

Lived experiences of patients with COVID-19 infection: a phenomenology study

Ali-asghar Jesmi¹, Zohreh Mohammadzade-tabrizi², Mostafa Rad³, Elyas Hosseinzadeh-younesi⁴, Ali Pourhabib⁴

¹Department of Nursing, ²Department of Paramedic; Sabzevar University of Medical Sciences, Sabzevar, ³Department of Nursing, Nursing and Midwifery School, Iranian Research Centre on Healthy Aging, Sabzevar University of Medical Sciences, Sabzevar; ⁴Department of Nursing, Faculty of Nursing and Midwifery, Golestan University of Medical Sciences, Gorgan; Iran

ABSTRACT

Aim To describe experiences of patients with COVID-19 infection.

Methods This qualitative research was conducted using a phenomenological approach, and participants were selected via purposive sampling. In total, 14 patients with COVID-19 were selected (nine women and five men) aged 20-60 years. Data were collected via in-depth interviews with open questions and through observation. Data analysis was performed using Colizzi's phenomenological approach.

Results Three themes and nine categories were extracted; the main themes were mental strains, physical manifestations, and coping mechanisms. Mental strains entailed concerns, fears and isolation, on the other hand, physical manifestations comprised nervous, respiratory and gastrointestinal system, and systemic disorders. Coping mechanisms included religiosity and home remedies categories.

Conclusion Mental strains were the most important issues in the patients with COVID-19, which were interwoven with concerning physical manifestations. Most of the participants used self-medication and spiritual resources to cope with the disease. Therefore, it is recommended to carry out proper planning by healthcare personnel to psychologically and spiritually support these patients, while alleviating physical manifestations of the disease.

Key words: infection, coronavirus, qualitative research, nurses

Corresponding author:

Mostafa Rad
Department of Nursing,
Nursing and Midwifery School, Iranian
Research Centre on Healthy Aging,
Sabzevar University of Medical Sciences
Sabzevar, Iran
Phone: +98 5144018308;
Fax: +98 5144018322;
E-mail: radmostafa633@gmail.com
Ali-asghar Jesmi ORCID ID: <https://orcid.org/0000-0003-2671-9286>

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INTRODUCTION

Coronaviruses are a large group of viruses that cause mild respiratory infections (e.g. common cold), as well as severe illnesses, such as SARS and MERS (1). Recently, the virus has been known as COVID-19, and its outbreak began in December 2019 in Wuhan, China (2). COVID-19 easily spreads in some geographical regions that are infected with the virus. This local spread causes virus infection of the residents in the region, including those who are unsure how and when they have been infected (3). The World Health Organization (WHO) has confirmed COVID-19 in the regions such as Africa, America, East Mediterranean, Europe, Southeast Asia, and the Western Pacific (4). The symptoms of the virus infection vary from mild to extremely severe; the signs of the infection include fever, coughing, and difficulty breathing (5). Anxiety is a common sign in patients with chronic respiratory diseases, which could considerably affect their quality of life. In most cases, anxiety may give rise to physical issues that overlap with the symptoms of chronic respiratory disease and medication side effects (6). In addition, clinical anxiety affects two-thirds of the patients with chronic respiratory disease and may reduce their quality of life and physical performance. However, data are scarce regarding the experience of anxiety in the patients diagnosed with severe respiratory symptoms (7).

Currently, the trend of COVID-19 morbidity and mortality in Iran is distressing (8). Restrictions and deprivations due to international sanctions, the unknown nature of the disease, inefficient use of the information technology capacity to manage the public opinion, and lack of a multi-sectoral view of health have caused fear and emotional reactions in the society (9). Fard et al. in the study aimed to predict psychological health of patients based on anxiety and social solidarity caused by Corona in 2020, suggesting that the quarantine has had positive and negative psychological and social effects and practical implications for the formulation of crisis interventions during the Corona outbreak (10). On 4 February 2020, WHO declared the outbreak of COVID-19 as a public health emergency, recommending that the contact of people (especially patients and staff of healthcare departments) should be reduced to control the spread of the disease in the world. Un-

fortunately, personal distancing did not suffice, leading to the increased number of new cases of COVID-19 and showing the presence of a huge number of the ‘‘silent carriers’’ of the coronavirus in the community, which forced some regions to carry out full quarantine (e.g. China and Italy), or implement preventive care at the national level (Iran, the UAE, South Korea) in cities, provinces or even the whole country (11).

Despite positive consequences, the implementation of these health policies has been associated with negative psychological consequences at the community level (12). In fact, mental health of community members has been threatened due to fear of the disease, fear of mortality, publishing misinformation and rumours, interference with daily activities, regulations for the prohibition or restriction of travel and commute, decreased social relations (co-workers, friends, family), financial and occupational problems, and tens of other consequences in this situation (10).

Phenomenological methods allow researchers to assess internal aspects of the lived experiences of individuals. With a participatory design, these methods provide an opportunity for the participants to express their inner feelings narratively (13). Understanding the lived experience of patients with COVID-19 is of paramount importance to develop the perception of care. Phenomenological methods help improve the health and social consequences of the disease for the patients (15). Given the close contact of nurses with patients, one of the main responsibilities of nurses is to help decrease the patients’ concerns. As such, it is extremely crucial to recognize the problems and concerns of patients and their feeling about the disease.

The aim of this study was to evaluate the lived experience of patients with COVID-19 infection.

PATIENTS AND METHODS

Patients and study design

This qualitative research with descriptive phenomenology approach attempted to capture the essence of lived experience of patients with COVID-19 infection. The data were gathered through interactive interviews. Eight patients were interviewed face to face and six were interviewed by phone call. All interviews were simultaneously recorded by tape-recorder and transcribed

verbatim during the first 24 hours. Memos and field notes were used to enrich the interviews.

The purposive and snow ball sampling methods were used to invite participants for interviews. Participants were recruited from discharged patients from Sabzevar Vasei Hospital (a governmental COVID central hospital), Iran. Inclusion criteria were confirmed diagnosis of COVID-19 infection by a chest CT scan and PCR test, being 18 years old or older, being able to communicate and willing to share their experiences. A total of 14 participants, who had experienced severe disease conditions and passed the acute phase of the infection, were interviewed in this study. Nine of the participants (64%) were females, seven of them (57%) were housewives; the age range was 25-53 year.

The first participant was a faculty member. He was interviewed face to face in his workplace; seven of the participants were interviewed at Vasei Educational Centre, Sabzevar, Iran in a quiet room located outside the wards; six participants were interviewed by telephone due to disagreement with the face-to-face interview (the reason of their disagreement was fear of transmission of the infection to others or re-infection). Interviews were held between April 2020–July 2020, and lasted for 20-50 minutes with respect of participants' tolerance. All interviews were held by the first author. Data saturation was reached by 14 participants (Table 1).

Table 1. Characteristics of 14 participants

Ordinal number of the patient	Gender	Age	Job position	Marital status
	M	36	Faculty member	Married
	F	38	HW	Married
	F	50	Lab technician	Widow
	M	53	Nurse (infected)	Married
	F	43	HW	Married
	F	32	HW	Married
	F	50	HW	Married
	F	25	HW	Married
	F	26	Psychologist	Single
	F	43	HW	Married
	F	36	HW	Married
	M	29	Teacher	Married
	M	42	HW	Married
	M	25	Nurse (infected)	Single

F, female; M, male; HW, house wife

All ethical research codes such as the confidentiality of participants' identity, taking permission for audio recording of the interview and the right to withdraw from the study, were considered. All participants received required information about the purpose, method and ethical rights, and eight of them completed an informed consent. For the

participants who were interviewed by phone informed consents were gathered verbally. The study was approved by the Research Deputy and Research Ethics Committee of Sabzevar University of Medical Sciences (No 99030, Ethics Code: IR.MEDSAB.REC.1399.024).

Methods

A semi structured interview with open-ended questions was used for data collection. The participants were asked to describe their experience of involving with COVID-19 infection. Some of the questions were: Please describe your experience of infection with COVID-19. Can you describe your feelings when you were informed about your COVID test result? Compare your experience from COVID-19 infection with what the people and audiovisual media describe. Can you describe the experience of one day dealing with this disease? What comes to your mind when you hear the word COVID-19 infection? Which challenges did you experience with COVID-19 infection? What were your expectations from those around you? What comes to your mind when you think of a problem? The main questions probed to deepen participants' experiences: Could you please explain more? What do you mean? etc. Participants' nonverbal reactions were recorded by the interviewer and used in the data analysis.

All interviews were recorded by voice recorder and listened by the researcher many times for deep involvement. On the same day, the interviewer transcribed the tape recording verbatim and reviewed it frequently with frequent stops. Questions were added or revised according to emerging information during the review process. Members of the team then revised the text of the transcript. Interviews were continued until no new themes emerged. The Colaizzi phenomenological approach was used for data analysis, including seven steps: 1) read all the patients' descriptions about COVID-19 Infection, 2) extract significant statements, 3) formulate the same meaning statements, 4) categorize the classified meanings into clusters of themes, 5) integrate the findings into an exhaustive description of the phenomenon COVID-19 infection, 6) return the descriptions to some patients to assess how they compare with their experiences, and 7) correct suggested changes in the final description of the essence of the phenomenon (11). One note software was used for the data analysis.

Trustworthiness of this study was based on Lincoln and Guba's evaluative criteria (15). Credibility is one of the most important criteria for establishing trustworthiness. Results are credible when the phenomenon under the study was recognized by participants and experts and it reflects their personal experience. The authenticity criterion refers to the fact that results must be in line with or reflect the experiences described and lived by participants. With the aim of meeting these criteria, the principal investigator used bracketing, read the interviews many times over, went back and forth between the data collection and analysis, reached data saturation, used peer reviewing and held debriefing sessions with other authors regarding the data collected, analysis and interpretation. In order to authenticate the data a member check was used. In the member check, the interview codes were returned to eight participants, and they verified the codes extracted by the researcher.

RESULTS

In total, 406 initial codes were extracted. The combination of similar meaning and concept codes led to the remaining 230 initial codes. Afterwards, the initial codes were classified into subcategories based on meaning and conceptual similarity. Overall, 31 subcategories were formed, subsequently they made 9 categories, and finally three themes included mental strains, physical manifestation, and coping mechanisms emerging from the data analysis (Table 2).

Table 2. Themes and sub-themes that emerged from data analysis

Themes	Categories	Subcategories	
Mental strain	Concerns	Worsening of the symptoms	
		Losing the job position	
		Future of children	
		Persisting complications	
Fears	Isolation	Fear of death, Fear of dependence	
		Loneliness, Boredom	
Physical manifestations	Nervous system disorder	Headache, Impaired sense of smell and taste, Dizziness, Insomnia, Nightmare	
		Respiratory system disorder	Coughing, Dyspnoea, Shortness of breath, Chest burning, Throat ache
	Gastrointestinal disorders	Systemic disorders	Loss of appetite, Nausea, and Vomiting, Diarrhoea, Constipation.
			Fever, Chills, Weakness, Myalgia, Illness
Coping mechanisms	Religiosity	Religious activities	
		Religious beliefs	
	Home remedies	Family support	
		Complementary therapies	

Mental strain

The mental strains reported by the participants were divided into three categories of concerns, fears and isolation.

Concerns. The majority of the participants reported similar concerns, such as worrying about the deterioration of the symptoms, losing the job position, future of children, persisting complications, and disease disclosure.

One of the most common concerns among the participants was worrying about the deterioration of the symptoms. The majority of the participants were concerned about the deterioration of their own and their family members' symptoms, especially shortness of breath. These concerns led to anxiety and tension and increased sleep disorders in the participants (e.g. insomnia and nightmares). For example, participant number six claimed, "I was constantly worrying about the changing symptoms, especially since my mother had the disease at the same time as me. I was more worried about her and checked up on her frequently. I constantly asked her about her breathing and whether she was experiencing shortness of breath. I was particularly concerned about her because she has hypertension" (6th participant). Another participant mentioned, "I constantly thought about my breathing becoming worse. I would take frequent deep breaths to see whether I can breathe easily" (1st participant).

One of the concerns of the participants (especially the males) was the loss of their job, which was more evident in those who were self-employed or had no job security. In this regard, participant number nine expressed, "One of my major concerns during the quarantine was the fear of the lack of improvement and inability to return to work, which would create economic issues for my family. This is most concerning because of the current situation of the country. My wife was very comforting though" (9th participant).

Another concern mentioned by some of the female participants was worrying about the future of their children. The participants were concerned about this issue mostly because of their fear of death. For example, participant number eight remarked, "I always wondered what would happen to my children if I died. Sometimes I cried and was very worried about them." (7th participant)

One of the major concerns of the participants was the lack of improvement and fear of persistent complications for life. In this respect, one of the participants stated, "I always thought that I would not get better, especially in the first days, I was so busy thinking that I even had a panic attack" (6th participant).

Some of the participants expressed concern about the disclosure of the disease to their relatives and family members and were reluctant to inform them about the disease. The main reason for this subject was avoiding others and not making close relatives such as parents worried. In this regard, one of the participants remarked, "We did not inform our neighbours in the building and even the family members in order not to make them anxious" (4th participant).

Fear. The main fear of the majority of the participants was fear of death and dependence. The participants viewed daily media reports of deaths and shortness of breath as the main causes of escalating tensions and fears.

One of the common symptoms of the disease as reported by the participants was shortness of breath, which caused a sense of impending doom. For instance, one of the participants stated, "...I was always afraid that I would die, especially when I was hospitalized and experiencing severe shortness of breath" (13th participant).

One of the issues mentioned by some participants was fear of disability and dependence on other family members (spouse and children), which was due to the weakness and inability of the patients to meet their basic needs. In this respect, one of the participants stated, "I was always worried that the disease would be permanent. I would not be able to take care of my personal affairs, and my spouse would be forced to take care of me. I was really sick at the time and very weak" (3rd participant).

Isolation. This category comprises of social isolation and mood declining.

Most participants experienced feeling of loneliness in the period of the disease. The main reason for this subject was quarantining at home to prevent transmission of the disease to others, avoiding others, even relatives, from the patient and mental pressures. For example, one of the participants said, "When I was quarantined at

home even my children avoided me because of fear of transmission. I spend two full weeks in a room and just my wife fed me. Nobody came to our home. Even neighbours avoided my wife and children. It really bothered me" (5th participant).

Another issue raised by the participants was their boredom over house quarantine. They spent the time watching TV, listening to music, studying, saying prayers, sleeping or chatting with friends. One of the participants stated, "Sometimes I didn't know what I can do. I was quarantined in a room. I was really boarded. I wished to get released from that situation, sometimes I prayed for gaining my health again and leaving the house" (9th participant).

Physical manifestations

Various forms of physical manifestations were expressed by the participants. The virus had attacked several body systems of the patients, and the physical manifestations included nervous system, respiratory system, gastrointestinal, and systemic manifestations.

Nervous system disorders. These manifestations were among the early symptoms of the disease in most patients, and the main cause of referral to medical centres was reported to be neurological manifestations such as headache, impaired sense of smell and taste, insomnia, and nightmares. However, the most common nervous system manifestation was headache, which was reported in the range of mild to extremely severe pain. In this regard, one of the participants stated, "I had extreme headache, and I had never experienced these symptoms in my life. I visited a physician primarily due to headache that had become intolerable" (1st participant). One of the manifestations reported by the participants during the peak period of the disease was the loss of the sense of smell and taste, and intensification of the sense of smell in some cases. Some of the participants considered this disorder to be the cause of their loss of appetite. For instance, one of them mentioned, "My condition deteriorated after experiencing shortness of breath. I lost my sense of taste but had an intensified sense of smell. For instance, the smell of oil would make me nauseous" (3rd participant). In addition, some of the participants experienced sleep disorders (e.g. insomnia and nightmares) in the acute period of the disease. Some participants

attributed this to anxiety and mental stress during the illness, while others attributed it to the rise of the body temperature. For instance, one of the participants affirmed, "I had nightmares at night, I do not know why. I did not have stress at all before the symptoms started, but when my symptoms became severe, I had nightmares. One of the frequent nightmares was that I transmitted the disease to my parents" (8th participant).

Respiratory system disorders. Respiratory disorders were the most important cause of referral to medical centres and patient hospitalization. In this regard, the patients mostly complained of issues such as coughing, shortness of breath, chest pain, and sore throat. The disorder was mild in some cases, and the patients had no complaint of respiratory problems. Nevertheless, the main complaint of some of the patients was respiratory disorder symptoms. In this respect, one of the subjects expressed, "I was choking and could not breathe easily. I felt extreme aching in the chest area and had difficulty breathing" (9th participant).

Gastrointestinal disorders. Another common complaint among the participants was gastrointestinal problems, including the loss of appetite, nausea and vomiting, diarrhoea and constipation. For instance, one of the subjects claimed, "I wanted to eat but could not, as if something was blocking the path to my stomach and intestines. My wife would open my mouth and my mother would pour a spoonful of soup into my mouth. I felt like I was eating poison" (1st participant).

Systemic manifestations. Systemic manifestations were also common among the participants, which affected their daily activities and led to their dependence on the family members to meet their basic needs. In this regard, some of the common systematic manifestations included fever, chills, weakness and lethargy, myalgia, boredom, and muscles were jelly. "I could not stand on my feet and felt extreme pain in my arms and legs" (14th participant).

Coping mechanisms

The participants applied different mechanisms to address the challenges of this infection. These mechanisms were divided into two categories of religiosity and home remedies.

Religiosity. Several participants used religiosity as a mechanism to reduce their tensions and

worries. These categories comprised of religious activities and beliefs.

Two main activities reported by the participants included praying and reading the Quran that is rooted in the Muslim cultural and social context. In this regard, one of the participants who was pregnant asserted, "I read the Quran, prayed and asked God that this infection was not transmitted to my son (foetus). It really makes me calm" (11th participant).

The participants disclosed their beliefs upon God and appeals to him magnified in the period of illness; nearly all participants declared this subject increased their energy and gave them hope for recovery. For example, participant number five said, "When I was ill I could really hardly breathe. God helped me and declined my anxiety. It was not predictable, I might have died. Thank God I survived. It's a miracle." (1st participant)

Home remedies. Most patients used several methods at home to reduce the symptoms of the disease. Most of these remedies were taken to alleviate the systemic symptoms of the disease such as fever, chills, and myalgia, as well as to reduce respiratory symptoms such as throat ache and shortness of breath. These categories included complementary therapies and family support.

Consuming supplements such as vitamins, eating soup, herbal tea were common complementary therapies that participants did for strengthening their physical condition. They believed that these therapies were effective for regaining their lost energy. For example, participant number six said, "I lost my appetite, lost my weight and got truly weak. My husband made soup for me; I would eat only four or five spoons. It was really effective. For my throat ache the doctor recommended eucalyptus incense. It was effective too" (6th participant).

One of the important and effective factors in the recovery of patients was the care of relatives such as spouse, parents and children help reducing the symptoms of the disease. These actions include both physical and mental care. Participants disclosed that without family support surviving was very hard. One of the participants stated, "Without my wife's support and care, I could have hardly survived. She gave me hope when I was really disappointed. She fed me patiently and when I was suffering from fever she applied wet sponge frequently to my forehead and feet for

declining my body temperature. I owe my recovery to my wife” (1st participant).

DISCUSSION

In the present study, most of the participants suffered from psychological strains such as fear, concern, and anxiety about the disease. The fear of death, dependence, deterioration of symptoms, and transmission of the disease to family members were the most common psychological issues reported by the participants. In this regard, the results of several studies conducted on patients with COVID-19 in China during the outbreak of the infection were indicative of the high prevalence of psychological disorders such as anxiety, fear, depression, emotional changes, and insomnia (16,17). Some of the most important influential factors in the psychological health of individuals infected with the virus were an unbridled surge in the spread of the virus, unfavourable status of the patients isolated in the ICU with acute respiratory problems, lack of an effective treatment for the disease, and mortality due to the disease (18,19). Home quarantine was another issue that might have caused psychological disorders in the patients. Overall, the studies assessing the psychological disorders of quarantined individuals have denoted several signs of psychological damage such as emotional distress, depression, stress, mood fluctuation, irritability, insomnia, decreased attention, post-traumatic stress disorder (PTSD), anger, and emotional instability (20,21).

According to the results of the present study, the patients with COVID-19 infection had a low psychological capacity and experienced psychological disorders (e.g. anxiety, fear, depression, and negative thoughts) due to the current status of the disease in the world. Sleep disorders were another issue in these patients, which might occur in isolated wards or during the quarantine. The results of a study performed in China during the outbreak of the virus in Wuhan indicated an extreme decrease in the sleep quality of the patients infected with the virus (22). Meanwhile, it seems that some of the influential factors in the occurrence of psychological symptoms in the general public could be linked to the concerns about the risk of the disease, future employment status, and sources of income for individuals and families, as well as long periods of home qua-

rantine. In the current research, the participants expressed their concerns in this regard as well. Since the psychological symptoms are common in these patients, it is recommended that health care providers pay special attention to this dimension of this new emerging disease (2). It seems that in some cases this aspect is dominant to physical dimension and needs medical intervention (4). The clinical manifestations of the disease are not clear, and the disorders related to the disease vary from mild to severe (23). Several physical issues were reported by the participants in the present study in addition to the psychological aspects of the disease. In this regard, some of the most common physical issues were fever and coughing. In the studies by Shi et al., Tian et al., and Song et al., the prevalence of fever and coughing was reported to be 72.8% and 59.2%, 82% and 47.8%, and 96% and 47%, respectively (24-26). In this systemic manifestation, fever, weakness and myalgia were common among our participants; in addition, the most common manifestations of the disease in the presented research included myalgia, fatigue, pneumonia, and shortness of breath. However, the lower prevalence of symptoms such as headache, diarrhoea, and a runny nose has also been reported (27), which is consistent with our findings. In our study, in order to alleviate these symptoms most of the participants took measures such as gargling salt water, drinking herbal teas, eating soups, and taking wet sponge. Furthermore, the patients used various strategies to cope with the disease and alleviate their concerns, the most important of which was religious activities such as praying. Several studies have confirmed the positive effects of religious activities on the improvement of the mental and psychological status of various patients. For example, Nadeem et al. referred to religion as an alleviator of stress, anxiety, and depression (28). In another research by Chong et al. religious activities were reported to decrease internal conflicts in cancer patients (29). Moreover, Lee et al. reported a significant decrease in the anxiety and depression of patients with seizures through religious activities (30).

In conclusion, the patients with COVID-19 infection experienced various challenges such as clinical manifestations and mental strains that ranged from mild to severe depending on the pa-

tients' conditions. Furthermore, most of the patients used spiritual strategies to reduce these strains. They applied home remedies concomitant with medical prescriptions in order to alleviate their clinical symptoms. Since psychological symptoms are common in these patients, it is recommended to seek help from a psychotherapist in treating these patients.

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