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ORIGINAL ARTICLE

Life Experiences of Individuals with Covid-19: A Qualitative Study

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Introduction

Diseases caused directly or indirectly by small organisms such as bacteria, viruses, parasites, and fungi, which can easily spread from one person to another, are called infectious diseases [1]. One of the natural disasters that threaten the life of mankind is undoubtedly epidemics caused by infectious diseases. Over the course of history, epidemics have profoundly affected individuals, states, economy and societies and paralyzed social life [2]. With the emergence of a new coronavirus called SARS-CoV-2 in late 2019, this unprecedented viral pneumonia outbreak caused worldwide concern [3]. On January 30, 2020, the World Health Organization (WHO) declared that this new type of coronavirus outbreak with unknown etiology was an international public health emergency, and on February 11, 2020, the disease was officially named Coronavirus Disease-2019 (COVID-19) and the agent was named SARS-CoV-2 [4].

COVID-19 infection physically threatens the integrity of the body and affects a person's mental health, social, work, and economic life [5,6]. While adapting to this new period with the pandemic, uncertainties, fear of transmission of the disease, anxiety about losing loved ones, social isolation, panic-purchase of necessities, and concerns about unsafe living environments led to a global atmosphere of anxiety and depression, resulting in behavioral problems and communication difficulties [7-9].

COVID-19 patients were isolated from the normal course of life while being treated in hospital, temporarily resided in an artificial environment and suffered from disconnected relationships due to limited contact with their loved ones. In a study conducted in China, people diagnosed with COVID-19 and treated in COVID-19 services reported experiences such as stress, mental anguish, internalized stigma, guilt of infecting loved ones, shame of infecting others, and anger towards themselves [10]. In addition to the problems created by the pandemic, stigmatization of COVID-19 patients increases the risk of psychopathology [11]. Public health strategies such as forced isolation and social distancing lead to an increased sense of loneliness. This in turn leads to depressive symptoms, stress-related disorders, sleep disorders and mental coping problems that can result in suicide [12]. In his study, Guo, et al. [13] reported that coping styles were associated with mental health problems associated with COVID-19, and problem-oriented coping relieved individuals' symptoms of post-traumatic stress, depression and insomnia. In his study, Epstein, et al. [14] noted that long-term behavioral changes occurred in patients infected with a potentially deadly virus, and reported that some hospitalized patients attempted suicide due to fear, loneliness and anger.

Studies on COVID-19 have mostly focused on the experiences of health workers [15,16]. When the literature on the subject is examined, there are qualitative studies examining the experiences of COVID-19 patients in different countries [17,18], but qualitative study conducted with COVID-19 patients

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in Turkey is limited [19]. Therefore, the present study was conducted to provide detailed information about the life experiences of individuals with COVID-19, to examine, explore and identify the reflections of the disease on patients in detail. The research was carried out in order to obtain detailed information about the life experiences of individuals who were COVID-19 positive and receiving inpatient treatment at the time of the study, and to examine, explore and identify the reflections of the disease on the patient in detail.

Methods

Study population and sample

This qualitative study was designed with the descriptive phenomenological research pattern. Phenomenology examines how individuals make sense of the world. The aim of phenomenological research is to focus on participants' lived experiences. Study population consisted of COVID-19 patients receiving inpatient treatment in a pandemic hospital in eastern Turkey between July 2021 and January 2022. This study was performed according to the Consolidated crieteria for Reportig Qualitative Research (COREQ) (See Supporting information File S1).

Purposeful sampling was used in this research and attention was paid to include people with knowledge and experience about the research question in the sample. Furthermore, instead of increasing the sample size, the focus was to ensure that the selected sample would answer the research questions. In order to ensure diversity in the research, patients who were hospitalized due to COVID-19 and patients who were discharged after COVID-19 treatment were included in the research.

In the literature, it is stated that it is important in qualitative studies to select the sample size according to the method used in data collection and that a sample of approximately 30 people are sufficient in in-depth individual interviews [20,21]. In addition, the concept of data saturation, which refers to the point where answers become repetitive, is also considered an important criterion for determining the number of participants in qualitative research [21]. The study was completed with 22 participants after data saturation. Study sample consisted of 10 COVID-19 patients receiving inpatient treatment and 12 discharged patients. None of the selected participants dropped out of the study. Of the 22 COVID-19 patients included in the study, 50% were women and 50% were men. Mean age was 41.81 ± 14.99 years (range 22 to 70), 63.7% were married, and 63.7% had children. 36.3% of the participants were university graduates, 36.3% were high school graduates, and 27.4% were elementary school graduates. Inclusion criteria were determined as follows: Being over 18 years of age, having no communication problems, having been diagnosed with COVID-19, receiving at least 10 days of hospital treatment with a positive diagnosis of COVID-19, having a mobile phone, and volunteering to participate in the study.

Data collection tools

In the present study, the data were collected using "Personal Information Form" containing socio-demographic information and "Semi-Structured Interview Form".

Personal information form

This form consists of questions about personal information of the participants (age, gender, marital status, children, education level, and income status).

Semi-structured interview form

The interview form consists of 8 questions prepared in accordance with the relevant literature with the aim of conducting an in-depth interview to reveal the experiences of the patients on the subject [15,16]. After a comprehensive literature review of the research subject, a conceptual framework for interview questions was determined. When creating the interview form, attention was paid so that questions were fluent and easy to understand, and leading questions were avoided. Opinions were obtained from 10 experts on qualitative research methods to assess the reliability of the "Interview Form". Questions were then revised in line with expert opinions.

Pilot study

As a pilot study, the draft form prepared as a result of literature review and expert opinions was applied to 3 patients receiving COVID-19 treatment in the hospital. Based on the results of the pilot study, the questions that were not understood correctly were further revised and necessary questions were added to the interview form. The patients included in the pilot study were not included in the sample.

Data collection

The researcher C.G. (Master student and Principal Investigator) participated in the "Online Qualitative Research Methods" training in order to increase his knowledge about qualitative research techniques during the planning phase of the study. In-depth semi-structured interview technique was applied during the interviews with patients. The initial brief meeting with the patients who participated in the study was conducted face-to-face and the patient and researcher were involved in the hospital ward. The second interview, which lasted longer, was conducted over the phone. Due to the fact that the second interview (25-40 minutes) posed a risk for infection for researchers and patients, and institutional permission was obtained with the condition that the interview is done over the phone, the in-depth interview was carried out

over the phone. The researcher wore an n95 mask, visor, overalls and adhered to social distancing rules during the initial meeting. The patients were given the necessary information about the research and oral informed consent was obtained. After the patients were informed about the purpose and duration of the study and consent was obtained, personal information was obtained from the patients. Phone numbers were recorded so that the in-depth interview could be conducted over the phone and the time of the interview was scheduled. For patients who continued to receive inpatient treatment, the interview was conducted over the phone in the hospital environment while not disrupting the treatment processes. Patients who were discharged before the interview were followed up and the interview was conducted over the phone on a date scheduled with the patient. The interviews were held at the times scheduled with the participants. Calls were recorded and notes were taken with the permission of the participants. In the second interview, general and open-ended questions were discussed in depth to identify the COVID-19 related life experiences of patients. During the interview, momentary reactions of the individuals such as crying and silence were noted. The interview ended with thanks. The initial meetings lasted an average of 3-5 minutes, and the in-depth interviews lasted an average of 25-40 minutes.

Statistics

Both researchers were female and had analyses of data. Phone calls recorded with the audio recorder were transferred to the computer environment 24 hours after each call and all data were backed up. The calls were transcribed by the researchers and an 82-page interview report was obtained from the interviews. Transcribed texts were read aloud and the excerpts related to the subject were highlighted in different colors. Content analysis was used to evaluate the expressions that were semantically compatible with each other. Content analysis is a hierarchical system in which each datum is encoded in a few words [22]. Each datum is encoded and similar patterns were obtained. These patterns were hierarchically collected under emerging concepts, categories and themes. After content analysis was carried out by the researchers, the themes, sub-themes and codes created were checked using the Nvivo 21 program. Then, the obtained data were evaluated and interpreted. Three main themes and further sub-themes were created based on content analysis (Table 1).

Ethics

The text you provided appears to be a statement regarding a research study conducted with the approval of Atatürk University Faculty of Medicine Non-Interventional Research Ethics Committee on June 26, 2020. Necessary permissions were obtained from the relevant Health Directorate to conduct the research, and also from the Ministry of Health COVID-19 Scientific Research Evaluation Committee.

Participants were included in the sample after providing information about the purpose of the study, the confidentiality of their answers, and how the data would be used, and those patients who volunteered to participate.

Results

Theme 1: Physical responses to the disease

Patients receiving COVID-19 treatment mentioned the physical responses to the disease during the interviews. Patients mentioned that they experienced COVID-19 related symptoms such as fever, muscle pain, and dyspnea. Most of the participants mentioned that they had decreased appetite due to disease symptoms, experienced weight loss due to loss of appetite, and resorted to natural, herbal foods to reduce the risks of the disease and took supplementary foods to strengthen their immunity. All of the participants mentioned the sleep problems they experienced due to the disease. Patients stated that the pain caused by the symptoms of the disease and dyspnea prevented sleep. They also stated that they experienced sleep disturbance due to fear of death, loneliness, and negative thoughts. Excerpts from the statements of the participants are given below.

"... I have fever, my muscles hurt, my bones hurt..." (G2, MALE, AGE 48)

"... I can't sleep at all. I have pains, I'm having all kinds of thoughts at night, the more I think about them, the more I can't sleep..." (G6, MALE, AGE 57)

" ... I've lost my appetite; there were instances where I could not eat anything. When I get out of the hospital, I will eat completely organic and natural foods..." (G8, MALE, AGE 46)

Table 1: Themes regarding patients.

Themes	Sub-Themes
Physical responses to the disease	
Mental responses to the disease	• Emotions in the early period • Medium and long-term emotions • Stigmatization
Coping methods	

"... I've lost the sense of taste and smell. It was such a bad feeling. I wasn't eating anything; even water had no taste..." (G15, FEMALE, 29)

"... I've lost appetite during this period, I lost weight, but I paid attention to my diet, I started eating healthy and organic..." (G17, WOMEN'S AGE 25)

"... Sleep was forbidden to me. At night, the nurses were giving me medicine, so that I could relax and fall asleep. Sudden coughs were waking me up at night. The oxygen support was drying my mouth, but I couldn't sleep without it..." (G18, MALE, AGE 44)

Theme 2: Mental responses to the disease

When the data obtained from the participants on this theme were evaluated, three sub-themes emerged as emotions in the early period of the disease, emotions during medium- to long-term emotions, and stigmatization.

Sub-theme 1. Emotions in the early period: When participants learned that their COVID-19 tests were positive, they were found to experience negative emotions such as shock, sadness, fear of transmission, fear of death. The following are excerpts of the participants' opinions.

"... Of course I had fear of death... A relative of mine had died of this disease, and when I was hospitalized, I was afraid of dying, I was shocked ..." (G10, FEMALE, AGE 70)

"... When I first found out, of course, I felt bad, I just thought about my family, whether they were infected too, and I wondered what I'd do if they were infected, I was so afraid..." (G17, FEMALE, AGE 25)

Sub-theme 2. Medium and long-term emotions: It was found that patients, whose treatment progressed positively later during hospitalization experienced relief, calmed down and felt positive emotions; whereas patients who did not respond well to treatment continued to feel the negative emotions in the early period, felt lonely and worried about going to intensive care.

"... Between the intensive care unit and the Covid ward, I felt like I was facing death. What if they put me back in intensive care..." (G8, MALE, AGE 46)

"... When my treatment went well, I was extremely happy, there was relief, although my symptoms continued, I was relieved..." (G14, FEMALE, AGE 43)

"... You can't do anything, I don't know, it's bad, there's only four walls in the hospital room, there's no one to talk to, there's nothing to do, you're already having trouble breathing, you're feeling lonely..." (G12, FEMALE, AGE 37)

"... My mind was always on my family, we were apart, I missed it so much..." (G17, FEMALE, AGE 25)

Sub-theme 3. Stigmatization: Participants mentioned that because they were COVID-positive, they were stigmatized by other people, people were distant to them and their behavior was accusatory. The selected excerpts from the participants' statements are given below.

"... I came to the hospital by ambulance and the people around us were looking at me in a very different way, it felt like it was a shame to have this disease or as if I had committed a crime..." (G7, FEMALE, AGE 27)

"... When my friends found out, they were so scared of me, but actually they were afraid for themselves, not for me. They used accusatory sentences and made me even more depressed..." (G18, MALE, AGE 44)

Theme 3: Coping methods

Participants were asked about how they coped with the problems experienced during the disease. The participants mentioned that they tried to support themselves psychologically by engaging in various activities such as watching TV shows or movies, reading books, listening to music and playing games so that they could pass this time more comfortably mentally. Participants included in the study stated that social support provided by family, friends or other people during the disease helped tremendously to get through this process. Many of the participants expressed a sense of gratitude towards the health professionals working in COVID-19 wards, and that receiving the necessary medical support during the disease positively affected their mental health. Participants mentioned that their religious beliefs made the process of dealing with the disease easier. The following are excerpts of the participants' opinions.

"... My friends called so many times, I couldn't return all the calls anymore. Many of my friends from various provinces of Turkey called..." (G3, MALE, AGE 58)

"... I was motivating myself by thinking about leaving the room at night and walking around the parks and coming back to my room..." (G6, MALE, AGE 57)

"... During my intensive care hospitalization, the nurses were constantly giving me hope, keeping my morale and motivation quite high..." (G8, MALE)

"... When I felt good, I was reading something, watching TV. I was going through the day by believing that this would eventually be over..." (G14, FEMALE, AGE 43)

"... I tried to the nurses a lot because of my anger at myself, but they've always done their job patiently. They did their best to support me, to reduce my pain... (G18, MALE)

"... What could I do but seek refuge in God? I prayed all night..." (G19, MALE)

"... I spoke to my family with video-call, they were

very supportive..." (G21, MALE, AGE 51) "... I prayed to God. I knew the healing would come from Him..." (G22, FEMALE)

Discussion

The first theme of the study was "physical responses to the disease". It was determined that the patients experienced disease symptoms and nutritional and sleep problems. Sleep disturbance therefore may be due to symptoms, negative thoughts, and emotions, as the participants themselves have stated, as well as the virus's effect on the brain. Considering that sleep is involved in regulating immunity, adequate sleep is also important for the patients to combat infection. Similarly, a phenomenological study conducted by Liu, et al. and Chen, et al. [23,24] found that many participants experienced symptoms of infection after being hospitalized. Consistent with the results of the present study, there are numerous studies reporting that patients lost weight due to loss of appetite, tried to eat a balanced and steady diet and took food supplements to strengthen their immune system and overcome the disease more easily [25,26]. Healthy nutrition is crucial for improving the immune response and preventing infection [27]. It can be said that the patients are aware of the importance of nutrition. It was found that most of the participants had sleep problems due to disease symptoms and negative thoughts. These results are consistent with the literature [8]. Coronavirus can cause sleep disturbance by affecting the prefrontal cortex, basal ganglia and hypothalamus, where sleep regulation is important [28]. Sleep disturbance therefore may be due to symptoms, negative thoughts, and emotions, as the participants themselves have stated, as well as the virus's effect on the brain. Considering that sleep is involved in regulating immunity, adequate sleep is also important for the patients to combat infection.

The second theme of the study was "emotional responses to the disease". Participants expressed shock, sadness, fear of infecting loved ones, and fear of death in the early period. During the course of the treatment, patients responding well to treatment felt relaxed and had positive emotions, whereas patients who did not respond well to treatment continued to feel negative emotions, felt loneliness and had concerns about going to intensive care. Many studies in the literature support these findings [29,30]. In the qualitative study conducted by Chen, et al. [24] it was stated that the participants experienced fear in the first days of COVID-19 diagnosis, and they were looking forward to discharge in the medium and long term, with some patients calming down while others were still nervous. A phenomenological study of hospitalized COVID-19 patients conducted by Liu & Liu [23] concluded that having an unknown infection made participants feel extremely vulnerable against death. In a qualitative study conducted by Wang, et al. [30] it was found that after a confirmed COVID-19 diagnosis, most patients were concerned about the possibility of transmitting the virus to someone close, especially someone in the family. Similarly, Shaban, et al. [25] stated that the physical characteristics of hospital rooms led to a feeling of disconnection from the outside world. Statements of the participants demonstrated that COVID-19 negatively affects not only the physical health of patients, but also their psychological health.

In the stigmatization sub-theme of the study, participants mentioned that other people distanced themselves, acted distantly and exhibited accusatory attitudes because they were COVID-positive. Throughout history, those who contracted the disease during outbreaks and were likely to get sick were subjected to stigmatizing, devaluing, discriminatory behavior and attitudes by other individuals. This increases the mental invulnerability of people subjected to stigma [31,32]. A qualitative study of stigmatization in COVID-19 patients found that the most important reason participants chose not to disclose the disease was fear of stigma and discrimination. Similar results were found in qualitative studies conducted by Sun, et al. [16].

The final theme of the present study was "coping methods". It was determined that the participants tried to support themselves, received support from their families, friends, health workers, and tried to cope by turning to spirituality. There are numerous studies in the literature that are in line with the findings of the present study [33-35]. Sun, et al. [8] reported that most patients motivated themselves by making cognitive adjustments, diverting attention, and setting achievable goals every day. Whitehead & Torossian [34] reported that the most commonly stated sources of relaxation were family, friends and close relationships, digital social contact, and hobbies. In a qualitative study conducted by Nielsen, et al. [35] all participants emphasized that the health personnel made a difference by being friendly, positive, supportive and understanding. In the qualitative study conducted by Son, et al. [33] participants expressed gratitude to the healthcare providers who cared for them at the risk of infection and stated that they trusted the healthcare providers who comforted them with kind words. The COVID-19 pandemic has increased admissions inpatient treatment institutions and the number of beds in intensive care units. Health workers have had to work longer hours than ever before to meet the growing patient needs [36,37]. During this period, health workers have tried to provide the best service to patients despite the increased workload and this has been perceived by patients as a support. The fact that the patients included in the present study especially emphasized nurses among health workers may be due to the fact that the treatment and care procedures during hospitalization are carried out by COVID-19 nurses and patients make the most contact with nurses.

Spirituality, patients mentioned that concepts such as patience, worship and prayer brought by the belief of Allah made coping easier. Spiritual and religious attitudes that play a role in how people approach to the inevitable reality of death can reduce death anxiety and enable the patient to successfully cope with the experiences related to the disease [38]. In the qualitative study conducted by Cervantes, et al. [39] some participants stated that they turned to their beliefs and prayed not to die. Gashi [40], Banerjee [28] conducted a study with people who recovered from COVID-19, and reported that religious belief had a significant effect on understanding and making sense of the disease in the majority of the participants, and religious factors such as prayer, patience, worship and surrender contributed significantly to coping with the disease. Studies [38-40] and observations show that there is a link between resorting to spirituality and coping with mental problems that arise during difficult life periods, understanding and making sense of the situation. Religious and spiritual practices that emerge or become more common during the difficult hospitalization process also facilitates overcoming and coping with the disease.

Conclusion, Implications, and Future Directions

The theme identified as physical responses to the disease demonstrated that patients showed symptoms such as fever, dyspnea, and pain, had sleep problems due to both symptoms and negative thoughts, lost weight due to nutritional problems, and tried to take supplementary food to strengthen their immune system. The theme identified as emotional responses to the disease demonstrated that patients experienced various emotions in the early stages of the disease, such as shock, sadness, fear of transmitting the virus, and fear of death. Patients who responded well to treatment experienced relief, calmed down and felt positive emotions in the mid- and long-term, whereas patients who did not respond well to treatment continued to feel the same negative emotions in the early period. Furthermore, the patients were stigmatized by other individuals. In the theme identified as coping methods, the patients stated that social support by family, friends or others; spirituality, self-motivation, and receiving the medical support they needed improved their morale, helped them cope with the disease, and had a positive effect on their mood.

In conclusion nurses monitor patients' physical health, assess symptoms, administer medications, and implement treatment plans. Therefore, understanding and accurately assessing the physical symptoms experienced by patients is an essential part of nurses' duties. Knowing the symptoms that COVID-19 patients experience and how these symptoms affect them helps nurses make appropriate interventions. Nurses should consider not only monitoring patients' physical health but also their emotional well-being. COVID-19 patients can experience a range of emotional difficulties due to their illness, treatments, and isolation processes. Fear, anxiety, sadness, stigmatization, and other emotional issues are just a few of the emotional responses patients may experience. Nurses can help patients cope with these challenges by understanding their emotional needs, providing emotional support, and, if necessary, referring them to professional psychological assistance resources. By observing patients' emotional responses and communicating about them, nurses can make the treatment process more effective. Nurses play a crucial role in understanding and supporting patients' coping mechanisms. COVID-19 patients may encounter various stress factors due to their illness and treatments. These stress factors can lead to emotional and psychological challenges. Nurses can identify different coping strategies and provide support to help patients deal with these challenges.

Considering that the patients included in the present study were at risk for mental illnesses, it is recommended to provide professional psychological support to the patients, to examine the experiences and problems faced by the patients in order to appropriate policies should be developed for possible future outbreaks. Nurses should be concentrate on patients' feelings such as fear, sadness, loneliness, longing. Education and policies should be established to combat stigma.

Limitations

This study has several limitations. The fact that the in-depth interview was conducted over the phone and recorded made it difficult for patients to participate in the study. Due to the restrictions brought about by the pandemic, the interviews were held in a limited time frame. There were difficulties in reaching the patients after being discharged from the hospital and scheduling interview times. Researchers did not provide feedback on the findings to the participants. The results obtained in the present study can be generalized to the patient group included in the study and does not represent the entire patient population.

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Conflict of Interests

The authors declare that they have no conflict of interest.

Authors Contribution

Research idea: CA, KG; Design of the study: CA, KG; Acquisition of data for the study: CA; Analysis of data

for the study: CA, KG; Interpretation of data for the study: CA, KG; Drafting the manuscript: CA, KG; Revising it critically for important intellectual content: CA, KG; Final approval of the version to be published: CA, KG.

Ethics

This study was approved by Ethics Committee of Atatürk University Faculty of Medicine Non-invasive Research (approval date 26.06.2020 and number 36).

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