Evidence Based Care Journal
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The online version of this article can be found at
http://ebcj.mums.ac.ir/article_18383.html

Evidence Based Care Journal 2021 11: 44 originally published online 04 July 2021
DOI: 10.22038/ebcj.2021.57471.2499

Online ISSN: 2008-370X

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Evidence Based Care Journal

Original Article

OPEN ACCESS JOURNALS

Patients' Experiences of Living with Coronavirus Disease 2019: A Qualitative Study

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Received: 08/05/2021
Accepted: 04/07/2021

Evidence Based Care Journal, 11 (1): 44-50

Abstract

Background: The emergence of this coronavirus disease 2019 (COVID-19) is now a public health crisis that leads to various challenges. There is a significant scientific gap in this field, including the necessity of updating the definitions and information about this disease. This disease causes a lot of physical and psychological problems and leads to changes in and reduced quality of life. However, one of the definitive pieces of data about this disease is human-to-human transmission and its very high prevalence, which itself carries certain social and psychological risks.

Aim: This study aimed to explore patients' experiences of living with COVID-19.

Method: The present qualitative study was conducted based on a conventional content analysis method. The statistical population of this study (n=17) consisted of recovered patients from COVID-19 with a history of admission to the intensive care unit of Afzalipour Hospital in Kerman, Iran, selected using a purposive sampling method. The data were collected through semi-structured interviews and analyzed using the qualitative content analysis method proposed by Graneheim and Lundman.

Results: Data collection and analysis led to the determination of 1 theme, 4 categories, and 18 subcategories. The theme was identified as "Coronavirus as a prison of time" and the categories were "behavioral challenges", "human flourishing", negative emotions", and "psychological distress in quarantine".

Implications for Practice: Study participants had both positive and negative experiences. The results of this study can help healthcare providers to identify the needs of these patients and design a care model for these patients.

Keywords: Content analysis, COVID-19, Coronavirus, Pandemic, Qualitative study

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Introduction

Coronavirus is one of the common pathogens between humans and animals, which has been the cause of various respiratory diseases (1). In December 2019, a new type of coronavirus (coronavirus disease 2019 [COVID-19]) caused an acute respiratory disease that spread from Hubei Province, Wuhan City, China, and reached to all countries after a short time and caused a lot of deaths all over the world (2). Iran was also one of the countries that were infected with this virus, with the first cases of the virus being discovered on February 19 (3).

Patients with COVID-19 have mild to severe respiratory and non-respiratory symptoms. Due to the high risk of transmission of the disease, patients with COVID-19 need isolation, which can lead to severe mental problems and distress (4). Patients with COVID-19 experience severe physical and psychological crises even in the post-hospital period, which is similar to other pandemics, such as Severe acute respiratory syndrome (SARS) and Middle East respiratory syndrome (MERS) (5). Since the outbreak of COVID-19, studies have been conducted on the clinical aspects of the disease and the patients' experiences and psychological status (6, 7).

The results of studies showed that in addition to physical problems, these patients experience such problems as anger, guilt, shame, anxiety, stigma, ambiguity, fear of death, or fear of transmitting the disease to others and family members (8-10). These issues highlight the importance of the need to develop the knowledge of the health dimensions of patients with COVID-19 (11). One of the ways to achieve the mentioned goal is to know and understand the experiences of these patients (4); in other words, knowing the experiences of these patients and understanding the problems caused by COVID in these patients during the involvement of patients with this disease and after this crisis can be effective in expanding knowledge on how to better deal with this disease in the future and improve preparedness and reduce potential problems (12).

The identification and revelation of the experiences of COVID-19 patients can guide healthy people in the community to better protect themselves or maintain the quarantine. Additionally, the medical staff can use these measures to better help COVID-19 patients recognize their feelings or the strategies they adopt to fight the disease and help other patients by reporting these strategies. Therefore, the present study aimed to explain patient's experience of living with COVID-19

Methods

The present qualitative study was conducted using a conventional content analysis approach. Qualitative research methods seek to discover and understand the inner world of individuals, and since experiences constitute the structure of truth for each individual, the researcher can only discover the meaning of phenomena from their point of view by entering the world of individual experiences (13). The statistical population of this study (n=17) consisted of patients recovered from COVID-19 with a history of admission to the intensive care unit (ICU) of Afzalipour Hospital in Kerman, Iran. The participants had been quarantined for 2 weeks after being discharged from the hospital. After discharge, patients were transferred to a convalescent home coordinated by the hospital. Since the patients admitted to the ICU were not in good physical and mental condition for the interview, the interviews were conducted immediately after the end of the quarantine period. The inclusion criteria were having a history of admission to the ICU due to COVID-19, ability to speak Persian, negative serological test after quarantine without COVID-19 complications (e.g., weakness, shortness of breath, and cough); and being willing to participate in the study. On the other hand, the patients who used mechanical ventilation and sedatives during hospitalization were excluded from the study. The samples were selected by a purposive sampling method. Semi-structured interviews and field notes were used to collect data. The participants provided their verbal and written consent forms, and then, determined the place and time of the interview. The subjects were informed of the possibility of study withdrawal at any research stage. The interview guide questions were as follows:

"Please tell us about your illness and symptoms? What happened when you were hospitalized? What experiences have you had with COVID-19? Could you please talk about your experiences with the disease?"

During the interview, probing questions, such as "Can you explain more? and Can you give an example", were also used to extract more details or explanations. All interviews were audiotaped and transcribed verbatim on the same day. The duration of each interview varied between 60 and 90 min. A total of 18 interviews were conducted with 17 patients. If a patient was critically ill and did not feel

well mentally and physically, the interview was postponed to a later time when the patient was feeling well. All interviews were recorded in a quiet location, and they were conducted until data saturation was reached, meaning no new information was available from additional interview research. Maximum variance sampling was considered for gender, age, hospitalization length in the ICU, comorbidities, disease severity, treatment interventions, education level, and employment status.
At the same time as the interviews, the data were analyzed according to the method proposed by Granheim and Landman (14). At the end of each interview session, the researcher's audio file and notes were carefully transcribed. Recorded and transcribed interviews were read several times to ensure an in-depth and general understanding. The initial codes were extracted by a continuous comparison and then classified according to their similarities and differences. Data analysis was performed using Max-Q software (version 10). The quality and trustworthiness of the data were assessed using the criteria proposed by Guba and Lincoln (15). To ensure the credibility of the data, the interviewer's skills were improved using the interview guide and assistance and support of the members of the research team and conducting some pilot interviews to fully understand the subject. To increase the dependability of the extracted codes, the researchers had them reviewed by some participants and then revised them according to their views. Moreover, to ensure the conformability of the findings, they were peer-checked by experts and professors.

Results

In this study, 8 and 9 participants were female and male, respectively. The participants' age ranged from 28 to 80 years with a mean score of 42.25±1.37 years and their education ranged from illiterate to master degree. The mean length of hospital stay in the ICU was obtained at 12.70±2.41 days. More than 60% of patients experienced involvement of one lung, while the rest of them experienced involvement of both lungs. Non-invasive mechanical ventilation and oxygen reservoir bag-mask were used for 58% and 42% of patients, respectively. Furthermore, eight patients reported a history of such problems as diabetes, high blood pressure, and respiratory problems.
Data collection and analysis led to the determination of 1 theme, 4 categories, and 18 subcategories. The theme was identified as "coronavirus as a prison of time" and the categories were recognized as "behavioral challenges", "human flourishing", "negative emotions", and "psychological distress in quarantine".

Behavioral challenges

The first identified category from the participants' experiences was behavioral challenges. This

Table 1. Theme, categories, and subcategories extracted from COVID-19 patients' experiences (n=17)

Subcategories	Categories	Theme
Social stigma Family challenges Social media challenges Social judgment	Behavioral challenges	Coronavirus as a prison of time
Communication with yourself Personal relationship with God Astonishing lesson in gratitude	Human flourishing	
Economic concerns Fear of death Fear of job loss Vague fears Fear of infecting other family members	Negative emotions	
Depression Anxiety Feeling hopeless Isolation and withdrawal from others Loneliness Ambiguity of quarantine duration	Psychological distress in quarantine	

category included some subcategories, such as social stigma, social judgment, social media challenges, and family challenges. The participants considered the community members' attitudes toward patients with coronavirus disease one of the factors affecting these patients. According to them, the people's misconceptions about COVID-19, the individuals' wrong judgments of society, the stigma and taboo of being the coronavirus-stricken, and the people's lack of knowledge about coronavirus disease caused discomfort and resentment to these patients. This made the patients hide their illness from others and prevent themselves from being judged by others. According to one of the participants: "*...Some people think those with COVID-19 are very dangerous. This attitude makes patients angry. Some even don't call patients. Maybe they think they get infected on the phone*" (Participant 9).

Additionally, the participants believed that media and online social networks make the public terrified of the coronavirus disease. Although there are many effective training programs offered by media to raise public awareness, false news and unreliable videos have led to increased fear and stress in the community. One of the participants stated, "*…The media has frightened most people. It's true that the coronavirus is a serious infectious disease, but they are better to provide training on prevention methods rather than scaring people. The coronavirus disease does not kill everyone, but they are always repeating that it has killed so many people*" (Participant 6).

Human flourishing

The analysis of the experiences of patients with COVID-19 showed that these people went through some changes and developments in their life since they were affected by the disease. This category included subcategories, such as communication with yourself, personal relationship with God, and an astonishing lesson in gratitude. Among some of the experiences reported by the patients with COVID-19 were feeling the divine presence more frequently in life, deciding to change behavior, and expressing more love to others after illness, feeling closer to death after developing the disease, understanding the value of every single moment of life and appreciating one's health, looking positively into the future, and exposing oneself to less stress. One of the participants stated, "*…Now I realize how worthless life is. I'm trying to live better and have a happier life. I try not to fret about unimportant things and appreciate others more than before*" (Participant 12). Another participant stated, "*…I have been closer to God since I became ill. I pray more frequently because the coronavirus is a deadly disease and makes one feel closer to God*" (Participant 4).

Negative emotions

This category included such subcategories as economic concerns, fear of death, fear of job loss, vague fears, and fear of infecting other family members. The exploration of the patients' experiences showed that they had a lot of preoccupations and worries after developing the disease, including how long the disease lasts and how long they are safe from re-infection, how the disease has made them weak and vulnerable to other diseases, concerns about the persistence of the disease in the lungs and their lung dysfunction after a partial recovery, and concerns about the uncertain future waiting for them. The patients were also concerned about the possibility that their children and older family members would be infected with the disease after discharge. For example, one participant stated, "*…They say the disease has almost permanent side effects on the lungs and the body becomes weaker and more prone to the disease and the lungs are involved. The idea that I can't have a normal life after the disease is very stressful for me*" (Participant 5).

The participants also stated that they had economic concerns following post-illness disability, lack of adequate income, and having to pay treatment costs. Anxiety about their career future and unemployment had increased patients' worries. One of the participants stated, "*...Not only do I have to worry about my treatment expenses, but I also worry about my job. I work as a contractual employee and I am afraid they will fire me. I found this job with difficulty. This is as painful for me as the disease itself. I was very depressed. They say the immune system must be strong but how it is possible with all this stress and worry"* (Participant 10).

Psychological Distress in Quarantine

One of the most important categories revealed in the present study was related to the quarantine period and patients' experiences during this period. This category included the subcategories of

depression, anxiety, feeling hopeless, isolation and withdrawal from others, loneliness, and ambiguity of quarantine duration.

The patients had little or no communication with others at the time of hospitalization, after discharge, and during the recovery process at a convalescent home. In many cases, the emotions were negative and people felt lonely, depressed, not being with family and children, confined, dying alone, and lacking a companion. In a few cases, people considered quarantine a relief and were sure that they would not pollute others in this way. Moreover, some patients preferred quarantine in the hospital and convalescent home due to the presence of other patients and being entertained and talking. One of the participants stated, "…*When the coronavirus symptoms started and I was suspicious of the disease, my daughters and my wife left me alone and went to their relatives' home. At that time, I realized how terribly I was lonely and I had no one with me in this life. Loneliness is the worst torment I have ever suffered from*" (Participant 11).

The participants also pointed to the sense of meaninglessness, absurdity, and hopelessness they experienced when being alone in quarantine. They believed that life was completely meaningless and time did not move forward, rather was fixed at one point. One of the participants stated, "…*I really feel like I'm living aimlessly. My life is completely messed up and I'm really dying. I'm depressed, I've quitted everything, and nothing comforts me anymore*" (Participant 15).

Most of the participants stated that they were missing their family during the quarantine period and were concerned about not knowing about the family and not seeing them, "…*I just had to see them. I wish I could see them from behind the window. It can calm me down a bit*" (Participant 7).

Discussion

The present study aimed to explore the experiences of patients with COVID-19. Patients experienced behavioral challenges, negative emotions, and psychological distress during the quarantine period. With the outbreak of this disease, patients experience various negative emotions, including anxiety about the judgment and reaction of people in society. (16). The patients in the present study expressed dissatisfaction with the coronavirus label (social stigma), false beliefs, people's attitudes in the community, false news, rumor spread, family blame, and false propaganda. The World Health Organization(WHO) said, we know that a kind of information tsunami occurs with the outbreak of a disease, and this information always includes incorrect, unscientific information and rumors (17).

Farahani (2020) studied changes in individual and cultural attitudes, beliefs, and values during the COVID-19 pandemic and stated that the attitudes, beliefs, and values of human beings could shape the perception of people about the COVID-19 pandemic leading to individual and public fear of the disease (18). The patients in the present study pointed to the media as a cause of fear and anxiety in the community. Nourisaeed et al. (2020) compared online health information utilization, online shared identity, and online shared information usage in different levels of COVID-19 anxiety and showed that people with high levels of COVID-19 anxiety scored higher in terms of online health information utilization (19). Negative attitudes and judgments and blame not only harm patients and their relatives but also can be an obstacle to effective control of the disease.

The participants in the present study stated that COVID-19 disease had some positive effects in their life, in addition to negative effects. The present study showed spiritual and religious experiences as a powerful source of adaptation, optimism, gratitude, and hope. Musapur et al. (2020) examined spiritual and existential growth and the COVID-19 pandemic (20). Spirituality helps patients cope better with their illness and suffer less from the negative emotions and pressures of the illness and its effects (21). Religious and spiritual experiences in different ways lead to the creation of a positive mental atmosphere in patients, which results in a reduction in pain and redefinition of the phenomenon of death (10).

The third category that was found in this study was related to negative emotions. At present, due to the unknown nature of this disease and insufficient knowledge about it, patients experience a lot of fear and stress. The results of several studies conducted on patients with COVID-19 in China during the spread of the disease reported a high percentage of psychological disorders, including anxiety, fear, emotional changes, insomnia, and post-traumatic stress disorder, among patients (22). Eisazadeh et al. also pointed to COVID-19-related psychological consequences, such as stress and anxiety, guilt and anger, job worries, and unpredictable future, as well as the fear of death and the disease

development by other family members (23). The results of other studies also indicated that the most important psychological stress in patients with COVID-19 was the fear of imminent death, aggravation of symptoms and complications, and recurrence and unpredictability (4, 24). A patient with COVID-19 enters the hospital with the ambiguity of death or survival. These patients imagine a funeral ceremony that takes place without the presence of family and relatives and contrary to religious expectations and beliefs. All of the above issues disrupt the patient's expectations and perceptions of a good death.

The fourth category found in this study was psychological distress in quarantine. In addition to the long-term symptoms of the disease, which cause psychological and physical disturbances in the person with COVID-19, the experience of quarantine causes a feeling of loneliness in the patient due to limited human relationships. Rahmatinejad et al. also referred to the emotions caused by quarantine in patients with COVID-19. Painful emotional experiences in such patients can lead to delays and difficulties in the recovery process and experience of the pain of the disease; moreover, it imposes psychological suffering on the patients (10). According to Eisazadeh et al., the social consequences of coronavirus disease develop easily. The transmission of the coronavirus from one person to another and even through objects and surfaces cause patients to be separated from others and significantly reduce his/her social participation (23).

This study showed that patients' experiences of living with coronavirus disease were highly unique. Issues that strongly affect the psychological condition of patients include publishing false news and claims and feeling fear of death, social stigma, living in quarantine, and its consequences, all of which can disturb the recovery process. Therefore, the recognition of the experiences, social problems, and psychological disorders of these patients is necessary to develop and implement effective and targeted programs and solutions to maintain the mental health of patients and prevent further psychological and social consequences of the coronavirus disease. The present study was performed to explain the experiences of patients with COVID-19 with a history of ICU hospitalization in one of the cities of Iran. It is suggested to perform further studies in different medical centers to increase the generalizability of the findings.

Implications for Practice

Study participants had both positive and negative experiences. The results of this study can help healthcare providers to identify the needs of these patients, including psychological, social, and spiritual needs, and design a care model for these patients.

Acknowledgments

The authors would like to appreciate all the patients and the staff of Afzalipour Hospital who cooperated in this research. The present study was approved by the Ethics Committee of the Vice Chancellor for Research and Technology of Kerman University of Medical Sciences, Kerman, Iran (IR.KMU.REC.1399.178). The assigned number of the research was 99000061.

Conflicts of Interest

The authors declare that there is no conflict of interest.

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