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Original Article



Lived Experiences of the Patients with COVID-19: A Hermeneutic Phenomenology

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Abstract

Introduction: The COVID-19 pandemic is a considerable challenge for infected patients who require more attention for recovery. Therefore, this study aimed to explore the lived experience of patients with COVID-19.

Methods: This qualitative, hermeneutic phenomenological study was conducted in the southeast of Iran from March to May 2020. The data were purposefully collected from 16 patients with COVID-19. Data were collected using in-depth semi-structured telephone interviews and analyzed using the Van Manen method.

Results: The lived experiences of patients were categorized into five themes, including incredible clinical symptoms of COVID-19, horror and stigma, bad memories of hospitalization, trust in God and hope as recovery agents from COVID-19, and reborn after recovery from COVID-19. **Conclusion:** Patients with COVID-19 have experienced variety of physical and psychosocial challenges. Health care providers have to supply appropriate strategies to fulfill the infected patients needs in such a crisis.

Introduction

The COVID-19 pandemic is caused by severe acute respiratory syndrome coronavirus2 (SARS-CoV-2),1 which was first identified in Wuhan, the capital of China's Hubei province, in December 2019.² The common symptoms of COVID-19 include fever, cough, and dyspnea.³ The other symptoms are fatigue, muscle pain, abdominal pain, diarrhea, sore throat, and loss of smell. Although most cases experience mild symptoms, some patient experience severe problems e.g., viral pneumonia and multi-organ failure.³ Up to December 23, 2021, more than 277 million people have been reported in almost all countries, resulting in more than 5 million deaths.⁴ Given that, the number of patients infected with COVID-19 is decreasing worldwide. The majority of people with mild symptoms can be managed as outpatients. However, the disease causes severe respiratory problems in about 20% of people which require hospitalization in intensive care units.⁵ Patients with severe and critical illnesses require advanced treatment such as artificial ventilation and controlling secondary bacterial infections that may lead to chronic respiratory diseases such as COPD. The death rate is 15 to 22% higher in COVID-19 patients with underlying diseases and high levels of anxiety.^{6,7}

It is noteworthy that recovered patients from COVID-19 also encounter a variety of challenges. Studies on COVID-19 are focused more on diagnosis, treatment, and care from patients' perspectives. Besides, the results of qualitative studies for acquiring lived experiences of patients with COVID-19 are various based on the context. Phenomenological studies can provide a deep understanding of the lived experiences of clients or patients to healthcare professionals. These studies also afford evidence for COVID-19 growing databases to increase knowledge sources for developing therapeutic interventions, care, and support for future potential pandemics.

Humans are complex, multifaceted beings with intertwining social, cultural, and emotional aspects. Therefore, for a successful treatment, the patient must be considered as a whole.⁸ Describing and identifying the lived experiences of the patients with COVID-19 can lead to obtaining a comprehensive understanding of the related meaning and concepts. The lived experiences of the

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patients also favor the healthcare team, especially nurses, to understand the patient's needs and issues for providing a comprehensive care plan and effective support. As the quantitative research methods are inadequate to explore human lived experiences, qualitative phenomenological studies, seem to be more suitable for identifying the depth of lived experiences and the meaning of a complicated phenomenon.⁹ This study aimed to explore lived experiences of patients with COVID-19.

Materials and Methods

This hermeneutic phenomenology study was conducted using Van Manen's method in the southeast of Iran from March to May 2020. Hermeneutic phenomenology is applied for revealing a lesser-known or unknown phenomenon through an in-depth study.^{10,11} The present study has been written following Consolidated Criteria for Reporting Qualitative Studies (COREQ) reporting.

The participants were only male patients who recovered from COVID-19 due to cultural limitations. Telephone interviews were conducted for controlling the transmission of disease to the researchers. Firstly, the polymerase chain reaction (PCR) positive patients were identified and then followed up both in the hospital and at home. The patients were interviewed after a month after hospital discharge or recovery. The researcher (MM) who was a master of nursing and had the list of the patients during hospitalization invited them via a phone call to participate in the study. The study questions were given to those who had agreed to participate in the study 24 hours before the interviews. Informed consent was also obtained from all the subjects through email or WhatsApp. The inclusion criteria included recovery from COVID-19 and willingness to participate in the study via telephone. The participants were recruited by purposive sampling. In the present study, data saturation was achieved after 13 interviews. Besides, three more interviews were conducted to ensure that no more new themes emerge.

The data were collected through in-depth semistructured telephone interviews by two researchers (MF and AA). Ethical issues were also considered by providing both oral and written information on the study. The participants were reassured that their demographic information would be kept confidential and they were free to leave the study at any stage. The interviews' duration ranged from 10 to 30 minutes. The exploratory questions such as "Tell me about your disease with COVID-19", and "Tell me about your experiences when you were sick or hospitalized due to COVID-19" were asked in the interviews. When clarifications were required we requested more information. During the interviews, speech changes such as an increase or decrease in the tone of the participants' voice, pauses, crying, and laughter was recorded as well.

The obtained data were analyzed using inductive, iterative, and idiographic inferences to gain the participants'

lived experiences.¹² After each interview, the recorded interviews were transcribed verbatim by a researcher (MF) and then analyzed using Van Manen's interpretive phenomenological approach.¹³ The researchers read the transcripts several times to be familiar with each one of the recovered patients. Significant phrases were extracted, their meanings were formulated, and then clustered into themes. The extracted themes were compared with each other and across the transcripts. Additionally, the interviews were analyzed in sequence. Thereafter, several initial themes and subthemes were shared with the participants for confirmation or modification. Finally, the research team members discussed the label of themes and subthemes.

The trustworthiness of the obtained data was established through credibility, transferability, dependability, and confirmability criteria.¹⁴ In this regard, credibility was achieved through prolonged engagement with both the participants and interviews, member checking, peer debriefing, and holding collaborative sessions. Besides, confirmability was achieved through reflexivity and audit trial. The authors wrote their experiences and opinions before analyzing the obtained data to prevent any bias. Besides, two researchers independently analyzed the data and then discussed an agreement. Dependability was also achieved using an external audit in which an expert was requested to recheck the used method and analyses. Finally, a homogeneous sample with the maximum diversity in demographic characteristics, the COVID-19 symptoms, hospitalization, and quarantine were selected to maximize the findings' transferability.

Results

In this study, the included participants were 16 recovered men from COVID-19. The mean (range) age of the patients was 54 (25-72) years old. The mean duration of symptoms before the hospitalization was 8 days. The most common symptoms on the onset of COVID-19 were fever, body aches, nausea, diarrhea, and anosmia followed by coughing and dyspnea. Six patients had taken care of at home and ten patients had been hospitalized. Overall, five themes and 20 subthemes were extracted from the recovered patients of COVID-19.

Incredible Clinical Symptoms of COVID-19

Most participants experienced similar symptoms of COVID-19. However, they reported some symptoms that they had never experienced before. Besides, the process of disease and changing symptoms were fast and led to death in some patients. It was surprising when two patients with a similar condition were in the intensive care unit (ICU), one survived and the other died.

A 32-year-old man said:

"I was admitted to the intensive care unit after suffering from COVID-19 due to respiratory problems. There was a patient next to me who had the same symptoms as mine, but he died and I recovered. I think I was lucky."

The rapid change in the symptoms from fever, chills, and headache to sore throat, a change in voice, and dry or productive cough, as well as the onset of shortness of breath, made a feel of near death in patients. As the patients expected to be improved, they suddenly encountered new symptoms, which were confusing and frightening. Patients are also admitted with similar symptoms, but some died.

A 65-year-old patient stated:

"I'd chest pain, fever, chills, and muscle aches that I had to go to the hospital. I recovered, but some patients died. It was very amazing to me because I was in a worse situation and I was waiting for death"

A 48-year-old academic member said:

"I had difficulty breathing and coughing and I could only breathe and cough when the bed was a little upright and lying face up. But, the neighbor died suddenly with mild symptoms."

Horror and Stigma

Infection with COVID-19 leads to fear, stigma, and delay in visiting a health center for receiving proper treatments. As the family or relatives of the COVID-19 dead cases were not allowed to hold funerals for their loved ones, they urged the health systems to not record the positive diagnosis of COVID-19 for their dead.

A 57-year-old said:

"I was at home for a few days after being sick because my family didn't want others to know about that. Fear of rejection by others insisted on me stay home, but I got worse, and I had to go to the hospital for treatment."

Neighbors also attempted to be isolated from the families who had a hospitalized COVID-19 patient. Moreover, they did not travel with them because of COVID-19. These were a stigma for COVID-19 patients and their families.

A 25-year-old reporter also said:

"There was a terrifying atmosphere. All [patient] was frightened. You could see it in the eyes of passersby and even the hospital guards. I felt something bad was happening when looking for the infectious emergency unit."

Bad Memories of Hospitalization

Many patients hospitalized in the intensive care unit with a sudden change in their health status. Some patients with difficulty in breathing were connected to artificial ventilators and underwent cardiopulmonary resuscitation, and some of them died. The scene was frightening, such as a real hell.

A 50-year-old patient stated:

"The hospital was so scary. Some of the patients were connected to the breathing device and monitors, and the alarms were so annoying. The patient who spoke yesterday now is connected to the ventilator or doesn't exist more. The ICU scene was a horrific tragedy that left a bad memory." The patients stated that the ICU was scary. It was terrifying because of the moral deterioration of the medical staff and physical problems such as difficulty in breathing and pain. They also had nightmares about the experienced events.

A 48-year-old man indicate:

"It was scary. Every few hours crying and screaming of the patient's family in the hospital notified them someone has died."

Trust in God and Hope as Recovery Agents from COVID-19

The participants stated that a strong mind and hope for recovery were the keys to defeating COVID-19. Hope enabled them to overcome the fear of COVID-19.

A 54-year-old man with a history of exposure to a chemical agent in the Iran-Iraq war had recovered from COVID-19 said:

"A patient with COVID-19 was brought to the hospital by a stretcher with an oxygen mask on his face. He was so stressed and complained of blurred vision. So, doctors were forced to scan his brain, but he didn't have a particular problem. He was scared and kept the oxygen tank everywhere even in the restroom. I was discharged earlier despite having lung problems because I hoped for recovery and trusted God."

Fear is one of the harmful factors leading to death in patients. Hope for recovery and positive thinking about strengths subsequently results in positive effects on the immune system and overcoming the disease.

A 57-year-old said:

"Based on what I heard in the media and on the Internet, fear of illness even leads to death.... Since I got the disease and my symptoms became worsen, I decided to think about the value of life and not to be afraid. And I was confident. So, I recovered from the disease."

Reborning after Recovery from COVID-19

The participants experienced a life-threatening situation in hospitals. Some of them had reached the brink of death or lived in quarantine with death anxiety. In these patients, recovery from COVID-19 was a new opportunity for living. A 32-year-old narrated:

"I was near death once, I'm better now and happy. I was born again and embraced life also with all my being. I believe whatever God wants will happen."

The patients had a strong belief that they will be recovered by appealing to God. They considered the second opportunity of life as a gift from God and believed that they should better use this opportunity. The discharge from the hospital was very pleasing for them. A 60-yearold patient said:

"If we think positively and turn to God, we get over the disease."

A 35-year-old car driver said: "I was very ill, and I lost my consciousness, so [I] don't remember much. I think my

youthful energy will bring me back to life. I feel happier when I'm breathing again."

Discussion

This study aimed to explore the lived experiences of patients with COVID-19. In this regard, five themes were extracted, including incredible clinical symptoms of COVID-19, horror and stigma, bad memories of hospitalization, trust in God and hope as recovery agents from COVID-19, and reborn after recovery from COVID-19.

Incredible Clinical Symptoms of COVID-19

Participants identified the onset of early symptoms of COVID-19 and their progression as a sign of life and death. They experienced acute fever and dyspnea that worsened. Moreover, the symptoms were dissimilar among patients. Symptoms such as shortness of breath, hypoxia, and pulmonary involvement insist the patients be hospitalized. However, the process of disease was also surprising for the patients. Sometimes death and return to life were unbelievable for patients. In general, for all the participants, the symptoms that they experienced were a turning point in the disease. It was indicated that the patients' confusion and experience of different symptoms affect their health and recovery. The results of a study showed that the symptoms of COVID-19 are unpredictable. One of these symptoms is dyspnea, which is more common in patients who died of COVID-19. Most patients admitted to the ICU also have pneumonia and dyspnea. Patients' chances of recovery from these symptoms are reduced, corrupting patients' lives and leading to more deaths.¹⁵ The results of another study show that the onset of symptoms of COVID-19, according to the news that is published about high mortality, first, the patients' minds are disturbed and their lives are affected. As the symptoms worsen and the patients are at risk, the thought of death increases, and the chance of recovery decreases.¹⁶ Also, the results of a study show that when people infect with COVID-19 and symptoms are worsening, their lives are disrupted. Changes in health increase the fear of death and symptoms severities.¹⁷

Horror and Stigma

The pandemic news in the media and the internet and patients' experiences cause some psychological problems in them. They usually experience fear, anxiety, and worry, which could be seen in health staff as well. According to the patients' quotes, the fear and nightmares caused by COVID-19 lead to a lack of sleep quality and peace of mind, which consequently result in a lack of immune system and susceptibility to the disease. Besides, the patients are stigmatized regarding being infected with COVID-19 from the onset of symptoms to the time of hospitalization by their relatives and friends. Accordingly, all these reactions have negative effects on the morale, health,

and treatment process of the patients. The results of the present study show that for most patients, this pandemic became a source of anxiety, and even some patients suffer from panic attacks due to this condition. Patients with panic attacks may also suffer from COVID-19 anxiety, feel short of breath, and have the disease. In some patients, this becomes a vicious cycle ruining their normal life.¹⁸⁻²⁰ In line with the results of the current study, horror, and stigma are directly related to each other, and labeling a patient with COVID-19 increases the patients' anxiety and fear, which consequently weakens the patient's immune system and makes their condition worse.²¹ The results of another study showed those who are sick or guarantined may experience shame, guilt, or stigma. Previous studies have also shown that the prevalence of psychological distress is associated with more extended quarantine periods. Patients also suffer from post-traumatic stress disorder and depression under this condition.²²

Bad Memories of Hospitalization

Hospital wards had become a real hell due to a large number of patients with different health conditions and inadequate personnel and facilities. The patients were not in good condition, some had a fever, and some were connected to artificial ventilators. In one bed a patient recovered from a heart attack, and in another bed, a dead patient was prepared for leaving the ward. In the entrance hall of the ward, which was crowded by many concerned companions, their cries indicated that their loved one had died. The stable conditions of hospitals are disrupted by the pandemic, the increased number of patients who need hospitalization, and inadequate facilities. Patients with COVID-19, who had mild symptoms at first, became ill within a few days and required intensive care, so they were transferred to ICUs. The limited space of the ICU is frightening for patients, and there are heartbreaking scenes of patients suffering to death that would have a bad effect on the other patients. These conditions represent a real hell, which is in line with the previous study.²³ The patients with COVID-19 are mostly afraid of the ICU due to the increased mortality rate, mechanical ventilation, cognitive impairment, long hospitalization time, and coma. These cause negative memory in the survivors' minds.24,25

Trust in God and Hope as Recovery Agents from COVID-19

Hope plays a crucial role in patients' recovery. In this regard, these patients should not be afraid of the disease, because positive thinking and increased morale strengthen their immune systems. As a consequence, the patients' general condition improves, and their resilience rises. The results of a previous study showed that training safety tips, isolating, and observing health tips are effective in preventing coronavirus, with hoping that patients will deal with COVID-19 in the best way.26 Patients with COVID-19 face many fears and psychological problems related to hospitalization and death. Hope is a positive inner force that can help patients face problems with a positive attitude and solve them. Hope is a crucial factor that can reduce the negative emotions felt under acute stressful situations and enable patients to cope with COVID-19 disease.^{27,28} Having hope when facing unknown and incurable diseases causes long-term, painstaking, and definitive treatment for these complications. On the other hand, at the early stages of life, patients mostly have a positive effect on their lives, and a greater tendency to identify the positive aspects of life and to provide opportunities for family members to enjoy their life-saving opportunities. Having a positive attitude toward life strengthens your immune system to overcome disease.^{26,29} As an inner being, hope is a rich life source. Patients with severe illness are powered to look beyond their current disorder as well as their pain and suffering.30

Reborn after Recovery from COVID-19

The patients infected with COVID-19 experienced death and life together. Some critically ill patients also experience comas. They do not remember that time, but after recovery, life has become more worthy, enjoyable, and energetic for them. Moreover, their faith and belief in God have increased after recovery. Several studies have previously shown that patients experience a new life with a different outlook and become stronger after a serious illness. They could better understand life and are more reminiscent of both God and spirituality. Patients' abilities for healing diminish during suffering, but after recovery, values emerge more, and patients experience pleasurable situations and feel re-living and reborn.³¹ Recovery from disease is the other side of life, which gives hope and growth. Recalling the threat of death or experiencing near death during a serious illness are new contexts in a life story. Returning to life is enjoyable when facing some memories such as the experience of near death.³²

Although focusing on only male participants could be a limitation, it is a strength as a gender-based research. The other limitations during performing this research include, First, only a limited number of patients who recovered from COVID-19 participated in the study. Second, due to the special circumstances of these patients, performing face-to-face interviews was impossible, thus these were conducted by telephone and additional notes. Therefore, we had difficulty related to receiving patient reflections. Besides, some recovered patients had fatigue and could not talk for a long-time, so only some key questions were asked of them.

Conclusion

The patients with COVID-19 have experienced variety of physical and psychosocial challenges. In the pandemic COVID-19, infected patients experienced variety of symptoms especially in the respiratory, musculoskeletal, and immune systems. The symptoms gradually manifested and were worsen that leading to death in some patients. Infection to COVID-19 is horrible and the infected people attempt to hide their disease due to stigma. A crowd of patients in hospitals, a high rate of mortality, and inadequate facilities, medicines, and nurses have remained the bad memorial of hospitalization for the infected patients. On the other hand, trust in God and hope were the boosting elements for recovery from COVID-19. Health care providers have to supply appropriate strategies to fulfill the infected patients needs in such a crisis.

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Research Highlights

What is the current knowledge?

It has been argued that awareness of the lived experiences of COVID-19 patients could be informative to health care decision makers to provide care/support to reduce the negative consequences of the patients infected with COVID-19.

What is new here?

Patients with COVID-19 have faced to physical and psychosocial challenges.

The more fear and anexiety of the disease the patients experience, the worse symptoms they face.

The infected patients experienced faster recovery by appealing to God and being hopeful.

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Competing Interests

The authors declare no conflict of interest in this study.

Data Accessibility

The datasets are available from the corresponding author upon reasonable request.

Ethical Approval

The Ethics Committee of Zabol University of Medical Sciences authorized the permission to conduct this study (ethical code: IR.ZBMU.REC.1399.021).

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