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The perspectives and experiences of patients with COVID-19: a qualitative study

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A – Study Design, **B** – Data Collection, **C** – Statistical Analysis, **D** – Data Interpretation, **E** – Manuscript Preparation, **F** – Literature Search, **G** – Funds Collection

Summary **Background.** The expansion of COVID-19 and its unique transmission speed created an emergency situation in global health. This disease not only causes public health concerns but also has many psychological consequences for patients. In this situation, maintaining the mental health of individuals is essential. Therefore, focusing on the human aspects of the threat perceived by patients could lead the way for the provision of empathetic and effective care.
Objectives. The aim of this study was to investigate the perspectives and experiences of patients with COVID-19.
Material and methods. In this qualitative study, 27 patients with COVID-19 were purposefully selected and interviewed in semi-structured in-depth manner. Interviews continued until data saturation. All interviews were recorded and analysed using the MAXQDA 10 software and the contractual content analysis method via the Graneheim and Lundman approach. The accuracy and robustness of the research was obtained based on Guba and Lincoln criteria.
Results. The codes extracted from the interviews led to the emergence of two main themes including "negative emotions" and "sense of cohesion" and five categories of stigma experience, psychological distress, perceived threat, positive perception and spirituality.
Conclusions. Individuals experience critical crises in the face of stressful life events, including COVID-19, from negative emotions to psychological adjustment. Going through the crisis stage and achieving stability and peace requires a change of attitude towards everything around the person and the use of spiritual forces to achieve adaptation.
Key words: life course perspective, patients, COVID-19, qualitative study.

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Background

In recent decades, with the emergence of atmospheric phenomena, environmental changes and other known and unknown factors, new diseases have emerged, called "emerging diseases", which have affected the health of people around the world [1]. The COVID-19 pandemic is one of these and caused very serious damage to human society by creating public health emergencies around the world [2]. Studies of previous epidemics, such as SARS and Ebola, have shown dramatic changes in various aspects of patients' quality of life during illness and even long after recovery [3]. Therefore, focusing on the human aspects of the threat perceived by patients can pave the way for the provision of empathetic and effective care.

If the experience of these patients is examined, evidence-based knowledge can be used by health professionals and their planners to provide higher quality care so as to reduce mental illness [4]. In this regard, the World Health Organization emphasises the existence of a set of interventions designed to optimise performance and reduce disability in people with acute or chronic diseases [5]. Evidence shows that in the event of a disaster, early initiation of interventions and optimisation of functional capabilities, including cognitive functions and social reintegration, reduces disability and improves clinical outcomes and patient participation [6]. This is especially important in people who have survived COVID-19.

Accordingly, it seems that the culture of patient feedback is an important part of the day-to-day operations of healthcare systems. Patient experience-based feedback can also be an important indicator of community response to disease [7]. In this regard, qualitative studies can provide new and valuable insights into the unique challenges experienced by patients to healthcare systems in order to be more prepared to support at-risk groups in crises such as the current crisis [8]. Healthcare workers can use these results in making proper evidence-based planning to improve the holistic care of patients.

Qualitative research, while looking into the depth, richness and inherent complexity of phenomena around humans, can answer many deep and complex questions about man and related phenomena. This type of research is a way to gain insight through the exploration of meanings. This insight is not gained by finding cause-and-effect relationships but by perceiving the whole. Insights from this process can guide caregiving performance and aid in theorising to generate new knowledge [9]. By identifying and understanding the concept and dimensions of the experiences of patients diagnosed with COVID-19, new aspects of knowledge could be gained about the perceived threat posed by the disease to survivors and provide a solution for designing and formulating empowerment interventions based on their real needs in relation to enhancing and promoting physical and mental health. Therefore, this study was conducted to investigate the perspectives and experiences of patients with COVID-19.

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Material and methods

In this descriptive exploratory study, the conventional content analysis approach was used to explore the perspectives and experiences of patients with COVID-19. Content analysis involves summarising, describing and interpreting data and is useful in identifying the key themes in the text and evaluating individual experiences and attitudes toward specific issues [10].

Setting and selection of participants

The participants in the study were patients hospitalised in the COVID-19 treatment centres of Shahrekord University of Medical Sciences. They were selected using purposive sampling with maximum diversity (age, gender, level of education and inpatient ward (COVID and Post-COVID wards)). Inclusion criteria were: being hospitalised in COVID or Post-COVID wards with a definite diagnosis of COVID-19, being over 18 years of age, sufficient physical ability to conduct interviews, ability to speak and understand Persian language and willingness to participate in the study and description of cases and expressing their problems. Exclusion criteria included: psychiatric illness and cancellation of the interview. The interview was conducted after receiving two dosages of vaccine by the researcher at the time of relief of physical symptoms and partial relief of the patient's respiratory symptoms. All of the participants were interviewed in a quiet room with proper ventilation and full observance of the health protocols.

Data collection procedure

Data collection was performed from August to March in 2021 using in-depth semi-structured interviews and was continued until data saturation. In this study, data saturation was performed in the first 25 interviews, and 2 additional interviews were performed to ensure more data saturation. The scope of the interview questions included general questions such as: How did you find out you had the disease? What happened to you when you were diagnosed with the disease? Please describe your experience of getting sick and treating your illness. What mostly comes to mind when you think of COVID-19? What has been the biggest challenge? Tell me about your quarantine experience. How do you think the coronavirus has affected your life? The interview continued with more detailed questions based on the participants' answers. During the interview, all conversations (with the consent of the participant) were recorded. Each interview lasted from 30 to 35 minutes. A subsequent telephone interview was conducted for 10 to 20 minutes with each participant to complete the categories that appeared during data analysis.

Data analysis

MAXQDA10 software and the Grenheim and Landman method (2004) were used for data analysis [11]. Firstly, the recorded interviews were converted into text after being heard several times by the researcher and carefully reviewed over and over again. The semantic units were then identified and coded. In the next step, the codes were formed based on the similarity of the categories and subcategories. Afterwards, the sub-classes formed were merged in terms of similarities and differences and named as classes. Lastly, by merging the classes, the main themes were determined. The accuracy and robustness of the data were evaluated using Goba and Lincoln (1985) criteria [10].

Ethical considerations

This study was conducted under the code of ethics IR.SKUMS.REC.1399.046 and by obtaining a letter of introduction from the university and obtaining permission to conduct the research in the research environment. Informed consent was also obtained from the participants, and they were assured that they will be able to leave the study at any time and that their details will remain confidential.

Results

The participants in the study were from 26 to 65 years of age, and all of were Muslims. The demographic characteristics of the participants are presented in Table 1.

Table 1. Demographic characteristics of the participants

Character	Category	Number
Gender	female	16
	male	11
Marital status	married	23
	single	4
Degree	academic	9
	diploma	11
	high school	8
Job	employee	8
	housewife	7
	self-employed	12
Hospitalisation ward	COVID	11
	post COVID	16

The codes extracted from the interviews led to the emergence of two main themes, including "negative emotions" with three categories of stigma experience, psychological distress and perceived threat, and "psychological adjustment" with two categories including positive perception and spirituality, as mentioned in Table 2.

Table 2. Main category, categories and subcategories emerging from analysis of the interview

Subcategory	Category	Main category
Feelings of rejection, feelings of lack of support, feelings of worthlessness, inappropriate behaviour of the medical staff	stigma experience	negative emotions
A world of darkness, shock and disbelief, pessimism, despair, negative emotions, death anxiety	psychological distress	
Economic problems, threats for family health, doubts	perceived threat	
Perceived support, understanding of illness, sense of worth	positive perception	psychological adaptation
Healing trust, a spirit of gratitude, forgiveness, patient resilience	spirituality	

The main categories of this study represent the different experiences of patients diagnosed with COVID-19 in a range from negative emotions to psychological adjustment, which is described below.

Negative perceptions

In the present study, the experience of anxiety and worries of a patient with COVID-19 that overshadowed his ability to cope caused feelings of inadequacy, and impaired perception in the range of his/her feelings and experiences led to negative emotions. This disorder manifests itself in the form of three categories: experience of stigma, psychological distress and perceived threat.

Stigma experience

When the patient's social and interpersonal relationships are disrupted due to society's negative beliefs about infectious and life-threatening diseases, he/she will experience identity changes resulting from the replacement of negative community beliefs with positive ones about him/her and experiencing stigma, which could also be very unpleasant for him/her. In this regard, the participants of this study had experiences such as feelings of rejection, lack of support, feelings of worthlessness and inappropriate behaviour of the medical staff, which made them feel humiliated and experiencing stigma.

Feeling of rejection

The study participants often experienced rejection by others, as well as painful feelings such as embarrassment, sorrow or sadness. In this regard, p10 said: When I was admitted to the emergency room, the nurses came to each other in a bad mood and said another COVID patient came. I was very embarrassed. It felt very bad; I was very upset with them. I thought I had leprosy. Everyone was afraid to approach me or touch me. They carried out my affairs reluctantly.

P4 explained: My family wanted to get rid of me somehow. The doctor was urged to admit me so that I would not be at home. I was offended by their behaviour.

Improper behaviour of the medical staff

When a patient goes to a hospital or medical centre, the first expectation is that he or she will be treated with respect and kindness. In such cases, if the behaviour of the medical staff is inappropriate, the patient's trust in the medical staff will be lost. Participants also experienced a range of behaviours of medical staff.

In this regard, p21 said: They treated me as if I had deliberately acted to be sick, and now I have come to make them sick too. They were handing over all of my affairs to the novice nurses and telling him/her that this is your patient. They also complained about why we should deal with such patients. What should we do if we get sick? They also said that we are going to complain and so on! In general, their work was very, very insulting.

Feeling of lack of support

Feeling and understanding the fact that a person is not cared for and emotionally supported by others and cannot count on the help of others led to the feeling of lack of support in the participants of this study.

P18 said: My husband and I were diagnosed with COVID-19. My husband has been asleep since his test was positive, and I did everything I could as an employee. He did not even move a single plate for me. I did so much work inside and outside the house that I was not well and had to be hospitalised.

Feeling worthless

Elimination of the patient's previous roles and disregard for his/her position by his/her family members led to feelings of uselessness and futility and ultimately a sense of worthlessness by the participants in this study.

P15 said: I, who until yesterday had a lot of respect and value and did family work, now am not even allowed to do or touch anything. They don't care about me anymore. I am completely useless. I am very sick.

Psychological distress

The nature of COVID-19 and its consequences left the study participants in a state of psychological distress caused by negative changes in their inner sense of peace in life. Thus, they felt as if in a world of darkness, confusion and disbelief, and even imminent death, and experienced a range of mental disorders such as irritability, anxiety and depression.

A world of darkness

The participants in the study were pessimistic and viewed everything negatively and had a largely complex and unpleasant response to social constraints and the mental and emotional effects of COVID-19. Because of this, they believed in a darkness in life, as well as confusion and the feeling of imminent death. In this regard:

P25 said: Everything was bleak for me; nothing mattered to me anymore. I thought I lost everything.

P20 said: I do not understand what these doctors and nurses mean. They do not answer correctly. They do not say whether we will get better or not. Some of the patients die and some get well and are discharged. It is not clear what our fate will be and which category we belonged to.

Death anxiety

A patient diagnosed with COVID-19 enters the hospital in a situation where there is uncertainty about his/her fate. An unfavourable physical condition during the whole period of hospitalisation not only makes one afraid of imminent death but also limits social interactions, and the occasional death of other inpatients raise the fear of dying alone. In this regard:

P9 said: Last night, one of these patients died. I was very upset. I said this is our end. Here, far from our wives and children, we die like homeless people.

Additionally, p17 continued: I was afraid that I would die alone in a corner of the hospital and that no one would be beside me. My whole life was ruined.

Shock and disbelief

In this study, accepting an unknown and life-threatening illness for the participants was far from their minds, causing shock and disbelief about the incident, and thus they tried to deny the truth. In this regard:

P6 said: When I realised that I got COVID-19, it was as if the whole world was pounding in my head. I could not believe it at all. Oh why should I, who had observed all this, get COVID-19.

The mysterious and contagious nature of COVID-19 made the participants in this study not only pessimistic about their relatives and acquaintances regarding the causative agent of the disease but also made them pessimistic about their fate.

P11 said: I was pessimistic about everyone; I thought the others did not comply and got COVID, but they had no symptoms, so they did not tell me and made me sick.

P2 said: These nurses or doctors would not pass on another disease to us. How do they know if they may or may not have COVID-19 or another illness? If we die because of them, who will be responsible?

Negative emotions

Restrictions imposed on patients with COVID-19 and temperaments resulting from experiencing stressful conditions in the treatment process led patients to experience negative emotions such as decreased tolerance, resulting in anger, anxiety, depression and despair.

P12 said: I'm very nervous. I cannot stand it at all. I wish it was over. If I'm not going to get well, why do I have to suffer so much? I feel respiratory distress. I feel down.

P2 said: I feel like I'm suffocating, I cannot breathe. The doctor says I do not have a lung problem, but I cannot breathe properly. I'm always anxious. I'm worried about my children. I have a child. I do not know what will happen to him/her. I haven't seen him/her in a week.

Perceived threat

Perceived threat is a mental concern arising from perceiving how dangerous a situation is or the consequences of a situation from a personal perspective. In this study, the participants also experienced concerns such as economic problems, threats to family health and scepticism.

Financial problems

COVID-19 caused serious damage not only to the global economy but also to the economies of families, especially those affected by the disease, through direct and indirect costs. The participants in this study also experienced many economic problems due to the costs imposed by the disease.

P1 said: I am a construction worker. I have no income. I have a public insurance booklet. They say COVID medications are very expensive. I do not know whether they are insured or not. Now that I'm not going to work, my wife and children are also hungry. How can I pay for a doctor?

Threats to family health

In the presence of contagious diseases, especially life-threatening diseases, the responsibility, intense fear and concern for endangering the health of family members are doubled.

P9 said: My family is in danger. My mother suffers from cardiac disease. I'm afraid they will get COVID as well. I'm worried that I will pass COVID to them.

Doubt

In the course of human life, we are constantly faced with new situations and are forced to make decisions. These decisions play an important role in human life, and the right or wrong result of some decisions can change the course of a person's life completely. But stressful situations and a sense of responsibility towards loved ones can cast doubt on a person and affect their decision-making strength.

P4 said: I do not know what to do. My wife wants to take me home after hospitalising and isolate me. But I objected. Of course, I have no other place. I told myself I would go to my father's house, and then I thought they would get infected, too. Maybe I should rent a room in a guest house. Maybe I'll go and get a travel tent and live in a corner. Maybe it's better to stay in the car in front of my house.

Positive perception

Everyone categorises, identifies and interprets the ideas and perceptions they have about themselves. Naturally, if each person pays attention to his/her surroundings with a positive outlook, he/she will receive positive perceptions that this awareness can make him/her adapt. In this study, positive perception refers to a positive set of patient perceptions of human relationships, the nature of the disease and self-worth.

Perceived support

All human beings communicate with others as an accessible and appropriate resource to meet their needs and to enjoy their support. This issue is especially pronounced in medical settings due to the limitations of individuals. Therefore, by medical staff and his/her family understanding and supporting patients, they can create a sense of trust and hope in them and play an important role in their recovery.

P22 said: When you see this doctor and nurse, they take care of themselves and work so hard to help their patients, they do not worry anymore; they know that they are careful and do whatever is necessary.

P11 said: Even though I have been infected by COVID-19 and told my children that the hospital is infected and they shouldn't come, they keep coming and going. And because I do not eat the hospital food, they cook food for me according to the nurse's order.

Understanding the disease

Perception of the disease is based on one's perceived beliefs, and information about the disease can affect the patient's behaviour, his/her adaptation to the disease, the management of the disease by the individual and, in general, the outcome of the disease.

P3 said: Some of these patients still do not realise that following the instructions of this doctor and nurse is important for their own benefit and for their health. That's why they do not listen to them properly, and in this way, they endanger their own health and the health of others.

A sense of worth

Feeling valued is a fundamental part of every person's existence and emotional outlook, which determines how he or she feels about others.

P3 said: When a person perceives that all these doctors and nurses are trying to make their patients well, it makes her/him feel good. This is where one realises that the patients are important to them.

Healing trust

In Islamic culture, trusting in God means that human beings should consider God as his/her reliable support and leave all his affairs to him. This kind of devotion to God heals the pain and sufferings.

P5 said: I trusted in God from the beginning, and now it is the same. I asked God to take me back to my family. Thank God I am getting better day by day.

P14 continued: God says that whoever deals with me should not be afraid of anything. I just relied on God and just asked him to make things right.

Forgiveness

When people consciously display feelings and behaviours other than annoyance and resentment toward others, this leads to a positive wave of satisfaction and calm. The participants of this study also found peace as a gift by forgiving and avoiding enmity.

P13: I had a lot of trouble with my wife's brother. I could not see him, but since I got COVID, I felt death and said that it is better to put aside grudges and forgive him. I told my wife to call him and ask him for forgiveness. Now it has been solved by me. Now it is his turn to forgive the grudge if he likes, and if he does not like it, he continues, but I am at peace with myself.

P7: My husband's mother has been bothering me a lot since the beginning of our marriage. I was very upset with her, but I promised my God that I would put aside my worries. Only God can take this disease away from me.

Appreciation

Gratitude is one of the spiritual methods and the simplest and most enjoyable way to use the blessings of God as much as possible and create a good feeling in human beings. The participants of this study also enjoy the blessings of health by having a spirit of gratitude.

P3: I'm getting better. I thank God for giving me another chance to be with my wife and children. Rest assured, I will reciprocate this grace of God in another way. Finally, in the way I know, I do something and God is pleased with me.

Patient resilience

In this study, resilience is considered as the ability of individuals to adapt properly to stressful situations and the difficulties that are created in the shadow of patience.

P8: Saying that the problem is getting massively worse, but it goes away little by little. Well, we have to wait for the disease to go away. We should not expect a disease so severe that it has killed so many to be cured so easily. With patience, everything will be figured out.

Discussion

The findings show that COVID-19 is a challenging disease and, like many life-threatening diseases, affects not only the physical condition but also the psychological state of the patient. The participants of this study also experienced a range of negative emotions to psychological adjustment. According to the theory of symbolic interaction, human beings do not react directly to the outside world, but they give a social meaning to the outside world and react to that meaning. Since we live among symbols, as well as in a material world, our social life is a constant process of interpreting the meanings of our actions and the actions of others [12]; therefore, actions such as keeping others away from the patient and understanding the lack of proper communication of others by the patient can highlight the feeling of worthlessness and discrimination in the patient, ultimately leading to a sense of inferiority, inadequacy and reduced self-esteem and self-efficacy, and they may even experience stigma. All of these troubles are the products of the negative attitudes of the individual and society towards the disease.

Based on studies of ignorance and contradictory facts about disease transmission, fear of death is one of the effective factors in experiencing the stigma of a patient with COVID-19. Therefore, adequate information and promotion of knowledge in this field can be among the strategies to change beliefs and create non-discriminatory behaviours in order to deal with the stigma caused by the patient. Epidemics are always associated with issues such as uncertainty, ambiguity and lack of control over the life events, each of which is known to trigger stress and emotional distress [13].

Psychological distress refers to a set of symptoms of perceived depression and anxiety and maladaptive psychological activity during stressful life events. It is a unique and distressing emotional state for a person in response to a particular stressor [14]. Thus, the loss of psychological support of family and friends due to the restrictions imposed on patients with COVID-19, an influx of unpleasant thoughts such as loneliness, labelling, denial, frustration and, to a greater degree, aggression exacerbate stress and psychological damage in the form of anxiety, depression, irritability, insomnia, fear, confusion, anger, frustration and impatience, and ultimately lead to more maladaptive strategies and more embarrassment, leading to increased death anxiety [15, 16].

Death anxiety is rooted in the awareness of death and is defined as an emotional response to the perception of real or imaginary signs of danger and a threat to one's existence, which can be evoked by environmental and situational stimuli, as well as internal stimuli in relation to the death of the individual or others [17]. Therefore, the preferences and beliefs that a person has about death and the process of death can play a role in creating death anxiety.

For example, the feeling of loneliness at the time of death is formed when a person not only experiences loneliness and separation from family and relatives but also when a person witnesses the death, and possibly sudden death, of other hospitalised patients.

However, humans have adaptive ways of dealing with death anxiety, and some people may use maladaptive and morbid methods to deal with death anxiety and experience psychological distress when faced with a severe stressful event or a threat to their health or that of their loved ones [18]. Therefore, reducing psychological distress and death anxiety can be one of the basic components of care and treatment in patients with diagnosed severe diseases.

Nevertheless, the mental worries caused by the increase in health costs and the resulting economic problems, on the one hand, and the fear and worry about the health status of the family, on the other hand, are other issues that can affect a person's mental health [19]. Health costs have always been one of the topics of discussion in the field of health. These costs fall into two categories: direct costs due to the diagnosis and treatment of the disease and indirect costs due to decreased productivity and patient work capacity [20, 21].

This is especially worrying in cases where there is no prepayment system, and families have to pay for health care out of pocket. This imposes a heavy financial burden on families [22–24]. Considering that health is generally considered a commodity and people should benefit from it, protecting individuals against the debilitating costs of health services should be considered as a desirable and satisfactory goal of health system policymakers [25]. People's perception of the internal stimuli of the disease, as well as its environmental stimuli, will shape their emotional, cognitive and behavioural responses.

Therefore, paying attention to the positive psychological variables in dealing with COVID anxiety can be important. Among these variables, we can mention the sense of cohesion, which is the ability of a person to identify the stressors of life, as well as the efficient use of coping resources and maintaining health [26]. This feeling is a personal orientation towards life.

People with a strong sense of cohesion can understand and control their environment to have a meaningful and appropriate behaviour or action [27]. This is possible through the three basic concepts of comprehensibility, manageability and significance of events from a person's point of view [28]. Research has shown that a sense of cohesion can be effective in reducing anxiety and protecting one's health from life-threatening conditions [29]. This concept is also useful in better understanding social support and its impact on health and disease. Communication with others and regular social interactions are tools through which people feel valued and maintain their social identity. Social support is the strongest coping force for successful coping in times of conflict with stressful situations and in facilitating patient tolerance [30], which can be provided in the form of psychological, emotional, informational, tangible and interactive support. In this regard, researchers have emphasised the existence of social support to reduce the negative psychological consequences of COVID-19 [31].

The present study showed that several factors, including spiritual experiences, positive thinking and perception of social support, in each of the stages of diagnosis, treatment and hospitalisation affect patients' perceptions of the disease and how to deal with it and is considered as a major facilitator for psychological well-being in stressful situations. Spiritual and religious experiences as a powerful source of adaptation, optimism, hope and meaning-making enable a person to alleviate the tensions and sufferings caused by patients' bitter experiences of illness.

Relying on religious beliefs and God's graces are considered as important sources of support and hope for overcoming the disease and uncontrollable conditions, as well as a way to deal with the concept of death [32]. In fact, religious and spiritual experiences lead to a positive mental atmosphere in patients in various ways, which result in relief from painful experiences and better adaptation to stressful events [33]. Religious beliefs lead to the formation of beliefs about a feeling of comfort and reward from God (due to suffering from illness) after death. Therefore, spiritual experiences can be considered as a strategy for coping, as well as emotional regulation [32].

Conclusions

In general, individuals in society judge and act according to the majority, creating normative or normative dualities and eventually, based on them, value others, which might have many social and psychological consequences. Patients diagnosed with COVID-19 are of no exception to this rule due to the highly contagious nature of the disease as judged by others.

Illness as an unfavourable situation in society causes an individual to be differentiated and to lose a part of social support, and it ultimately distorts the identity and experience of negative emotions by her/him. On the other hand, achieving stability and calmness during the stressful conditions of life-threatening diseases requires a form of psychological cohesion and adaptation. A positive attitude towards the disease and the events around it and by turning to spirituality, adaptation is formed and guides the patient in the face of the disease. Increasing our deeper understanding of psychological needs and anticipating the potential problems of these patients can be effective in promoting the mental health of this group of patients.

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