



## Lived experience caring for a child with Covid-19 disease: A phenomenological study

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### ARTICLE INFO

#### Keywords:

Lived experience

COVID-19

Phenomenological study

### ABSTRACT

**Background:** Caregivers of COVID-19 patients, including mothers with an infected child, are affected by adverse physical and psychological effects. Since mothers perform an important role in caring for a child with Covid-19, explaining their challenges and experiences positively affects the health conditions of children and society, in general.

**Aim:** This study aimed to explain mothers' experiences with children diagnosed with COVID-19, who were referred to Bandar Abbas Children's Hospital.

**Method:** The present study was qualitative and used the Van-Manen method. The statistical population included 13 mothers with children hospitalized for coronary heart disease and COVID-19, who were selected by purposive sampling. Semi-structured interviews were implemented to collect data until saturation. Data analysis was performed using MAXQDA 10 software. Lincoln and Guba's criteria were used to evaluate the data's accuracy and strength.

**Results:** The mean age of mothers participating in the study was  $37.92 \pm 4.87$ . On the other hand, the mean age of children was  $5.15 \pm 2.07$  years. Three main themes and 13 sub-themes were extracted from the data analysis. The main themes were "Inability to Caring", "Mental and Physical drain" and "Conflict of Roles and Responsibilities". In this study, when a child develops COVID-19 disease, the mother experiences a series of negative emotions, which lead to feelings of helplessness and inability to care for the child.

**Conclusion:** Mental and physical manifestations strains were the most important issues that the mothers experienced. The majority of the participants need psychological support to cope with the disease. Therefore, it is recommended to make a proper design to psychologically and socially support these mothers, while alleviating the physical manifestations of their children's disease.

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<https://doi.org/10.1016/j.heliyon.2023.e18481>

Received 17 October 2022; Received in revised form 17 July 2023; Accepted 19 July 2023

Available online 20 July 2023

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## 1. Background

Coronavirus disease 2019 (COVID-19) is an acute respiratory disease that appeared in late 2019, in Wuhan, China [1]. The mentioned disease has spread rapidly throughout the world due to its highly contagious property. In a short period, the Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) virus infected all countries and generated a pandemic [2]. According to the latest statistics released by the World Health Organization on June 22, 2021, the number of people diagnosed with COVID-19 in the world was 178503429, which represents a quarter of the Asian population. Iran, like other countries in the world, was immersed in the coronavirus pandemic [2]. The number of patients in the mentioned country, until July 1, 1400, was around 3117336 people. Children of any age can develop COVID-19 [3–5]. Studies show that between March and December 2020 in the United States, more than 1.2 million people with COVID-19 were children under the age of 18; 60% of the mentioned group were between the ages of 10 and 17 [6]. The mortality rate of COVID-19 also varies with age; less than one percent [7]. Has been reported in the under-18 age group and 2% in people between 10 and 39 years [8]. So Young Kim concluded in his study in 2022 that, the countries with compromised economic status presented a higher death rate despite relatively lower incidence of COVID-19 than the developed countries [9]. Contagious diseases that require family care are considered important stressors for parents [10]. Having a child with COVID-19 causes parents to experience new responsibilities in meeting their his/her emotional and physical needs, to maintain a normal family routine and other life commitments [11]. Studies show that crises caused by a child's illness are a major source of stress and anxiety for the family. Disbelief, guilt, anger, and frustration are some of the feelings that parents experience during this period [11,12]. Since the mother has a more colorful role in caring for her sick child, she has to take care of him/her while performing her job duties and balancing the needs of the family [13]. The results of a study performed by Mazzone showed that mothers of hospitalized children are very concerned about them. This situation generates stress crises in mothers; for that reason, it functions as a factor that prevents them from executing their care activities [14]. Problems are experienced both at the individual level, such as anger and irritability, and at the interpersonal level, such as uncomfortable interactions with the child [15]. The mentioned crises generate a special need, which is connected to paying attention to the mothers' concerns and requirements. To allow the mother to be able to provide adequate care and support for the child, she must be calm and immersed in a secure environment. Thus, she would be capable of understanding and managing her concerns and stressors, which would help her to provide higher-quality care to her child [16]. It can be said that, although the physical health of the mother is very important, it is important to know that it depends on her mental health. At the same time, mental health guarantees the health of her family and the child she raises. Maintaining and protecting mothers' mental health requires identifying their feelings, concerns, and problems related to the process of taking care of a sick child. Due to the rapid spread of COVID-19 worldwide and the psychological effects that the mother experiences after the infection of her child, it is necessary to execute a strategy focused on protecting their mental health. Firstly, the mother's challenges and experiences have to be identified and explained, as well as her needs and concerns associated with the pandemic. Subsequently, the collected information has to be presented to competent planners and care managers, who can create a solution to provide the infected child with comprehensive care and improve the health conditions of his/her mother, family, and community. An in-depth understanding of these experiences is possible only with qualitative research; it allows the researcher to enter the inner world of participants to determine the meanings formed in a particular group [17]. Therefore, the present study aims to explain the experiences of mothers with a child with COVID-19.

## 2. Method

This hermeneutic phenomenological approach (using the Van-Manen method) was used to describe, interpret, and understand the challenges associated with the experience of caring for a child with COVID-19. Phenomenology is a way to investigate subjective phenomena and is based on the belief that essential truths about reality are grounded in everyday experience. Hermeneutic phenomenology was selected for this study, considering that this approach is sufficiently competent to understand and assess complex human experiences. It focuses on the exact description of the world as it is experienced. In a hermeneutic approach to phenomenology, the researcher sought and interpreted the sense of unity using an established method [17,18]. In the study, phenomenology aims to arrive at an essential understanding of mothers who care for their children with covid-19 consciousness by describing features common to all people who have the experience. caring for a child with COVID-19 is a new phenomenon, and existing literature on the outbreak does not readily inform us about the inherent complexities and intricacies of other emotional responses to this unparalleled crisis. The researchers, through the interplay of six activities, used Van-Manen's method of phenomenological research.

### 2.1. Participants and setting

We conducted this qualitative study on mothers with children with COVID-19, who were hospitalized at Hormozgan University of Medical Sciences, Iran. The participants were interviewed at the mentioned hospital. Data was collected using a purposive sampling method through in-depth interviews. We interviewed mothers in the period between September and October 2021. The rationale for the sample size, in this hermeneutic phenomenological approach, was obtaining a diverse sample and having adequate textual data to make a maximum variation of qualitative data. The research environment was a pediatric educational and treatment center in Banadr-Abass, which is related to the Hormozgan University of Medical Sciences and has an active bed of 152 referral and hospitalization centers for children with COVID-19. The aim of the study was explained in detail to all mothers. Before the study, an informed consent form was taken from all participants. They received necessary information regarding voluntary participation, and confidentiality of the data, and they could withdraw from the study at any time. In selecting the participants, the investigator tried to include mothers of different ages, children of both sexes, the field of various cultures, children's diseases with different severity, and different levels of

education that have different experiences to provide maximum diversity in the samples.

The criteria for inclusion in the study were mothers who had a child with COVID-19 admitted to a children's hospital. All the participants were hospitalized in the pediatric ward or special care for children after a COVID-19 diagnosis was confirmed by the pediatrician. The mothers' willingness and ability to participate in the study were other included criteria. Time spent since the child's diagnosis was different. Exclusion criteria also included unwillingness to participate in the study. Mothers were chosen from a varied sample of participants, which included both employed women and housewives, with one or more children, and mothers with different education levels. Then, individual satisfaction was measured and the demographic information form included the child's age and education level. Finally, the selected participants were interviewed, adhering to biosecurity protocols.

The length of each interview was 30–45 min. Overall, 13 mothers were interviewed. In the present study, the researchers performed the processes of data collection and analysis simultaneously. When data saturation was obtained, the identified data and class were duplicates of the previous data, and no new class was obtained, so the interviews were stopped.

The interview was conducted in a hospital meeting room. The room was disinfected and well-ventilated. For precautionary reasons, the researcher did not interview more than 2 people per day. Also, other precautions such as wearing masks, and gloves, and maintaining distance were done for more protection. Before the interview, the mother's trust was gained to participate in the study by explaining the work process, the purpose of the study, and that you have full authority to refuse the interview and withdraw from the study at any time during the interview. At the end of each interview, the participants were asked for permission to continue communication, so that if there is a need for further interviews or the recorded sentences are ambiguous, they will be contacted and the interview will be conducted again. Of course, it should be mentioned that all the interviews were conducted in one stage and no interviews were repeated. According to Van-Manen, the best way for entering a being's lived world is through participation in that place, time, and world, which requires near observation as both an observer and a participant at the same time [19]. As a final point, after the meaning of caring for your child had COVID-19 was clear to all of the involved investigators, they searched for texts and articles to find lived experiences in any other possible place. Also, they used a narrative of a mother who had a child who had COVID-19 and had written about her experience with caring.

All interviews were digitally recorded and immediately transcribed. Each interview was handwritten word by word immediately after its execution. Then, to immerse ourselves in the data and get a general sense of it, the text of the interview was re-read several times and analyzed through the Van-Manen method. When an interview was analyzed and the organized concepts were shaped, the next one was conducted. This method continued until completing all the planned interviews. Data were analyzed in a way that extracted the semantic units from the participants' statements, which included their lived experiences. Subsequently, the text of the interviews was read and coded line by line. Then, the codes that had similar meanings were placed under the classes. Thus, the sub-themes were formed. After reaching this point, it could be stated that the main analysis process was finished.

The interview form consisted of two categories: main questions and follow-up questions. Key questions included, "How did you feel when you found out your child had COVID-19?" and "How did you spend these days?" Afterward, follow-up questions were asked. They included, "How people around you felt when they found out about your child's illness? Individual interviews started with questions about the mother's experience after the diagnosis of COVID-19 in her child. They continued with questions about her experience related to her child's hospitalization. We developed the interview guide for this study based on our experience with a specific family. Also in the study, observations were done within three shifts inward of COVID-19 or one month. In addition, we used the data analysis results of each interview as the leader for the next interview. Sampling was performed continually to the point in which no new code could be extracted and data was saturated.

The demographic information of participants in all stages of the research was analyzed using descriptive statistics. MAXQDA 10 software was used for data analysis.

To confirm the validity and accuracy of the research in the present study, four criteria presented by Lincoln and Guba, including credibility, dependability, confirmability, and transferability were examined [19,20]. Increasing the number of interviews was the first step that the researchers performed to increase the data credibility. After conducting the interviews, the study findings were presented to the participants and they expressed their views on their consistency and coherency with their experiences. They communicated their opinions to the researchers and evaluated their accuracy. To ensure dependability and to review the interviews and extracted common meanings and patterns, some qualitative research colleagues were asked to review the text. It was done to assess the accuracy of the analysis process. Other activities that contributed to the credibility of this research included: conducting research based on the research design, recording participants' statements, and writing them down. The researchers' interest in the phenomenon that was being studied, the constant conflict with data, the preservation of documents in all stages of research, and the review process of observers and qualitative research experts were the factors that guaranteed confirmability. To increase the data transferability at the time of sampling, the research samples had maximum variability.

### 3. Results

#### 3.1. Participants

This descriptive phenomenology study was conducted on 13 mothers. The result shows the specifics of the participating samples. To identify and collect the life experiences of mothers who had a child with COVID-19, 16 semi-structured interviews were conducted with 13 participants. The researcher interviewed 3 participants twice to have an in-depth interview. Participants were exclusively mothers who had at least one child with COVID-19. All of them lived in Bandar Abbas and spoke Persian. The ages of participants were between 30 and 45 years ( $37.92 \pm 4.57$ ). The education levels of these mothers were different: two mothers had primary education,

three mothers had high school education, three mothers had a diploma and two mothers had a university education. The ages of children with COVID-19 were between 1 and 8 years ( $4.69 \pm 2.28$ ). Five mothers had more than one child and one of the mothers had two hospitalized children.

We acquired three themes including “Inability to Caring”, “Mentally and Physically Drained” and “Conflict of Roles and Responsibilities” (Table 1). In one of the interviews, a participant stated: “I can seriously say that I felt I would lose. This thought made me very anxious; anxiety and fear have doubled and included anything and everything that could come to a person’s mind.”

### Theme 1. Inability to caring

This theme consists of seven sub-themes in the areas of psychological responses related to caring for children. Sub-themes that led us to the theme of inability to care are: **Overwhelmed in caring, exhausted with caring, feeling lonely in caring, failing in care, anger in care, unsafe care, and care mixed with fear.**

In this study, when a child develops COVID-19, the mother experiences a series of negative emotions that lead to feelings of helplessness and inability to care for the child. We call this, an “Inability to care.” Sub-themes that led us to the theme of inability to care are: **Overwhelmed in caring, exhausted with caring, feeling lonely in caring, failing in care, anger in care, unsafe care, and care mixed with fear.**

#### 1 Overwhelmed by Caring

This sub-theme refers to the type of care that participants provided for their children. They believed that they would spend all their time caring for their children. In this regard, the first participant stated. “*I am always busy taking care of my child, there is no time left to take care of myself. You may not believe that I have not even looked at myself in the mirror once during this time!*” Participant No. 4 indicates that: “*Even when my child is asleep, I check regularly to see if he is breathing. I will not forgive myself if something happens to him.*”

#### 2 Exhausted with caring:

**Participant No.10** describes how she feels about caring for her sick child: “*My child is sick. I’m weak. I’m helpless*” **Participant No. 7 says:** “*It is raining heavily. I want to leave the house. I have been imprisoned at home for a long time*”.

#### 3 Feeling lonely in care:

Due to the nature of COVID-19 and the severe spread of the disease, most participants found themselves alone while caring for their children. Social isolation was their main complaint. It also resulted in the experience of loneliness and depression. They experienced loneliness in two dimensions, on the one hand, the experience of being alone in the path of care and carrying the entire burden of care. On the other hand, they experienced a feeling of deep loneliness in society. They talked about losing contact with others as well as losing the support of others. **Participant No.9 says:** “*I did not think there would be a day when I could not meet my parents or they are unaware of me and my child. It’s strange that even though they are so close to me, I do not meet them!*” **Participant No. 10 notes:** “*I felt lonely while caring for my sick child*”. **Participant No. 3 notes:** “*Being imprisoned in the hospital and not being able to visit my family and friends for a month made me feel agitated and depressed.*” **Participant No. 2 notes:** “*I didn’t leave the hospital at all. I was going crazy with depression. I was sick of the hospital because I was alone.*”

#### 4 Failure is caring:

One of the unpleasant feelings of mothers that was evident in the interviews was the feeling of failure in caring for their sick child. They felt that they had reached a dead end. The feeling of failure in the difficult path of care and the feeling of wasting all efforts are

**Table 1**  
Mother’ lived experiences of caring for children with Covid-19 patients at a general hospital in South Iran, 2021.

Themes	Sub-themes
Inability to caring	1. Overwhelmed by Caring 2. Exhausted with caring 3. Feeling lonely in the care 4. Failure is caring 5. Anger in caring 6. Distrust of car 7. Care in an aura of concern
mentally and physically drained	1. Emotionally drained 2. Physically drained 3. Inability to manage stress 4. Feel guilty
Conflict of roles and responsibilities	1. Disrupting the normal routine of life 2. Conflict of roles

among the annoying things that mothers expressed in this theme.

**Participant 12**, whose child has leukemia and recently developed COVID-19 said,

“I have been suffering from my son’s illness for two years. It has just gotten a little better. But unfortunately, it has taken a corona ... I was completely disappointed.”

## 5 Anger is caring:

Anger was one of the topics extracted from the interviews.

**Participant No. 11 states:** *“Do you believe that I have been very angry for three weeks? From the medical staff, from my wife, from myself ... I am completely nervous.”* **Participant number 2 states:** *“I’m so angry that my family all have COVID-19.” I am very angry about the misfortune that has befallen us.”* She also said, *“My husband would wear a mask whenever he left the house, but he didn’t care as much as I did, he brought the corona home”*

## 6 Distrust of care:

The lack of a clear picture of the disease and the prolongation of the pandemic had worried many mothers. For example, participant no. 6 said during the interview: *“I can not imagine what will happen.”* When asked what she meant, she said: *“I feel that nothing will return to the situation before the outbreak of the disease, I think I will lose my family” ... “The doctor came and said that now we are starting the medicine to see what happens. No one is sure of the result of what he does. Everyone is hesitant”*

## 7 Care in an aura of concern

One of the concerns of a mother while caring for her child is the fear of getting sick and infecting other family members. **Participant No. 1 notes,** *“I feel sick too. My body hurts.”* **Participant No. 10 says** *“I’m afraid the disease will spread to the rest of my family. Who will take care of them?”*

Mentally and physically drained:

The mother’s words expressed their sorrow. The most commonly used expressions by many mothers were: “I am heartbroken”, “I can’t express my grief”, “my heart was hurt by this tragedy”, “I do not feel anything”, “I feel pain” I faint, “I’m sad,” “This is a nightmare,” and “I wish it was a bad dream.”

## Theme 2. Mentally and physically drained

The second main topic extracted from the interviews was “mentally and physically drained”. The pressure of parents to take care of their children and their loneliness due to the quarantine have made them feel mentally and physically drained. This theme had four sub-themes: **emotionally drained, physically drained, inability to manage stress, and feeling guilty.**

### 1 Emotionally drained:

In the majority of interviews, there was a common feeling among the participants that led us to the topic of being “emotionally drained”. Only three participants reported physical fatigue, while the majority complained of “emotional and mental fatigue.” Many of them stated that they had sleep disorders due to severe mental fatigue. **Participant #9 states,** *“When my child gets better, I have to go somewhere to be alone. I have to rebuild myself.”*

### 2 Physically drained:

The nature of the disease and its spread to all members of families has multiplied the responsibility of mothers, and all these factors have caused them physical fatigue. **Participant No. 12 says:** *“My wife, who was helping me take care of my child, also got sick. I no longer have the power to continue caring.”* **Participant No. 7 says:** *“The mothers felt that they were not being sufficiently supported during this period, while their children were hospitalized.”* **Participant No. 10 says:** *“The thing that I was unhappy with the most was that any person provided support to Miserable mother.”*

### 3 Inability to manage stress:

The interviewed mothers were aware of the effects of stress in times of child hospitalization. Many interviews showed high levels of stress among participants. Several mothers stated that they could not control their emotions and, sometimes, they cried involuntarily. They received a large amount of information from various sources, such as the media, doctors, nurses, etc., which increased their stress.

Another source of distress for mothers was that, from the beginning of the pandemic, hospitals no longer allowed the ingress of companions and family members. Mothers also experienced other worries, such as their husbands or older family members becoming infected. In some ways, the worry for the husbands becoming infected was because of the close nature of husband/wife relationships. In addition, mothers were also worried about being infected as well. **Participant No. 13 says:** “What can we do with so stress these days? With these stresses, how can I be a healthy mother and give care to my child.” **Participant No. 2 says:** “Right now, my anxiety about Corona is due to me having to be alone child caring. I wish that it would not continue.” **Participant No. 1 says:** “I was aware of the importance of stress management strategies but I was unable to use them due to severe mental and physical fatigue.”

#### 4 Feeling guilty:

Sometimes the mothers' grief was mixed with guilt because they considered themselves responsible for the illness of their family members. **Participant No. 5**, whose entire family was infected, said, “It's my fault. I could not prevent my family members from contracting the disease. I did not do my job properly.” In this case, feelings of guilt are accompanied by grief over the illness or lack of recovery from the illness of family members. **Participant No. 11 shared her experience:** “Physically and mentally, I feel more tired mentally. I have a guilty conscience and I consider myself responsible for my family's illness.”

#### **Theme 3.** Conflict of roles and responsibilities:

One of the most important concerns of mothers was the conflict of roles and responsibilities. In interviews with them, we came across two sub-themes:

##### 1 Disrupting the normal routine of life and Conflict of roles.

With the novel coronavirus, COVID-19, causing widespread changes to everyday nature, it is more important than ever to support mothers with innovative ways to reconnect with our lives in isolation. “The restrictions caused by COVID-19 are dramatically affecting how parents live their everyday lives.” Children's hospitalization has heightened emotions for many parents, especially mothers. There are also added disruptions to daily living.

##### 1 Conflict of roles

Almost all mothers in interviews mentioned that COVID-19 has caused conflicts between parental roles. During the lockdown period, the normal routine of life was disrupted and, as a result, parents had conflicts in performing their duties, which offended all family members. Playing multiple roles at the same time can cause some of these tasks to fail. The role of caring for a sick child or another family member can affect other roles of the mother, especially if she has lost her support resources (such as the grandmother or other relatives) due to specific disease conditions and quarantine. Sometimes, the anxiety and stress created by this disease cause the mother to not be able to perform her roles properly. **Participant No. 12 shared her experience** “My mother is in the hospital. I'm worried and I do not know what will happen. I'm so worried that I cannot take good care of my sick child.”

#### 4. Discussion

This qualitative study studied mothers whose children were hospitalized due to COVID-19 experiences. We extracted 3 themes and 13 sub-themes from the executed conversations with mothers. Their experiences denote intense “Inability to Caring”, “Mentally and Physically Drained” and “Conflict of Roles and Responsibilities”. In this study, when a child develops COVID-19, the mother experiences a series of negative emotions that lead to feelings of helplessness and inability to care for the child. The findings of the study showed that mothers of children with COVID-19 expressed experiences such as the need for support, anxiety, and depressed mood.

The unknown and unpredictable disease of COVID-19 has created a wave of anxiety that had negative effects on the health of communities, especially on caregivers and patients. The results showed that caring and hospitalization caused children to experience hardships and severe stress in their daily lives. Stress, worry, anxiety, fear, feelings of loneliness, and depression were common among mothers during the child-caring process. According to other studies, most of these responses were also present in other groups during the COVID-19 pandemic crisis [21,22].

“Inability to Caring”, “Mentally and Physically Drained”, and “Conflict of Roles and Responsibilities” were the main themes that emerged from the mothers' statements. Fear and worry about the child's illness and the illness of themselves and other family members was the most important challenge for these mothers. Witnessing the death of other patients and colleagues, substandard care conditions, and lack of support were the most pressing concerns identified by the mothers. In this study, it was identified that, when a child develops COVID-19, the mother experiences a series of negative emotions that lead to feelings of helplessness and inability to care for the child. The mothers' negative emotions were more pronounced with child caring. Caring for children is a bitter experience and a bad memory from the time they were hospitalized. Caregivers of COVID-19 patients, including mothers with children infected in the present study, also faced many care challenges. Our findings in this study guided us to the main theme “Inability to Caring”. From the point of view of childcare mothers, the topic was divided into seven sub-themes: overwhelmed in caring, exhausted with caring, feeling lonely in caring, failure in care, anger in care, unsafe care, and care mixed with fear are defined.

The mother is the best caregiver for a child with COVID-19. Unusually, high caring hardships, because of these central themes, must be countered with self-care, to allow mothers to continue providing high-quality, genuine patient care [21,23]. Lack of proper self-care

by a mother can have serious consequences for a child with COVID-19 [24,25]. The concerns and anxieties of the mothers involved in this study were often directly linked to the care and support context surrounding a child with COVID-19. The first theme of mothers' statements, emotional condition, follows unpleasant events. All of these caring central themes have interfered with the care focus and performance of mothers.

The mothers' declarations in this study show that the main theme, the caring context surrounding children with COVID-19, has been ineffective at providing appropriate services and care for them. Moreover, existing stress, ambiguous disease status, complicated patient care, and healthcare system inefficiencies can affect the quality of care [25]. Weakening care quality threatens patient safety [22]. Child care and protection are the most important objectives of mothers [26]. The results of this study show that care and protection under these conditions are jeopardized and difficult. Mothers should make extreme efforts to remain focused on genuine patient care [27].

Mothers need the support of nurses and medical staff to provide the best care for their children and to be able to overcome their critical situations. Continuity of nursing care is beneficial to the health and welfare of patients [28]. One of the elements that nurses can give to mothers is emotional support. The findings showed that mothers needed emotional and informational support during their children's hospitalization. This issue was also raised in the study of Kyritsi, in which Greek parents identified the need for information about the prognosis and condition of their children as the most important need [29]. Although this support was provided by the participants' families, such as mothers or sisters, they emphasized emotional support from the spouse that was not well-formed. In this regard, the results of studies showed that, frequently, parents try to support each other at the time of hospitalization, but sometimes they do not play the role well due to unfamiliar and critical situations [30,31]. According to the participants, another factor to help mothers to solve their problems while caring for their children during hospitalization is the emotional support of nurses and doctors to them and their effective presence. Educating, guiding, and accompanying the mother as an active listener can be effective in reducing her worries. Brinchmann stated that the ability of healthcare providers to communicate and support parents with a sick child is one of the basic skills that they must have [32]. Participants also stated that since COVID-19 is an emerging disease, parents did not have much information about it and needed it from hospital staff. Due to a lack of information about the disease process and its treatment, mothers were very worried. In this regard, the results of the study conducted by Kohan showed that one of the problems of mothers in the intensive care unit is the lack of knowledge about the condition of the baby. It causes mothers to request more information and interact with doctors and nurses [33]. Yuan also states in his research that parents with hospitalized children always need to receive information and honest answers to questions. When the previous necessity is fulfilled, their stress and anxiety are reduced, creating a sense of peace and security in them [34].

The second theme of the study, which was obtained during the interviews, was COVID-19 anxiety. Common anxiety reactions associated with COVID-19 are mostly due to being unknown, which generates cognitive ambiguity in people about the virus. Fear of the unknown reduces a person's perception of immunity and generates anxiety [35]. Mothers with an infected child had common physical symptoms, such as sleep disorders, palpitations, anxiety, and stress due to concerns about their children's conditions. In other studies, individuals and families experienced diverse emotions, such as anxiety, restlessness, irritability, headache, and panic during illness [23–25,36]. The results of Rahimi's study showed that the majority of caregivers of patients with COVID-19 feel anxious and experience physical problems, such as sleep disorders and anorexia [37].

The experiences of participants in the present study revealed that most of them had obsessive behaviors. Obsession involves recurrent thoughts or emotions and consciously coercive behavior [38]. After a child develops COVID-19, fear of infection has led mothers with obsessive-compulsive behaviors to reduce their anxiety by doing things like frequent hand washing and extreme disinfection [39].

The result of a study showed that some patient caregivers have various problems, such as allergies and sensitivity to disinfectants, due to their high use of them during the COVID-19 pandemic [25], which is coherent with the results of the present study. In addition, the participants' experiences showed that they worried too much about the disease. This was more frequent in mothers who were also infected when their children were sick. These thoughts occupy a person's mind and, in some cases, they hinder his normal and effective functioning.

In this regard, the results of the study by Rahimi showed that family caregivers of patients with COVID-19 had many worries about the outcomes of the disease [37]. Anxiety among participants can also be due to fear of the social stigma of COVID-19. They stated that they tried to hide their child when he/she became ill. Essentially, they were not interested in sharing their child's illness with their relatives. Stigma is an inner feeling about having an unwanted situation, along with the fear of discrimination due to low status or rejection by society, which depends more on the culture of each community [35]. Numerous studies have addressed the issue of social stigma caused by the disease [28,37,40].

In the results of Lyu's study, it is stated that mothers with children with leukemia tend to avoid telling their neighbors about their child's illness because they may be blamed by them for having a child with cancer, which brings bad luck to the family [41]. Therefore, special attention should be paid to the final consequences of telling the child's illness to others and its impact on parents' mental health, and this requires the evaluation of the psychological symptoms of the mentioned individuals.

The third theme discovered in the study was the presence of depressed mood among the participants. It refers to a state in which a person often feels sad. Participants were confused at the beginning of their child's illness because it was unknown and its information was limited. They did not know what to do to help their children. The majority of mothers have sought information about the course of the disease and the appropriate treatment methods for the illness. In this regard, The results of the Jafari-Oori study showed that the lack of knowledge, support, and unknown prognosis of the disease put the caregivers of the Covid-19 patients in a difficult situation and they felt confused and disappointed [42].

Early hospitalization is a key time for physicians and nurses to provide parents with accurate information about the disease,

identify risk factors, and reduce parental confusion overall. The findings showed that mothers feel sadness, grief, and despair after a child becomes ill. Mothers also experienced some degree of sadness at the time of diagnosis. In the present study, some mothers were frustrated, had a vague future, and had no motivation to continue caring. These perceptions create many problems for the family. As a caregiver, the mother makes great efforts to solve the problems and since there is less chance of success and recovery, they believe that they cannot change the situation. As a result, the mother may stop continuing treatments. Chimeh also concluded in their study that the initial reaction of mothers when diagnosing a child's illness is the apparition of severe depression, confusion, and hopelessness [43].

One of the strongest findings of the study was the feeling of guilt among mothers. Guilt is expressed as a painful and negative feeling. In this study, some mothers felt strongly guilty and blamed themselves for believing that they had failed to take good care of their children. Chen's study of the experiences of family members of intubated patients with COVID-19 showed that some people felt guilty about the events that led to the illness of their loved ones [44]. Excessive or irrational feelings of guilt lead to distress, maladaptive relationships, and generally severe psychological damage [45]. According to the reviewed studies, the need to create more areas of psychological support for these people should be considered opportunely.

In the current study, themes such as disappointment, fear, the feeling of failure, an uncertain future, and the possibility of abandoning childcare were seen from the mothers' experiences. This was present in mothers not only early in the disease but also during the disease. It is normal for mothers to experience psychological symptoms such as stress and anxiety, depression, and confusion in reaction to the diagnosis of their child's illness, but after a few days and knowing the course of the disease and treatment, the severity of the symptoms will decrease. But in the present study, we saw that, on the one hand, due to the emerging nature of the disease and the lack of sufficient information on the part of the personnel, there was no significant support from the medical personnel for the mothers, and also the doctors were not fully confident about the outcome of the treatment. These doubts made mothers feel defeated and disappointed and imagine a vague future for their children. On the other hand, the daily death rate of infected people in the hospital increased, and there was a possibility that mothers would not take care of their children.

Due to the nature of this disease, such as its contagiousness, high probability of death, and lack of sufficient information about the course of the disease, the mother may face many challenges in terms of care, but we must not forget that during the covid-19 pandemic and since the beginning of the disease, the number of infected increased very quickly. Hospital beds were not sufficient for this number of patients. Also, lack of facilities, equipment, and drugs have been influential factors in mothers' care experiences.

It is worth noting that the present study is the first study that investigated the experiences of mothers with children infected with Covid-19. Because the studied community was mothers, the results showed that mothers have experienced role conflict and disruption of normal life routines, and feelings of guilt. However, many themes such as the presence of obsessive-compulsive behaviors, psychological symptoms such as stress, anxiety, and depression, feeling lonely and tired, lack of support from the spouse, and fear of social stigma have been similar to other studies.

The results of the present study indicated that the experiences of mothers with children with COVID-19 are very unique. Mothers, as the main caregivers of hospitalized children, were more exposed to stress and physical problems due to the lack of information about the course of children's diseases. In addition, the lack of proper support from medical staff and spouses also affected them. Mothers, in this study, experienced emotions such as depression, anxiety, social stigma, guilt, and obsessive behaviors. Based on the results of the present study, it is vital to assess the experiences and psychological needs of mothers with children with COVID-19, to protect their physical and psychological health. Also, it is necessary to develop programs and provide appropriate strategies oriented to caring for hospitalized children and preventing adverse consequences associated with their diseases.

The present study has limitations, for example, it can be pointed out firstly, the lack of resources and research background related to the experiences of mothers with children infected with Covid-19 in Iran and the world. Considering the role of cultural and geographical factors in the spread of this disease and its difference in other regions, it should be noted that the present research was conducted in one of the cities of Iran (Bandar Abbas) and it is necessary to be careful in generalizing the results.

According to the findings of the study, it is suggested to increase the knowledge of nurses in the field of reducing psychological symptoms such as stress, anxiety, fear, and depression of mothers with children with covid-19 and also to update the information on the treatment team about the unknown disease of covid-19, holding workshops and training courses with the approach of psychological needs of caregivers and updated disease information for medical personnel, especially nurses, will be effective.

## 5. Conclusion

The results of this study show that mothers' children with COVID-19, in hospitals and care centers designated for patients, are experiencing inappropriate mental and emotional conditions. Despite these obstacles, mothers had to continue providing proper care for their children. The findings of the study and the experiences of mothers during this pandemic are a guide for medical staff to determine the psychological needs of mothers. It is useful to seek solutions to heal different psychological disorders, such as anxiety and depression present in mothers with children with COVID-19. Negative experiences, fear, and anxiety have created a difficult scenario; mothers need more support in the setting of COVID-19 care because their care activities put them at serious risk.

## Ethics statement

It should be noted that this research was approved by the Ethics Committee of Hormozgan University of Medical Sciences with the ethics ID IR. HUMS.REC.1400.295 and informed consent form was taken from all participants.



## Author contribution statement

Fariba Asadi Noghabi: Conceived and designed the experiments.  
 Mohsen Yousefi; Elnaz Gosalipour: Performed the experiments.  
 Aref Zarei: Analyzed and interpreted the data.  
 Hadi Yousefi: Contributed reagents, materials, analysis tools or data.  
 Tahereh Sadeghi: Conceived and designed the experiments; Wrote the paper.

## Data availability statement

No data was used for the research described in the article.

## Additional information

No additional information is available for this paper.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Acknowledgment

Thanks to the mothers, who spent a lot of time participating in this study, for sharing their opinions and experiences with the researchers. We would also like to thank Hormozgan University of Medical Sciences and Bandar Abbas Children's Hospital for their assistance in conducting this research and for providing us the opportunity to execute the study.

## References

- [1] Z. Jannat, COVID-19 and the elderly with chronic diseases: narrative review, *J. Mil. Med.* 22 (6) (2020) 632–640.
- [2] S. Shahyad, M.T. Mohammadi, Psychological impacts of Covid-19 outbreak on the mental health status of society individuals: a narrative review, *J. Mil. Med.* 22 (2) (2020) 184–192.
- [3] Y. Dong, X. Mo, Y. Hu, X. Qi, F. Jiang, Z. Jiang, et al., Epidemiology of COVID-19 among children in China, *Pediatrics* 145 (6) (2020).
- [4] S. de Lusignan, J. Dorward, A. Correa, N. Jones, O. Akinyemi, G. Amirthalingam, et al., Risk factors for SARS-CoV-2 among patients in the oxford royal college of general practitioners research and surveillance centre primary care network: a cross-sectional study, *Lancet Infect. Dis.* 20 (9) (2020) 1034–1042.
- [5] O. Irfan, F. Muttalib, K. Tang, L. Jiang, Z.S. Lassi, Z. Bhutta, Clinical characteristics, treatment and outcomes of pediatric COVID-19: a systematic review and meta-analysis, *Arch. Dis. Child.* 106 (5) (2021) 440–448.
- [6] E. Leidman, L.M. Duca, J.D. Omura, K. Proia, J.W. Stephens, E.K. Sauber-Schatz, COVID-19 trends among persons aged 0–24 years—United States, March 1–December 12, 2020, *MMWR (Morb. Mortal. Wkly. Rep.)* 70 (3) (2021) 88.
- [7] E.J. Anderson, J.D. Campbell, C.B. Creech, R. Frenck, S. Kamidani, F.M. Munoz, et al., Warp speed for coronavirus disease 2019 (COVID-19) vaccines: why are children stuck in neutral? *Clin. Infect. Dis.* 73 (2) (2021) 336–340.
- [8] L. Cirrincione, F. Plescia, C. Ledda, V. Rapisarda, D. Martorana, R.E. Moldovan, et al., COVID-19 pandemic: prevention and protection measures to be adopted at the workplace, *Sustainability* 12 (9) (2020) 3603.
- [9] S.Y. Kim, A.Ö. Yeniova, Global, regional, and national incidence and mortality of COVID-19 in 237 countries and territories, January 2022: a systematic analysis for World Health Organization COVID-19 Dashboard, *Life Cycle* 2 (2022).
- [10] P. Chamboredon, C. Roman, S. Colson, COVID-19 pandemic in France: health emergency experiences from the field, *Int. Nurs. Rev.* 67 (3) (2020) 326–333.
- [11] O. Misirli, F. Ergulec, Emergency remote teaching during the COVID-19 pandemic: parents experiences and perspectives, *Educ. Inf. Technol.* 26 (6) (2021) 6699–6718.
- [12] L. Shields, I. Kristensson-Hallström, We have needs, too: parental needs during a child's hospitalisation, *Online Braz. J. Nurs.* 3 (3) (2004) 3–16.
- [13] F. Mashayekhi, S. Rafati, F. Rafati, M. Pilehvarzadeh, M. Mohammadi-Sardo, A study of caregiver burden in mothers with thalassemia children in Jiroft, 2013, *Modern Care J.* 11 (3) (2014).
- [14] L. Mazzone, L. Battaglia, F. Andreozzi, M.A. Romeo, D. Mazzone, Emotional impact in  $\beta$ -thalassaemia major children following cognitive-behavioural family therapy and quality of life of caregiving mothers, *Clin. Pract. Epidemiol. Ment. Health* 5 (1) (2009) 1–6.
- [15] S. Zadafar, M. Kheradmand, S. Faramarzi, Psychological dimensions of the parent-child relationship in the COVID-19 epidemic: a review study, *Rooyesh-e-Ravanshenasi J. (RRJ)*. 10 (2) (2021) 151–160.
- [16] F. Araghian Mojarad, A. Sanagoo, L. Jouibari, The lived experiences of the mother of a child with Werdnig-Hoffman syndrome: a qualitative case study, *J. Qual. Res. Health Sci.* 5 (1) (2020) 127–135.
- [17] N. Mohammadi, M. Shamshiri, A. Mohammadpour, K. Vehviläinen-Julkunen, M. Abbasi, T. Sadeghi, 'Super-mothers': the meaning of mothering after assisted reproductive technology, *J. Reprod. Infant Psychol.* 33 (1) (2015) 42–53.
- [18] C. van Nieuwerburgh, M. Barr, A.J. Fouracres, T. Moin, C. Brown, C. Holden, et al., Experience of positive psychology coaching while working from home during the COVID-19 pandemic: an Interpretative Phenomenological Analysis, *Coaching* (2021) 1–18.
- [19] M. Shamshiri, N. Mohammadi, M.A. Cheraghi, K. Vehviläinen-Julkunen, T. Sadeghi, Disciplined care for disciplined patients: experience of hospitalized blind patients, *Holist. Nurs. Pract.* 27 (6) (2013) 344–348.
- [20] C. Matta, Philosophical paradigms in qualitative research methods education: what is their pedagogical role? *Scand. J. Educ. Res.* (2021) 1–14.
- [21] J. Xie, Z. Tong, X. Guan, B. Du, H. Qiu, A.S. Slutsky, Critical care crisis and some recommendations during the COVID-19 epidemic in China, *Intensive Care Med.* 46 (5) (2020) 837–840.
- [22] J. Hamers, M. Nijhuis-van der Sanden, R. Ettema, M. Heinen, G. Huismans-de Waal, J. de Man-van Ginkel, et al., Essential nursing care: most provided, least evidence based. The basic care revisited program, *J. Adv. Nurs.* 72 (S1) (2016) 51.
- [23] E. Morgül, A. Kallitsoglou, C.A.E. Essau, Psychological effects of the COVID-19 lockdown on children and families in the UK, *Revista de Psicologia Clínica con Niños y Adolescentes.* 7 (3) (2020) 42–48.

- [24] C.-C. Lai, T.-P. Shih, W.-C. Ko, H.-J. Tang, P.-R. Hsueh, Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and coronavirus disease-2019 (COVID-19): the epidemic and the challenges, *Int. J. Antimicrob. Agents* 55 (3) (2020), 105924.
- [25] L. Sun, Z. Sun, L. Wu, Z. Zhu, F. Zhang, Z. Shang, et al., Prevalence and risk factors of acute posttraumatic stress symptoms during the COVID-19 outbreak in Wuhan, China, *medRxiv* (2020) 1–17.
- [26] A.J. Hessels, T. Wurmser, Relationship among safety culture, nursing care, and Standard Precautions adherence, *Am. J. Infect. Control* 48 (3) (2020) 340–341.
- [27] K. Stewart, O. Doody, M. Bailey, S. Moran, Improving the quality of nursing documentation in a palliative care setting: a quality improvement initiative, *Int. J. Palliat. Nurs.* 23 (12) (2017) 577–585.
- [28] P. Rahmatinejad, M. Yazdi, Z. Khosravi, F. Shahisadrabadi, Lived experience of patients with coronavirus (COVID-19): a phenomenological study, *J. Res. Psychol. Health* 14 (1) (2020) 71–86.
- [29] B. Seyedamini, Fears, needs and nursing support of mothers during their child's hospitalization, *Iran J. Nurs.* 24 (72) (2011), 2008-5923.
- [30] C.W. Jones, M.R. Lynn, Blogs written by families during their child's hospitalization: a thematic narrative analysis, *J. Pediatr. Nurs.* 41 (2018) 110–116.
- [31] K. Loewenstein, J. Barroso, S. Phillips, The experiences of parents in the neonatal intensive care unit: an integrative review of qualitative studies within the transactional model of stress and coping, *J. Perinat. Neonatal. Nurs.* 33 (4) (2019) 340–349.
- [32] B. Støre Brinchmann, R. Førde, P. Nortvedt, What matters to the parents? A qualitative study of parents' experiences with life-and-death decisions concerning their premature infants, *Nurs. Ethics* 9 (4) (2002) 388–404.
- [33] M. Kohan, F. Borhani, A. Abbaszadeh, J. Sultan Ahmadi, M. Khajehpoor, Experience of mothers with premature infants in neonatal, *J. Qual. Res. Health Sci.* 1 (1) (2020) 41–51.
- [34] R. Yuan, Q.-H. Xu, C.-C. Xia, C.-Y. Lou, Z. Xie, Q.-M. Ge, et al., Psychological status of parents of hospitalized children during the COVID-19 epidemic in China, *Psychiatr. Res.* 288 (2020), 112953.
- [35] S. Sadeqi, S. Sharifrahnmo, A. Fathi, S. Mohamadi, Predicting Covid-19 anxiety and its social stigma experience based on the dimensions of internet addiction after the first age of epidemic in students, *Health Res. J.* 5 (4) (2020) 268–278.
- [36] COVID CP Deaths: Focus on Ages 0–18 Years .
- [37] T. Rahimi, N. Dastyar, F. Rafati, Experiences of family caregivers of patients with COVID-19, *BMC Fam. Pract.* 22 (1) (2021) 1–10.
- [38] B. Benatti, U. Albert, G. Maina, A. Fiorillo, L. Celebre, N. Girone, et al., What happened to patients with obsessive compulsive disorder during the COVID-19 pandemic? A multicentre report from tertiary clinics in northern Italy, *Front. Psychiatr.* (2020) 720.
- [39] F. Bagheri Sheykhangafshe, E. Sadeghi Chookami, Obsessive-compulsive disorder during the coronavirus epidemic 2019 (COVID-19), *SSU J.* 28 (6) (2020) 2700–2704.
- [40] S. Rizvi Jafree, S.A. Naqi, Significant other family members and their experiences of COVID-19 in Pakistan: a qualitative study with implications for social policy, *Stigma Health* 5 (4) (2020) 380.
- [41] Q-y Lyu, F.K. Wong, L-m You, X-w Li, Perceived family impact during children's hospitalization for treatment of acute lymphoblastic leukemia: a cross-sectional study, *Cancer Nurs.* 43 (6) (2020) 489–497.
- [42] L. Valizadeh, M. Akbarbegloo, M. Asadollahi, Stressors affecting mothers with hospitalized premature newborn in NICUs of three teaching hospitals in Tabriz, *Med. J. Tabriz Univ. Med. Sci.* 31 (1) (2009) 85–90.
- [43] n Chimeh, hr pouretamad, R. Khoramabadi, Need assessment of mothers with autistic children, *J. Family Res.* 3 (1) (2007) 697–707.
- [44] C. Chen, E. Wittenberg, S.S. Sullivan, R.A. Lorenz, Y.-P. Chang, The experiences of family members of ventilated COVID-19 patients in the intensive care unit: a qualitative study, *Am. J. Hosp. Palliat. Med.* 38 (7) (2021) 869–876.
- [45] T. Malti, Toward an integrated clinical-developmental model of guilt, *Dev. Rev.* 39 (2016) 16–36.