provide insights regarding living with COVID-19 for NPs to provide care for patients infected with the virus. Future research should include a replication of the study aimed at health care providers diagnosed with COVID-19 and the long-term sequela of the psychological impact of the disease.

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