

## Title page

**Manuscript title:** Interpreting the Lived Experiences of Home Caregivers in the Families of Patients with Covid-19 in Iran: A Phenomenological Study

**Running Head:** home caregivers in covid-19

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## Interpreting the Lived Experiences of Home Caregivers in the Families of Patients with Covid-19 in Iran: A Phenomenological Study

### Abstract

**Background:** Following the spread of Covid-19, many patients received home care services for recovery. The family is one of the informal caregivers who provide daily physical and psychological support to the patient, and they have the most contributions in the care of patients. Accordingly, this study explains the experiences of home caregivers in the families of patients with Covid-19.

**Methods:** This is a qualitative study with a hermeneutic phenomenological approach. Purposeful sampling was applied, and semi-structured interviews in the Center of Covid-19 Control in Khoy, Iran, were used to collect the information. Twenty-three family caregivers, who had already provided care for patients with Covid-19 at home, participated in the study. The themes emerged from interviews. The interviews were recorded and transcribed then analyzed using Dickelman's interpretive phenomenological approach.

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**Results:** 13 primary concepts, six sub-themes, and three main themes were extracted from the data analysis, including "Irrational fear of disease" with sub-themes: fear of getting infected and Indulging in strength of immune system, "Increasing the burden of care in caregivers" with sub-themes: lack of support and caregiver's family challenges and "Self reinforcement" with sub-themes: highlighting positive features and turning to spirituality.

**Conclusion:** Understanding the complexities, experiences, and beliefs of family caregivers about living with a Covid-19 patient provides a comprehensive perception of the psychological and physical consequences of care. Executive decision-makers, health care personnel, and mental health professionals can also take the necessary strategies to support and manage home caregivers and interdisciplinary cooperation.

**Keywords:** Family Caregivers, Covid-19, Experience, Phenomenological Study.

## **Introduction**

Covid-19 is the third known animal coronavirus after Severe Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome (MERS) [1]. Although that Covid-19 can be transmitted through droplets, close contact (within 1 m), aerosols, and possibly oral-fecal transmission, patients can also transfer the virus to other people in the incubation period [2, 3]. It is associated with Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome (MERS), but shows some specific pathogenic, epidemiological, and clinical features that are not fully understood to date [3].

There have been 26,468,031 confirmed cases of Covid-19 globally, including 871,166 deaths in the world and 382,772 confirmed cases of Covid-19 with 22,044 deaths in Iran based on the report of the World Health Organization (WHO) on September 5, 2020 [4].

Patients with mild symptoms of Covid-19, without chronic conditions that are aware of the disease can be care and treatment at home by compliance with all precautions. Family caregivers should apply the principles of home care to these patients. Despite the existence of numerous epidemiological studies on the outbreak of disease, there is little information for support family caregivers of patients with Covid-19 [5]. The effects of Covid-19 may have impacted caregiving intensity, which is defined as the amount and type of care provided by informal caregivers [6]. It also may have affected caregiver's caregiver burden, which is defined as the impacts on physical and mental health, and health-related quality of life may also have changed due to the pandemic [7]. One study found that informal caregivers are likely at greater risk for adverse effects on their health due to the pandemic as they have been found to have particularly more stress and suffer from more depression and physical problems [11].

The different nature of Covid-19 and the need to maintain public safety, will limit the physical presence with patients, and therefore caregiving in this situation will be unique for everyone involved. The importance of maintaining social distance to control the Covid-19 pandemic probably increased isolation, loneliness, psychological stress and other adverse health problems [12]. Social and family relationships are disrupted not only for patients but also for their caregivers [13]. Mirzaei et al (2020) indicated that caregivers of patients with Covid-19 face greater challenges compared to other caregivers because of limited training and resources at hand and their lack of knowledge about this emergent disease and the way to care for the patient [14].

The result of a review showed that sleep disorders, fatigue, and inadequate self-care were recognized as common physical health problems in family caregivers [15]. Other qualitative and quantitative study show that family caregivers may also grapple with anxiety, depression, apathy, disappointment, loneliness, and isolation because of reduced social interactions and social exclusion while providing that care [16, 17]. Covid-19 conditions have overwhelmed family caregivers, as well as others in the community, with new economic stressors such as job loss by the household head and high medical expenses. Many family caregivers have other roles in addition to the caregiving role such as managing

their job, housekeeping, child care and additional responsibilities and concerns about their children's education due to school closures from Covid-19. They also must strive to protect themselves and other family members from virus transmission and all of this is more difficult to manage than caring for other disease or in other situations [18]. Abendroth et al. also argued that the anxiety about caring for a patient at home can be reduced by seeking information in caregivers as an adaptive strategy [19].

Given the importance of home care follow-up and self-care education to patients and families, counseling centers and home care services are obliged to provide the necessary training to families to provide care services for patients at home according to the guidelines of Ministry of Health and Medical Education [20]. Under WHO guidelines, any patient with a severe acute respiratory infection should be triaged and admitted to the hospital. However, people who have the mild disease do not require hospitalization and, to continue the treatment and care in the home, can be referred to health centers [21].

The acceptable criteria of WHO for home care of patients with Covid-19 are as follows: Patients who do not tend to stay in the hospital, patients with mild symptoms, and those who do not have systemic diseases such as immune deficiency, cardiovascular disease, or the risk of developing complications. The patient and family should comply with the treatment, including isolation at home, hand washing, respiratory hygiene (sneezing, coughing, etc.), cleaning the environment, and can observe safety-related issues (e.g., prevention of fire when using detergents or hand rubs containing alcohol) [22].

Evidence shows home-based caregiving effects on caregiver's quality of life and life satisfaction. Due to the combination of social distancing recommendations, stay-at-home orders, limitations on gatherings, and the disproportionate impact of Covid-19 itself on mortality and morbidity among older adults, there is a critical and immediate need to understand the specific challenges and changes experienced in family caregivers [7].

Considering the peak of Covid-19 in Iran and the lack of human resources, physical space, protective and therapeutic equipment in hospitalization of patients, many Covid-19 patients with mild to moderate

symptoms are obliged to receive home care services. Since most of studies have focused on the experiences of patients or health care staff and few studies has been conducted on family caregiving experiences in Iran and global level, so the consideration of caregivers' experience and their problems is necessary to plan services and support them. Therefore, better understanding how the pandemic has impacted home caregivers can inform future interventions to address stress and health problems stemming from caregiving through the pandemic along with the everyday issues normally encountered. This study was conducted to explain the lived experiences of home caregivers in the families of patients with Covid-19.

## **Methods**

### **Study design and setting**

Phenomenological approach, was developed by Taylor and Bogdan, 1975 to the social sciences [23] but Diekelmann et al. 1989 applied hermeneutic phenomenological approach in health and nursing education [24]. So this qualitative study was carried out using Dickelman's method. This study is used when the researcher needs the revelation of the little-known or unknown phenomenon through an in-depth examination of the lived experiences of people involved in that phenomenon [25]. The present study was conducted in the Center of Covid-19 Control at the Khoy University of Medical Sciences, Iran.

### **Study Participants**

The study participants consisted of 23 family caregivers who provided care for patients with Covid-19 at home and willingness to participate in research. Participants were selected using purposeful sampling method. Inclusion criteria are participants who have patients with Covid-19 at home based on laboratory tests (PCR, or clinical symptoms and positive lung CT scan) and home caregivers who have cared for a patient with Covid-19 for at least 14 days and have not affected by Covid-19 during the care of a patient. Exclusion criteria included participants who showed clinical signs of Covid-19, home caregivers who cannot take care of the patient, incapable of verbal communication, and any psychological disorder that

causes a lack of transfer the individual experiences. Sampling continued until data saturation was achieved when the researchers perceived that no new themes were emerging. Saturation in qualitative studies constitutes the completion of code levels, and new conceptual information requiring new code or expansion of the existing code is not obtained [26].

### **Data collection**

The semi-structured interviews were used for data collection. After explaining the goals and importance of research to the participants, the informed consent was obtained to participate and record the interviews. Participants were assured that the obtained information would be used only for the research and would remain confidential. The interview was planned and implemented concerning the qualitative questions of research and focusing on the experiences of home caregivers of patients with Covid-19 (Table 1). Interviews were conducted individually with 23 participants at the private rooms of Covid-19 Control Headquarters, where there is no or minimal employees commuting to the place, having proper ventilation and a window to the outside of the building, while maintaining a social distancing of at least 2 meters with the participant, and using gloves and masks. Each participant was interviewed only once, the total number of interviews was 23 and there was no conflicting data. The interviews lasted between 45 and 60 minutes, and then interviews were transcribed by putting speech of participant into written or printed form. Data were collected from April to March 2020.

### **Analysis**

Phenomenological philosophy is based on beliefs of Taylor and Bogdan have dominated in the social sciences [23], but in the health and medical sciences especially in nursing used Dickelman's approach of hermeneutic approach for interpreting data [24]. This approach used when the research purpose is understanding the human lived experience. In this way, the researcher categorizes the data by interpreting the discourse of participants [24]. So in this study, the interviews were analyzed using the principles of hermeneutics phenomenology as developed by Dickelmann (1989). This qualitative approach was

selected because it gives a high level of access to participants' lived experience [24]. The analysis was done by a 6-member interpretive team and involves Dickelman's 7-step of analysis (Table 2).

## **Trustworthiness**

Credibility, Confirmability, Transferability, and Dependability by Lincoln & Guba (1985) were employed to achieve the trustworthiness and validity of the study [27]. Credibility means that the findings of the study are real and that the findings reflect the research objective and social reality of the participants. To ensure the credibility of the findings, there was a prolonged engagement with the participants and data. The findings were shared with some of the participants. For this purpose, the transcribed interview and the extracted primary codes were presented to the participants, and they commented on its accuracy, and in case of any discrepancies, they were considered. To ensure the confirmability of the findings, the interviews and all procedures taken to conduct the study were recorded and complementary comments of research team were applied in data analysis. To check the dependability of the findings, an external reviewer who was familiar with both the clinical setting and qualitative research was asked to review and confirm the results. The transferability of data was achieved by maximum variation of the samples such as different levels of age, education, occupation and family relationship with the patient.

## **Results**

Participants' demographic details and their relationship to the patient are presented in Table 3. The themes emerged from quotes of family caregivers (Table 4). The codes extracted from the interviews led to the emergence 13 primary concepts, 9 sub-themes, and 3 main themes (Table 5).

### **1- Irrational fear of disease**

#### **1-1- Fear of getting infected**

Because of the permanent intellectual engagement about the transmission of the Covid-19 to the caregiver and family members, frequent washing and disinfection of hands and home appliances was done. As some caregivers were suffering from respiratory allergies but, due to obsessive thoughts and fear about getting infected with the virus, could not emancipate themselves from these behaviors.

### **1-2- Indulging in strength of immune system**

Some caregivers had too much sensitivity to strengthen the immune system through which they could reduce the risk of affliction with the disease. They tried to consume diverse herbal teas, which properties of some of them have not been approved, to strengthen the immune system.

## **2- Increasing the burden of care in caregivers**

### **2-1- Lack of support**

Many patients and caregivers expressed that the government and medical team were unaware of their care problems at home. In most cases, patients are cared for in a shared room at home with other family members, and there was no separate room or suitable place in the house to care for them. Besides, necessary training about patient care was not given to the caregivers. Moreover, lack of financial resources, high cost of treatment, job interruptions, ... was caused financial burden in families and caregivers.

### **2-2- Caregiver's family challenges**

Patient care by the family caregivers provides a context for neglect and inattention of other family members. This issue is a predisposing factor for damage to family members. Therefore, many caregivers assumed that their pressure and stress they endure are more than patients. That is because the caregiver must not only meet the patient's needs but also be responsible for a lot of family problems and issues.

## **3- Self reinforcement**



### **3-1- Highlighting positive features**

Putting the caregivers under the challenging conditions of care provision caused the revelation of positive human characteristics such as patience, strength, and resilience in the face of hardships, calming down, increasing a sense of altruism, and helping people in need.

### **3-2- Turning to spirituality**

Given the exposure of caregivers to stressful events such as caring for a patient with Covid-19, spiritual growth emerged in them and made them more resistant to the hardships caused by the care. There were things like a change of attitude in life, deepening the relationship with God, appreciation for blessings, being thankful for God's blessings, and hoping in God in the direct quotes of these participants.

## **Discussion**

The themes obtained from the interview with the participants were an attempt to achieve the main purpose of the study that was to explore the experience of home caregivers of patients with Covid-19.

### **Statement of principal findings**

The results of this study showed that long-term care, performing tasks related to patients' daily activities and patients' psychological problems, along with the physical fatigue of caregivers, had caused mental disorders such as burden, obsessive behaviors and fear of disease transmission in caregivers. Of course, in addition, the participants had positive experiences such as tending or serving to strengthen itself. Therefore, it can be said that the disease had positive and negative consequences on caregivers. The development of obsessive behaviors, increasing the burden of care in caregivers and high human achievements are the important themes of the present study.

### **Interpretation within the context of the wider literature**

The Irrational fear of disease was one of the main themes. Participants stated that thoughts of fear of transmitting infection and disease automatically enter their minds. Due to these obsessive-compulsive behaviors, the duration and frequency of hand washing and sterilization of equipment dramatically enhanced in them. Caregivers said they were too sensitive to boost immune system to help the patient to overcome the virus and prevent other family members from becoming infected.

In this respect, the study of Brooks et al. (2020) demonstrated that fear of disease transmission and concern of getting infected with the Covid-19 increases dramatically in critical situations and epidemics. This concern in families with small children or pregnant women is much more than in other families [28]. Perhaps many people are not familiar with the nature of Covid-19, and infection is stigmatized as the patient not respecting their health and not following proper hygiene practices, therefore developing obsessive behaviors.

Due to fear of jeopardizing the family's health, participants were trying to strengthen their immune systems. In this regard, Caleo et al. (2018) indicated that individuals in critical conditions are incredibly concerned with their family situation and are continuously seeking extreme care for them [29]. Moreover, Louca et al. (2021) study showed that a number of micronutrients have been shown to play key roles in supporting immune function and in reducing risk of respiratory infection, also they observed modest but significant association between use of dietary supplements and lower risk of testing positive for SARS-CoV-2. However the results were significant only in women but not significant in men [30]. Considering that, it is reasonable to hypothesize that vitamin supplementations may enhance host immune responses against Covid-19.

The problems of patients, lack of support for the patient and family are the basis of many stresses that targeted the participants' souls. Hence, one of the themes derived from this study was the increased burden of care in caregivers. Wang et al. (2011) also revealed that some factors could influence increasing the care burden. Some of these factors are concerns associated with the risk of afflicting

disease, ambiguity in the status of career prospects, lack of income-generating resources, lack of adequate facilities at home in the period of home care, and the lack of sufficient support of the medical and governmental system of patients after discharge [31]. Asgari et al. (2020) identified several challenges in family caregivers of patients with Covid-19, the main themes of the study were "captured in a whirlpool of time" and "feeling helpless" and "loneliness". A part of these experiences was due to careers, to protect other family members and friends against getting the virus, isolating themselves due to a fear of others becoming infected [32]. Thus, providing relevant information on symptoms, medical and protective care, support in preventing disease complications, and identifying the factors that cause the burden of care on the caregiver is essential [33].

Many participants had economic concerns. The families of patients who are cared for at home and can not go to work suffer from great economic pressure [13]. The research performed by Brooks et al. (2020) indicated that financial concerns are among the adverse psychological outcomes of closure because of home quarantine. Governments and policymakers should make the necessary mutual trust to people in the community and offer financial compensation for their losses [28]. Furthermore, the findings of the study conducted by Hertz-Palmor et al. (2021) indicated that the most significant psychological problem that arose after the recovery of SARS in China was the reduction of financial resources and household incomes so that it was regarded as the highest predictor of reducing mental health [34].

One of the most prominent positive consequences caused by caring for family caregivers was self reinforcement. The caregivers felt that they had become a human being who were more insightful and mature in the care process. They expressed that caring has led to a deeper relationship with God, appreciation of blessings, gratitude for God's blessings, better acceptance of situation, and a positive direction in life.

Investigations have also indicated that those who use positive strategies to cope with stress decrease adverse outcomes and increase positive results [35]. Religious behaviors and beliefs have a positive

impact on the meaningfulness of life. Behaviors such as trust in God, worship, pilgrimage, etc. can bring inner peace to individuals through creating hope and encouraging positive attitudes and they can incur less damage in the exposure of stressful life events [36]. Besides, divine fate has been taken into consideration from two perspectives. Some people consider it as a God bless, others believe that these events awake people and they are an opportunity for people to be prepared for the present situation [32].

### **Strengths and limitations**

One of the limitations in this study was the personal characteristics and mental concerns of the participants affecting their response. Therefore, by explaining to the participants before the interview and conducting in-depth interviews, the researcher tried to minimize this limitation. In the case of lacking preparedness of participants, another time was considered for the interview. One of the strengths of the present study is variation in sampling. Attempted to sampled from the caregivers of different age, gender, cultural, social, and economic domains.

### **Implication for policy, practice and research**

Health care providers are required to consider the role of family members in providing care for patients and their home care challenges. Also, it is recommended that interventions such as education to the patient and his/her caregiver, counseling, family therapy, and referral to financial support groups to reduce the pressures of caring should be considered. This can both promote the quality of patient care and guarantee the physical and mental health of caregivers as unknown patients. It is recommended for the health staff to check the health of these people regularly via telephone and, if possible, provide in-person visits daily. Besides, sharing positive experiences of family caregivers allows the researchers to design interventions to decline negative consequences.

### **Conclusion**

This study implies that much attention should be paid to psychosocial, physical, Mental, family relationships health of caregiver to provide high quality care to the patient. We can conclude that the level of care pressure in caregivers of Covid-19 patients is high. It is possible that these pressures reduce the level of patient care and also jeopardize the physical and mental health of caregivers. It can also turn the families of these patients into vulnerable families who require intervention, counseling, and follow-up over time.

### **Contributorship**

All authors participated in the process of the initial drafting of the article, review, presentation of the initial idea and design, collection of the data, analysis, interpretation of the data, and all of them take responsibility for the accuracy of the material contained in the study.

### **Ethics and other permissions**

This paper is part of the results of a research project approved by Khoy University of Medical Sciences, Iran, which has been approved by the ethics committee of that university (IR.KHOY.REC.1399.022). Participants were given enough information, and each person signed an informed consent form to participate in the research and audio recording during the interview. Moreover, the necessary explanations about the optionality of participating in the study, the confidentiality of the information obtained, and the possibility of withdrawal from the study at any stage were provided to the participants.

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### **Conflict of interests**

No known conflict of interests.

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## Data Availability Statement

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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**Table 1.** Example of interview question

<b>Main Questions</b>
1. What does patient care mean?
2. What does it mean the care of a patient with Covid-19?
3. How did you feel when you accepted the care of a patient with Covid-19?
4. Express your experiences during caring for patients with Covid-19?
5. Give us some examples of your best experiences during this period?
6. Give us some examples of your most unpleasant experiences during this period?
<b>Probing Questions</b>
1. Can you elaborate further in this case?
2. What do you mean by this statement?
3. What is your impression of this case?
4. In your opinion, what is the meaning of this experience?

**Table 2:** Summary of Diekelmann's method of analysis and data analysis activity

<b>stages</b>	<b>Analytic process</b>	<b>Data analysis activity</b>
First	Reading and rereading descriptions	-Transcription was read as a whole to gain an overall understanding and impression of the narrative - Then, the narrative was reread line by line
Second	writing interpretive summaries and coding for	- Short interpretive summaries were written, and the common themes with exemplar quotations from the narrative were identified to support

	emerging themes	the interpretation -Clusters of themes were merged and these classifications were named.
Third	analyzing selected transcripts as a group to identify themes	- Collaborative analysis was performed, to do these meetings were held biweekly to discuss interpretations for similarities, differences, or contradictions.
Fourth	Returning to the text or to the participants to clarify disagreements in interpretation and writing a composite analysis for each text	- If conflict occurred or further interpretation was needed, the group returned to the original text and reread all texts to identify hidden meaning and link themes. - Or were consulted the original interviewers for clarification.
Fifth	comparing and contrasting texts to identify and describe shared practices and common meanings	- The researcher compared and interpreted the relational themes to uncover the constitutive patterns existing within the relational. The constitutive pattern expressed the relationship of all the previously identified themes
Sixth	validation of the interpretations	- Draft themes and constructive patterns were observed by the researcher's supervisor. - All responses and suggestions received were integrated into the final draft. - The individual texts and audiotapes were also reviewed many times to allow the researcher to become further immersed in the hermeneutic circle, gain an in-depth understanding of each participants' experiences, and further validated the interpretations.
Seventh	eliciting responses and suggestions on a final draft	- Excerpts from the participants' own words that reflected the strong meaningful transactions were included in the final written report.

**Table 3: Participants demographic details**

Characteristic	Classification	N (%)
Gender	female	17 (73.92)
	male	6 (26.08)
Marital status	married	18 (78.26)
	single	5 (21.74)
Educational level	elementary/diploma	13 (56.55)
	associate degree	6 (27.75)
	bachelor	4 (15.7)
Employment Status	employee	5 (21.74)
	housewife	12 (52.18)
	free job	6 (26.08)
Family relationship with the patient	mother	4 (17.39)
	father	3 (13.04)
	sister	1 (4.35)
	brother	1 (4.35)
	child	5 (21.73)
	spouse	9 (39.14)
<b>Age</b>	Mean (SD)= 43.5 ± 7.6	

**Table 4: Quotations of family caregivers and primary concepts**

Quotation	Primary concepts
"Every day, I have to disinfect the washbasin, the bathroom, the room surface, the door handles, and the dishes several times. On the other hand, I can't wash my spouse's clothes in the washing machine, and I have to wash them into the basin and pour	Frequent washing of

<p>disinfectant liquid on them. Doing all these things really takes a lot of my time, and I get tired. However, if I don't do these things, the children (members of the family) or I will get infected."</p> <p>"My health has changed a lot since my husband took the corona. I use masks and gels regularly and wash my hands frequently with soap and water."</p> <p>"Whatever I touch, I wash my hands, for example I disinfect the door handle regularly. I'm really afraid that the disease will be transmitted to me."</p> <p>"We washed our hands a lot with soap and alcohol, we became obsessed. When we go out on the street, if we do not shake hands, we will go home again after washing and wash our hands. Well, one is afraid."</p>	<p>hands</p>
<p>"Because of the constant washing of hands and disinfection of furniture and kitchen utensils with Javel Water (Sodium hypochlorite) before each use, I am suffering from lung problems, even my child has an obsession and washes his/her hands constantly."</p> <p>"Because my husband has a heart disease, both he and I were very upset about Corona. I even disinfect the inside and outside of the car and then I get in the car. I disinfect the phones several times a day. All of the things that I buy from the outside, first take out the bags and then, if they are washable, I wash all of them or disinfect their surface."</p> <p>"Previously, if I washed the fruit once, now I put the fruits in a pan, disinfect them with vinegar and salt, leave them for half an hour, and then wash them again."</p>	<p>Continuous disinfection of surfaces</p>
<p>"Permanently, I give my daughter strengthening foods and a variety of effervescent tablets at home to eat them and recover sooner because it is believed that Vitamin C and D are excellent."</p> <p>"The doctor said that I should give fruits that contain high vitamin C to my son at home because it strengthens the immune system. I also buy oranges, tangerines, lemons, grapefruits, oranges and kiwis wherever I saw, and then I would take the juice and let it eat."</p>	<p>Excessive use of vitamins</p>
<p>"My wife and me drink ginger and lemon herbal tea every day so that our bodies to be strong. I became highly sensitive to the immune system of myself and my family."</p> <p>"I knew that they get Corona, should drink plenty of warm fluids, so I went to a store of medicinal herbs and bought mint, thyme, chamomile and a few other herbs in combination and gave them to my parents to drink every day in a form of herbal tea."</p>	<p>Consumption of herbal teas</p>
<p>"Since my husband got afflicted with Covid-19, he does not go to work for about two months, and I think someone else was replaced to work in the factory. I don't know what to do; we have a lot of loans and installments that we must pay for them. On the other hand, we have to think about the monthly rent of the home and the cost of our needs."</p> <p>"Corona has caused part of the cost of living to be spent on prevention supplies. But now my husband cannot go to work due to illness. I also spent all the money we had saved during this time and I do not know what will happen next. We were really suffered financially."</p>	<p>Economic concerns</p>
<p>"There are strict rules in the hospital that do not let you see a doctor directly; additionally, they are always busy. They do not matter at all what my problems are concerning the care of my mother? And how do I deal with the problems? In addition to her illness, my mother is also depressed. She does not talk to anyone. These do not care for the medical staff."</p> <p>"Well, in terms of the potential of finding out, understanding, or effective use of health information, everyone is different. Some have enough information and skills, and others do not. I went to search for it and obtained the information; no one taught me, but many people, especially the elderly, do not have the condition and cannot do it."</p>	<p>Lack of responsiveness of the medical team after discharge</p>
<p>"During this period, I have taken after my father and done his work since I am the only son in the family (an only child); however, because of quarantine, I do not have access to my wife and child, and I cannot go to them. This has caused problems in my family".</p> <p>"I take care of my husband who took the corona in our house and sent the children to</p>	<p>Isolation of the caregiver</p>

<p>their grandmother's house. I was worried that would get a corona and that my children would be without a mother. It has been about two months since I did not hug my children, fed them or slept with them.”</p> <p>“I was worried about my mother having diabetes and heart disease. I had nightmares that my mother had taken a corona. I am very dependent on my mother and I am always worried about losing her.”</p>	
<p>"The patient's caregiver is more engaged in the situation and is under pressure than the patient himself because the caregiver follows up all the patient's work and needs. On the one hand, he is looking for drugs; on the other hand, looking for the cost of living. Moreover, he has to do all the sick work at home. Now, judge for yourself."</p> <p>“During this time I went to work and took care of the patient at home. I felt I had no strength left. Most of the relatives would call to ask for help, but I did not even have enough time talk to them.”</p>	<p>Strict conditions of caregivers towards patients</p>
<p>"We did not tell any of our relatives or neighbors about my father's disease, for we knew that if they found out, they were bothering us, would constantly ask how he was afflicted with the disease, why he did not respect, and they look at us completely differently as if we have a leprosy patient at home."</p> <p>“Community perception of Covid-19 is not just a disease and is not limited to a person with the disease, but is identified as a person who most likely did not have health behaviors and as a result of these unhealthy and careless behaviors, they have get corona. So we did not want anyone to know about the disease.”</p>	<p>Hiding the disease from relatives and others</p>
<p>"During this period, I became stronger and more patient. I think I can tolerate difficult situations more easily. Difficult situations can be in terms of finance, loneliness, and problems that can happen to humans."</p> <p>“My husband is a touchy and irritable person. He has made a thousand excuses since he got sick and I take care of him at home. But I think God has increased my patience and strength so that I can take care of my husband and children. Now I am facing the problems of life alone, well, this disease, which is not permanent, we have to increase our patience and endurance.”</p>	<p>Patience in difficult conditions</p>
<p>"Now, I have become more discerning, I have realized and understood my mother's love for myself more. I have found that if I am at this position at present, it is because of my mother's forgiveness and sacrifice."</p> <p>“Nothing makes me feel better and happier than seeing my wife calm and well, thank God I am by her side and I can help her.”</p>	<p>Opportunity for love</p>
<p>"Now, many things have changed a lot, I appreciate life more, I appreciate what God has bestowed me, and I appreciate my health so much more than before, maybe I was a little unaware of it, I thank God for all this."</p> <p>“In general, caring has given me knowledge, the knowledge of the path I am going to take, where I have made mistakes in life and where I have used the blessings of God correctly, it has made me aware that I am always grateful for the health that God has given me. In a word, I want to say that I became another human being.”</p>	<p>Appreciation for blessings</p>
<p>"This disease influenced me a lot. I got closer to God, the opening out of a heart for God makes me very calm, and it is the reassurance of my heart. I am less ungrateful, and I always think He knows the best of everything."</p> <p>“It is true that I did not leave anything for my son at home, but I was also worried about his condition. Every time I prayed and recited the Quran, and I even vowed that God would cure my son of this disease. God has helped me everywhere and I am sure that he will never leave me alone.”</p>	<p>Nearness and recourse to God</p>

**Table 5:** Main themes and sub-themes extracted from the interviews conducted

<b>Primary concepts</b>	<b>Sub-themes</b>	<b>Main themes</b>
Frequent washing of hands	Fear of getting infected	Irrational fear of disease
Continuous disinfection of surfaces		
Excessive use of vitamins	Indulging in strength of immune system	
Consumption of herbal teas		
Economic concerns	Lack of support	Increasing the burden of care in caregivers
Lack of responsiveness of the medical team after discharge		
Isolation of the caregiver	Caregiver's family challenges	
Strict conditions of caregivers towards patients		
Hiding the disease from relatives and others		
Patience in difficult conditions	Highlighting positive features	Self reinforcement
Opportunity for love		
Appreciation for blessings	Turning to spirituality	
Nearness and recourse to God		

ACCEPTED MANUSCRIPT