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Original Article

Challenges of families in caring for a patient with COVID-19 during the home quarantine period: A qualitative study

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Abstract

Background and aims: The significant spread of COVID-19 in Iran and the increasing number of cases and deaths caused by this deadly disease have faced the healthcare system with one of the biggest health challenges in the last decade. In such a situation, the role of families in dealing with challenges is inevitable. The present study was designed to explain the challenges faced by families in caring for a patient with COVID-19 during the home quarantine period.

Methods: In this qualitative design, data were collected from 38 family members of patients with COVID-19 who took care of their patients at home by using semi-structured interviews in Lar, Evaz, and Gerash between December 2021 and March 2022. The participants in the study were chosen using purposive and snowball sampling methods. The interviews were recorded and transcribed word-for-word in Persian. The content analysis approach of Graneheim and Lundman (2004) was used to analyze the data.

Results: This study's participants were 38 people, the average age of whom was 42.79±12.796 years. After analyzing the data, five main categories of personal factors, social factors, economic factors, environmental factors, and physical and physiological factors with 28 subgroups were extracted.

Conclusion: The results showed that families caring for patients with COVID-19 have faced many challenges. Based on this, social, economic, psychological, and educational measures and support can greatly reduce these challenges.

Keywords: COVID-19, Family, Quarantine, Qualitative research, Patient care

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Introduction

The increasing spread of COVID-19, coupled with the shortage of hospital resources and space for patient care, has led to the early release of COVID-19 patients from medical facilities. As a result, these patients have become a new group requiring home-based care. Family caregivers are helping to alleviate the mounting pressure on healthcare systems (1,2). Home caregivers are responsible for supporting patients in various ways, including helping with daily tasks, addressing treatment-related issues, facilitating communication, providing education, and motivating patients to become self-reliant in their care. These duties encompass assisting with everyday activities, managing health-related conditions, enhancing communication skills, offering instruction, and inspiring patients to take charge of their own well-being (3-5).

Iran has not been exempted from these conditions and crises created in the world (6,7). The spread of COVID-19 in all the provinces of Iran and the increasing number of cases and deaths caused by this deadly disease have made Iran's healthcare system face the most health challenges in the last decade (8). In such a critical situation, one of the key responsibilities of healthcare personnel is to protect the mental and physical health of the community.

In this regard, identifying the experiences of patients with COVID-19 while receiving care at home (9), as well as investigating and understanding the problems and challenges of their families (8), can increase the awareness of health officials and policymakers regarding the existing problems and challenges so that they can plan the structure and process of care activities (8,9). In various studies, most of the focus has been on healthcare personnel and patients (10-12), and the families of sick people and their challenges have been less investigated.

In summary, families play a vital and complex role in caring for someone with COVID-19, encompassing immediate care, emotional support, health monitoring, and long-term assistance. Their participation is essential for managing the illness, aiding recovery, and addressing the broader impacts of the pandemic on individuals and communities. Therefore, the researchers decided to study the issues that the families of sick people faced when caring for patients at home.

Material and Methods

Study participants and sampling

interviews were conducted with the families who cared for patients with COVID-19. Also, the researcher tried to find people who had rich experiences caring for a patient with COVID-19 during the home quarantine period and then continued the sampling by asking them to introduce other people with similar conditions. The conditions for entering the study include willing to participate in the research, having no evidence of COVID-19 disease in samples at the time of the interview, and the conscious desire of the participants to share their experiences about the care of a patient with COVID-19. If the participants did not want to continue participating in the research, they were excluded from the study.

Data collection tool and technique

At first, the interviewer introduced himself and explained the study's objectives. The interviewer tried to use probing questions such as "Explain more" during the participants' responses to collect more complete information. In this research, sampling continued until the data collection process did not create new themes and the researchers reached data saturation. In this study, the content analysis approach of Graneheim and Lundman was used to analyze the data (13).

The researchers in this study tried to guarantee the accuracy and strength of the findings by using the criteria introduced by Lincoln and Guba. This study ensured credibility via prolonged engagement with the study, immersion in the data, peer checking by experts in qualitative studies and mental health education, and member checking with participants. Transferability was ensured by providing detailed information about the study and its findings so that other researchers in the area of mental health clinical setting engagement can use the study's findings as a source of information. Dependability was ensured via an audit trail with detailed descriptions of data collection, an interview guide, data analysis, and participants' quotes.

Table 1. Characteristics of the participants

Variable	Number	Percent
Age		
<35	12	31.6
35-45	16	42.1
>45	10	26.3
Gender		
Male	13	34.2
Female	25	65.8
Level of education		
Illiterate	3	7.9
Elementary school	5	13.2
Middle school	10	26.3
High School	9	23.7
Academic	11	28.9

Results

There were 38 participants in this study, whose average age was 42.79 ± 12.796 years. The characteristics of the participants are summarized in Table 1. After multiple revisions, similar codes were merged, reducing the overall number of codes to five main categories of factors, including personal, social, economic, environmental, physical, and psychological, and 28 subgroups were extracted from the data (Table 2).

Personal factors

Responsibility for child care

A 41-year-old woman: *"I have three children. Apart from taking care of my sick husband, I have to take care of my children, and this is hard work."*

Responsibility for caring for the elderly

A 45-year-old woman: *"My mother-in-law lives with us, and she has memory problems, so we must always take care of her. Now that my husband has the Coronavirus, it is difficult for me to care for both."*

A large number of family members at home

A 39-year-old woman: *"My sister-in-law and mother-in-law live in the same house with us. My husband fell ill, and we are taking care of him at home. We suffered a lot during this time. I was always worried that others would get sick."*

Lack of experience and lack of patient care training

A 28-year-old man: *"My wife and I just got married. My wife got a coronavirus, and I took care of her. I had no experience caring for a patient, and no one taught me what to do if something happened."*

Table 2. Summary of the study findings

Themes	Subthemes
Personal factors	Being responsible for child care, caring for the elderly, having many family members at home, Lacking experience, lacking patient care training, and needing to get the patient out of the house.
Social factors	To be strange, disease stigmatization, no home visit
Economic factors	Having financial problems in providing personal protective equipment, having financial problems, working as a home caregiver, fear of creating problems on the job, problems with oxygen supply
Environmental factors	Having trouble getting a vehicle, no separate care area, small home
Physical and psychological factors	Refusal of others to take care of the patient, being a person with chronic diseases at home, the discomfort of the patient suffering, faced with confusion from different and even wrong information, fear of getting sick themselves, fear of getting sick and not having a caregiver, fear of infecting others, hide the disease, being forced to leave home, fear of neighbors getting infected, physical and mental fatigue in long-term care, inability to care for the patient alone.

Need to get the patient out of the house.

A 39-year-old woman: *"My mother was infected with the coronavirus. She was hospitalized, but the doctor prescribed an injection for my mother. We had to go to the hospital for injections."*

Social factors

To be strange

A 39-year-old woman: *"We are strangers in this city. Apart from a few friends, we do not have any relatives who can help us when we get sick."*

Disease stigmatization

A 41-year-old man: *"I was infected with coronavirus before, and now my wife and child are also infected. Others, even my family members, act as if we have leprosy. They don't even visit us. They only call us by phone."*

No home visits

A 45-year-old woman: *"For some people infected with COVID-19, the medical staff say they should be cared for at home. Unfortunately, they do not follow up on such patients. In these cases, the treatment staff should inquire about their condition by phone or visit the patients' homes."*

Economic factors

Having financial problems in providing personal protective equipment

A 45-year-old man: *"I am a construction worker and I do not have enough fixed monthly income. I am also a tenant. I have 3 children. Now, my wife has coronavirus. Honestly, how much do I earn to pay for my wife's medicine, and I don't even have money for masks and alcohol spray for the family?"*

Having financial problems

A 45-year-old man: *"When I got the coronavirus and got sick, I needed to rest at home, but I only stayed home for a week and had to go to work the second week because I had to pay daily expenses, rent, and other loans. Right after me, my wife got sick. I went to work as well as taking care of my wife."*

The working of the home caregiver

A 39-year-old man: *"My wife and daughter were infected with Corona. I am an employee and I had no leave, so I had to go to work. I was worried about caring for them and losing my job simultaneously."*

Fear of creating problems on the job

A 40-year-old man: *"My wife and one of my daughters got coronavirus. I did not tell anyone because my job is such that I would be in trouble if others found out about it. So I only met them a few times."*

Problem with oxygen supply

A 52-year-old woman: *"My husband, who was quarantined at home because of coronavirus, was having trouble breathing and needed oxygen. We did not want to be hospitalized, but it was difficult for us to get oxygen capsules."*

Environmental factors

Having trouble getting a vehicle

A 31-year-old woman: *"We do not have a car. So, we have to call a taxi or ask relatives to take my sick husband to the hospital for examination, tests, and drug injections. But the drivers do not accept easily and do not even come."*

No separate care area

A 27-year-old woman: *"My husband got sick, and they told us to care for him at home. At the same time, I and my two children are at home. There is no other place to take my husband to care. I wish there were a quarantine center."*

Small home

A 42-year-old man: *"My wife got COVID-19, and we had to care for her at home. Our house is small and not well-ventilated, so there is a risk of infection for me and my children."*

Psychological factors

Refusal of others to take care of the patient

A 55-year-old man: *"I have only one daughter. She is married and does not live with us. I have diabetes and high blood pressure. However, I have to leave home to work and earn money. No one, not even relatives and neighbors, agrees to take care of my sick wife when I am not at home."*

Being a person with chronic diseases at home

A 55-year-old woman: *"My daughter is divorced and lives with me and my husband. My husband is infected with the coronavirus. I have a heart problem, and my husband has diabetes. It is tough for me and my daughter to take care of him."*

The discomfort of the patient suffering

A 26-year-old woman: *"My husband got coronavirus two months ago. Currently, my 5-year-old child is infected. Their suffering tormented me. I remember sitting next to my sick child and crying."*

Faced with confusion from different and even wrong information

A 33-year-old man: *"My wife and child who got sick, everyone said something, for example, they said to give such and such medicine or prepare such and such food and give it to them or take them to a traditional doctor. Someone even told me to leave my baby in the sun until his body was warm enough to kill the virus sooner."*

Fear of getting sick themselves

A 51-year-old woman: *"My eldest son got sick. I was taking care of him at home. I was always afraid that I or the rest of my family would get infected."*

Fear of getting sick and not having a caregiver

A 44-year-old man: *"I was caring for my sick wife at home. I was afraid that if I got infected myself, who would take care of me and my wife?"*

Fear of infecting others

A 31-year-old woman: *"I was caring for my sick husband at home. In addition to doing housework and taking care of my husband, I also had to do things outside the home, like shopping. I was afraid of getting infected and going out and infecting others."*

Hide the disease

A 24-year-old woman: *"My husband got coronavirus. We had to quarantine him at home. We had to lie that he had gone on a business mission so that others would not know he was sick."*

Being forced to leave home

A 27-year-old woman: *"My husband got sick, and because I was pregnant, I was afraid that I would get sick too, so I went to my father's house. My husband's brother agreed to take care of him. I was worried about him."*

Fear of neighbors getting infected

A 24-year-old woman: "We live in an apartment. The neighbors told me that we did not get infected with the coronavirus during this time, but you, who have a person infected with the coronavirus in your house, are infecting us as well."

Physical and mental fatigue in long-term care

A 42-year-old woman: *"At first, I got sick, but luckily, I recovered quickly. Then, my eldest son got sick and was hospitalized for a few days due to lung problems and then quarantined at home for a few weeks. My daughter and husband fell ill immediately after my son recovered. I was exhausted and emotionally drained from weeks of caregiving."*

Physical factors

Inability to care for the patient alone

A 54-year-old woman: *"I am sick myself and had surgery last month. I really cannot take care of my husband alone."*

Being a person with chronic diseases at home

A 55-year-old woman: *"My daughter is divorced and living with me and my husband. He has contracted coronavirus. I have a heart problem, and my husband has diabetes."*

Physical and mental fatigue in long-term care

A 42-year-old woman: *"At first, I got sick myself, and fortunately, I recovered quickly. Then, my eldest son fell ill and was hospitalized for several days due to lung problems, and then he was quarantined at home for several weeks. My daughter and husband became ill immediately after my son recovered. I was tired of caring for weeks and mentally exhausted."*

Discussion

Usually, those who experience quarantine feel uncomfortable about it. Separation from loved ones, loss of freedom, uncertainty about the state of illness, and boredom can have many negative psychological burdens, and disorders such as anxiety, depression, dysfunction, or unwillingness to work following quarantine are inevitable (14). In the present study, it was found that essential family challenges in caring for patients with COVID-19 include personal factors, social factors, economic factors, environmental factors, and psychological and physical factors. Research findings indicate that some families experienced economic challenges, job loss, deteriorating mental health, and illness during the COVID-19 pandemic. Implementing measures such as physical distancing, quarantine, and staying at home impacted family life from the early stages of the pandemic (15). Simultaneously, various public spaces, such as schools, childcare centers, community programs, religious venues, and workplaces, have experienced abrupt closures. These changes have significantly affected social life, leading to isolation, psychological distress, substantial economic hardship, depression, and even incidents of domestic violence, including child abuse (16,17). Families of people with COVID-19 (living or dead) are among the social groups that are particularly affected by stress and mental tension (18).

Emotional shock and trauma to other family members following the death of a family member is inevitable, and the support of relatives and especially the community can help such families (19). However, the sudden death

of a family member to COVID-19, especially when the victim is young and has no underlying illness, can expose families to more shock and unhappiness (20). A study by Sun et al examined the psychological experiences of nursing care for patients with COVID-19. In this study, 20 nurses who cared for patients with COVID-19 in the first hospital from January 20 to February 10, 2020, were selected using the phenomenological method. The interview was conducted face-to-face or by telephone, and the data were analyzed using the 7-step Colaizzi method. The psychological experiences of these nurses were summarized in 4 topics. First, the negative emotions that manifested themselves in the early stages include fatigue, discomfort, frustration from working too hard, fear and anxiety, and worrying about patients and family members. The second theme was self-adjustment skills, including life and psychological fitness, philanthropic behaviors, team support, and rational cognition. Finally, the last theme was positive emotions, which happen spontaneously with negative emotions. The study's results showed that in the conditions of epidemic outbreaks, negative and positive emotions of frontline nurses occurred simultaneously. In the initial stage, negative emotions prevailed. Positive emotions gradually appeared, and models of self-adjustment and psychological rejection played an essential role in protecting the mental health of these nurses (21).

The most significant subgroups of the first theme in the present study included responsibility for child care, responsibility for caring for the elderly, a large number of family members at home, lack of experience and lack of patient care training, and the need to get the patient out of the house. In this regard, a study in Sweden reported that an increasing number of older people living at home with chronic illness or disability, with the expected increase in the need for home care, create new demands for the Swedish health and welfare system, and this creates many challenges in caring for these people (22).

One of the most critical subcategories in the social factor theme found is stigmatization. The global issue of stigmatizing individuals with COVID-19 can be exacerbated by factors such as race, occupation, social standing, religious affiliation, and vaccination status. This stigmatization can result in adverse outcomes, including discrimination and social exclusion for those who are stigmatized (23). During epidemics, stigma, followed by social isolation, rises as a result of people's dread and anxiety about sickness with an unknown source and a potentially lethal conclusion (24). According to Bhattacharya et al, the COVID-19 pandemic has resulted in societal stigma and discriminatory conduct among patients and their relatives (25). So, in addition to people with COVID-19 who are rejected by society, their families and caregivers are also shunned. This rejection, which stems from the patient's dread of disease and death, as well as the prevalence of rumors, persists even after the patient heals or dies. While victims' families need help from family connections more than ever at this time, they are being rejected, which can make the process of adjusting to the death of relatives more challenging.

The present study showed that environmental conditions are one of the factors that explain family challenges in caring for patients. Saffari et al also showed in their study that personal hygiene, use of gas and masks during care, hand washing, and appropriate disinfection of the environment and equipment are crucial in the care of COVID-19 patients (26). It is necessary for healthcare providers to assess whether patients and their family members can follow recommended precautions, including hand hygiene, healthy respiratory conditions, a clean environment, and movement restrictions inside or outside the home (27).

In the current study, economic problems and failure to meet some basic needs related to COVID-19 were essential issues. Although social distancing and quarantining effectively reduce the spread of COVID-19, many individuals encountered difficulties adhering to these measures due to factors like residing in crowded, multi-generational homes and providing unpaid family care (28). Therefore, during emergencies such as epidemics and other outbreaks of infectious diseases, parents need to meet many demands on their families that require time, energy, and access to resources to ensure the safety of their children and families. In addition to meeting the family's basic needs, parents should also provide emotional and psychological support to their children in these challenging times (29). Also, a study found that economic crises were inevitable following the COVID-19 pandemic and that even with the crisis, people were more likely to attempt suicide (30).

Limitation

The qualitative approach has provided the most pertinent outcomes for this study, yet these results may come with constraints. Consequently, it is crucial to exercise caution when extrapolating the findings.

Conclusion

Considering the many efforts of the government to control the disease of COVID-19, it seems that the existence of challenges associated with the epidemic of such diseases can have destructive effects on the control of the disease. Therefore, to successfully control the disease, it is imperative to address the challenges of people. In this study, the most critical challenges faced by families during COVID-19 included personal, social, economic, environmental, psychological, and physical factors. Providing social and psychological support from the government, friends, and experts in this field, financial support such as providing protective equipment from governments in the event of a crisis, helping to de-stigmatize such diseases from the government and people, prioritizing certain people for treatment like people with chronic diseases, holding counseling sessions, especially

for people at risk of COVID-19, and holding training courses for community members can be effective in reducing these challenges to a great extent.

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Competing Interests

There is no conflict of interest.

Ethical Approval

The present study is a research project (No. 1399-80) conducted at Larestan University of Medical Sciences. It was approved by the Ethics Committee of Larestan University of Medical Sciences (IR.LARUMS.REC.1400.022).

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