

Vigilant Care: Experiences of In-Home Caregivers of Coronavirus Disease 2019 Patients

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Abstract

Background: Home care is always appreciated as an effective alternative method to manage critical conditions, expand hospital capacity, and admit further cases suspected of more severe clinical symptoms.

Aim: The present study aimed to reflect on the experiences of in-home caregivers of patients with coronavirus disease 2019 (COVID-19) in Iran.

Method: For this qualitative descriptive study, 13 participants (i.e., the Iranian family caregivers of patients with COVID-19) were selected and included using the purposive sampling method. Caregivers were those who accompanied the patient to the outpatient department for three months from 22 June to 22 August 2021. An interview was conducted in a private room with family caregivers of patients. The data were obtained through a series of semi-structured interviews, each one lasting 30-40 min. The data were completed via the MAXQDA software (version 10). Analysis was performed according to the approach of Granheim and Landman 2004 by the conventional content analysis method.

Results: The results lead to the emergence of the final theme "vigilant care" containing four categories (e.g., Quarantine fence, Economic management as a bottleneck, Confusion and difficulty in care, as well as Conflicting adaptation and mitigation of psychological stress) and 14 subcategories.

Implications for Practice: Vigilance care is a major challenge for caregivers of patients with Covid-19 at home. Therefore, providing educational solutions or training booklets in outpatient wards during discharge can partially resolve the ambiguities and be effective in improving care.

Keywords: Caregivers, COVID-19, Home nursing, Qualitative study

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Introduction

One of the most challenging conditions facing the world for almost two years has been the coronavirus disease 2019 (COVID-19) pandemic (1, 2). The disease has also posed major challenges to the health care systems and facilities worldwide (3, 4). During the early pandemic, some management problems along with caregiver fear led to a large number of admissions and hospitalizations due to many referrals, even presenting with mild-to-moderate symptoms, which resulted in low hospital capacity and resources (4). Considering the current critical situation and a lack of resources in health care settings, the World Health Organization (WHO) recommended in early 2020 that patients diagnosed with COVID-19 could receive home care in the face of mild-to-moderate infections (5). In this regard, many countries, including Iran, Japan, and Italy, grappling with resource shortages at the peak of the pandemic, referred patients with mild-to-moderate symptoms, such as fever, cough, and fatigue, to stay in and continue treatment and care at home (6-9). In countries, such as the United States, interactive telemedicine systems were also exploited to provide patients with various aspects of health information, prevention, monitoring, and medical services at home during this period (10).

Home care can be also psychologically beneficial to patients and moderate the financial burden, as well as the risks of hospital-acquired infections threatening older adults (11, 12); therefore, it is an effective alternative method in critical conditions to expand hospital capacity and admit further patients suspected of more severe clinical symptoms (12). In contrast, home care poses many challenges to patients and their caregivers. The family members of COVID-19 patients accordingly have to tackle countless problems due to sudden conflicts, unstable disease conditions, fear of worsening signs and symptoms, as well as inadequate knowledge of patient care (13). Many of these individuals are even at high risk of psychological distress and need much more support in this process (14).

In this context, McPeake et al. in the United Kingdom found that the family members of patients infected with COVID-19 could be subjected to many problems after their discharge (15). In the Netherlands, Veenendaal et al. also reported that caregivers could suffer from a high burden of the disease after being transferred from intensive care units to homes (16). One study of patients' attitudes toward home care by Akbarbegloo et al. in Iran similarly revealed that problems, such as no support from the treatment team and others around along with some concerns about one's condition, were among the problems cited by the COVID-19 patients (7). Therefore, it is acknowledged that the pandemic and its protective measures have so far raised various experiences in patients and their caregivers; accordingly, it is of utmost importance to shed light on the thoughts, feelings, and needs of family members facing different problems in this area to help them (17).

Given the outbreak of COVID-19, low hospital capacity and resources, especially in times of the peaks, an increasing number of critically ill patients during the last peak of the pandemic in Iran, as well as a shortage of beds and medical resources in health care facilities in many provinces, home care has become more common for patients presenting with mild-to-moderate symptoms. Therefore, there is a need to reflect on the experiences of caregivers' problems regarding in-home care for COVID-19 patients. On the other hand, Due to the fact that COVID-19 is an emerging disease and has a very mysterious and unknown face, explaining the experiences of 24-hour caregivers continuously and monitoring the symptoms and complications can help in revealing the hidden face of the disease and guide the nurses in caring for patients. As most investigations have thus far explored the experiences of family members of patients admitted to hospitals and intensive care units, there are no studies on explaining the experiences of in-home caregivers of COVID-19 patients as the primary level of health care. As a result, the present study aimed to delineate the experiences of in-home care for patients with COVID-19 from the caregivers' perspectives.

Methods

This qualitative descriptive study was conducted based on conventional content analysis. A total number of 13 participants (i.e., the Iranian family caregivers of patients with COVID-19) were selected and included using the purposive sampling method. Caregivers were those who accompanied the patient referred to the educational hospitals affiliated to Shahid Beheshti University of Medical Sciences, Tehran, Iran, in the outpatient department for three months from 22 June to 22 August 2021. The interviews were conducted in a private room with patient caregivers until the medication was completed. To record the conversations, informed oral consent was obtained from all participants

at the onset of the study. The inclusion criteria were the willingness to contribute to the study and in-home care delivery to COVID-19 patients for at least 24 hours. On the other hand, the participants who had acute respiratory attacks and pulmonary involvement over 30% during treatment and required hospitalization were excluded from the study. In addition, companions who did not provide 24-hour home care were also excluded from the study.

The main question addressed during the interview was: "...Describe the experience of one day of home care and then explain the facilitators and barriers". During the interview, exploratory and clarifying questions, such as "...please explain further and give some examples" were utilized to shed light on the home care experiences. In this study, 13 caregiver experiences were extracted during 17 interviews. The interviews, each one lasting 30-40 min, continued until data saturation (i.e., no new information was added). The MAXQDA10 software was also utilized to record, transcribe, and analyze the data. The data analysis was performed by the conventional content analysis technique with reference to the approach developed by Graneheim and Landman (2017). In this method, the focus is on the abstraction and interpretation of data during the study process (18). Upon the completion of each interview, the researcher listened carefully to the recorded information as soon as it was possible and then transcribed them verbatim in the Microsoft Word 2016 software. The texts retrieved from the interviews were subsequently checked by the researcher and compared with the recordings. After ensuring their accuracy, the transcriptions were read several times to create a generally new idea by immersing in the data. Each interview was also considered a unit of analysis. The meaning units of each text were additionally identified and then converted into initial codes. Afterward, the codes that had the same meanings and concepts were summarized into one code. Such codes formed the sub-categories based on their similarities, and then several sub-categories constituted the main category. To meet the rigor of the data, Denzin and Lincoln's (2005) four-dimension criteria, including credibility, dependability, confirmability, and transferability, were used (19). For this purpose, four samples were randomly selected for data credibility, and the researcher was involved in the process of data collection and analysis for four months and immersed in them. The research team also constantly reviewed the interviews, transcribed them, read the field notes, compared the information, and deliberated on the categories, sub-categories, as well as the codes extracted. With regard to dependability, the data, codes, and categories extracted were reviewed and approved by eight participants and two experts in qualitative research with a doctoral degree in nursing, and then the accuracy and appropriateness of the codes were compared with them and the required changes were applied. To reach confirmability in the present study, all the research stages were illustrated in such a way that others were able to judge them by reading. Following that, the transferability of the data was obtained by transcribing the interviews immediately after their completion, describing the statements and objective experiences in an accurate manner, and providing some examples and quotes raised by the participants.

Prior to the interviews, the objectives of the study were explained, and oral informed consent was obtained from the participants in order to conduct and record interviews. At the beginning of the interview, participants were assured that the recorded voices would remain confidential by encrypting the files.

Results

The study results were elicited from 13 in-home caregivers. Most female participants had a mean age of 36 ± 8.54 years old. Other demographic characteristics are outlined in Table 1. The final theme in this study was "vigilant care", which was comprised of four categories and 14 subcategories (Table 2).

Quarantine fence

The first category under the final theme was quarantine/isolation fencing and its hazards, including the drawbacks of apartment living as a challenge to the quarantine and segregation of the patients with COVID-19 during home care, which could increase the likelihood of the disease transmission.

• *Implementing Quarantine/Isolation Strategies*

One of the best techniques suggested to prevent disease transmission was to keep the infected cases away from others. It was thus necessary to help them stay in a separate room with adequate

Table 1. Demographic characteristics of the participants

No	Gender	Age (Years)	Caregiver role	Education level	Interview duration (minutes)
1	Male	47	Wife	Diploma	32
2	Female	58	Child	High school	35
3	Female	26	Father	Bachelor's	40
4	Female	32	Mother	Bachelor's	28
5	Female	32	Other caregiver	Bachelor's	25
6	Female	28	Mother	Bachelor's	34
7	Female	35	Child	Master's	38
8	Female	33	Other caregiver	Bachelor's	40
9	Female	34	Husband	Bachelor's	25
10	Female	37	Husband	Diploma	22
11	Female	43	Husband	Bachelor's	40
12	Female	38	Other caregiver	Bachelor's	30
13	Female	39	Husband	Diploma	32

ventilation to control the spread of the disease. A mother, describing the experience of her child's quarantine during COVID-19, stated that:

"...The first thing I tried was quarantining my son. As we had a spare room in our parking lot, I put a bed there and I just visited him and did not let anyone go and see him." (Participant No. 2)

• *Observing Personal Safety Protocols*

All people in contact with COVID-19 patients were required to use personal protective equipment to save themselves from this viral infection. A mother, talking about her child's quarantine during the pandemic:

"...I was in constant contact with my son, so I put on gloves and a face mask. I tried to wash my hands regularly. I also put an alcohol container outside the room and then sprayed it when commuting there." (Participant No. 2)

• *Caregivers infected with COVID-19 simultaneously*

Keeping a safe distance from the infected person in a small home seemed very difficult, and it could lead to the transmission of the disease to others. This challenge could also infect other family members. Reflecting on the experience of caring for her mother-in-law, a female participant added that:

"...Unfortunately, we did not have enough space for quarantine. Such spaces must be very open, but we did not have a spare room for this purpose. We all got infected. The only thing we did was to open the doors and windows to ventilate the air." (Participant No. 12)

Another participant also shared his experience regarding in-home care delivery to his brother as follows:

Table 2. Subcategories, categories, and the final theme extracted from the participants' interview

Themes	Categories	Subcategories
Vigilant Care	Quarantine fence	<ul style="list-style-type: none"> • Implementing quarantine/isolation strategies • Observing personal safety protocols • Caregivers infected with COVID-19 simultaneously
	Economic management as a bottleneck	<ul style="list-style-type: none"> • Rich nutrition • Problems providing medicine • Access to medical staff and counseling
	Confusion and difficulty in care	<ul style="list-style-type: none"> • Ambiguities of complementary medicine • Dilemma of adherence to treatment • Instability of the patient's condition • Constant care
	Conflicting adaptation and moderation of psychological stress	<ul style="list-style-type: none"> • Implementing positive emotion-focused coping strategies • Strengthening spiritual and religious beliefs • Facing conflicts and tension and their role in family disruption • Self-sacrificing for care

"...My brother, his wife, and his child were infected with the virus at the same time. Since my nephew was critically ill, we had to go and see him at the hospital. On the other hand, my brother was also very ill." (Participant No. 8)

Economic management as a bottleneck

COVID-19 brought about many economic problems to families, and it had many negative effects on the livelihood and businesses of people, especially the heads.

• *Rich nutrition*

Nutritional strategies to control the COVID-19 symptoms were the first sub-category under the economic management during the pandemic as a bottleneck. The WHO had also declared that nutrition was one of the most important factors in maintaining health and controlling the disease. Moreover, people with a healthy and proper diet could have a strong immune system. In this line, one of the participants providing in-home care for his mother with COVID-19 said that:

"...We tried to prepare a more protein-rich diet for our patient. I even made some natural juices and cooked meat and various soups. I tried to use herbal tea, particularly thyme." (Participant No. 6)

• *Problems in providing medicine*

Severe COVID-19 conditions on the one hand and the suffering of getting medications on the other hand could be a double pain for the family of patients and even more painful than the disease itself. A mother, describing her in-home care experience for her daughter, maintained that:

"...It was very difficult to get medications and everyone had to go and search in many pharmacies. Buying an oxygen generator was also one big trouble. The expensive equipment on the one hand and the critical situation where we could not find the necessary tools and medicine was another trouble. I just remember the day after my daughter got infected and there were shortages of serum injections." (Participant No. 7).

• *Access to medical staff and counseling*

Another concern facing patients undergoing home care was the availability of a specialist physician and a nurse to give advice, resolve the existing ambiguities, and manage the disease symptoms at home, which were of utmost importance in patient care. Caring for her husband, daughter, and brother's wife, a female participant correspondingly highlighted the significance of consulting with the medical staff as follows:

"...We had some physicians around us. I was also in constant contact with them. I kept reporting on the phone. Actually, it encouraged me to find the inner strength to move forward. In fact, there was always someone at hand to stress that I was doing right or wrong." (Participant No. 11)

Confusion and difficulty in care

Confusion in the treatment process was the third category of the final theme, "vigilant care", addressed as another challenge in the delivery of in-home care to COVID-19 patients by caregivers. The limited number of hospital beds during the fifth peak of the pandemic, the high likelihood of the Delta variant transmission, the deficiency of serum injections, along with the conflicting prescriptions have also raised some concerns among the families of the COVID-19 patients and caused confusion in the treatment and care process. As the possibility of death and the success of the treatment process for COVID-19 were unpredictable, patients could suffer from much stress and anxiety because this critical condition could affect all body systems, making it difficult to care for the infected cases.

• *Ambiguities of complementary medicine*

The use of complementary medicine could resolve the confusion of patients' families. This was also effective in patients with mild-to-moderate COVID-19 symptoms. Accordingly, a female participant, caring for her husband, daughter, and brother-in-law, reiterated that:

"...I tried herbal tea, especially thyme. The crushed onion, put in a plastic bag to inhale, was also in effect in curing their lungs. I even heated sea salt and put it on their chest, which helped in their healing process. Now, I do not know how right and wrong it was?" (Participant No. 11)

- ***Dilemma of adherence to treatment***

Treatment adherence was another challenge in patient care. On the one hand, the severe symptoms of the disease, as well as the fear and anxiety of its deterioration, and on the other hand, the dilemma of the effectiveness of drugs to deal with the pandemic was among the challenges that could impair patient management. In this respect, a mother, sharing her experience of caring for her daughter with COVID-19 at home, affirmed that:

"...She herself observed treatment adherence very well, but whether we needed to receive the COVID-19 vaccine or not was a real dilemma. It was good if we did it, but it seemed very difficult to prepare, and the side effects of the drugs were also strong." (Participant No. 3)

- ***Instability of the patient's condition***

The worsening of patients' condition could be assumed as a warning sign that needed to be respected by caregivers. Accordingly, shortness of breath, chest pain, confusion and disabilities, chronic cough, and facial bruises were supposed to be taken into account, because they were among the warnings for unstable hemodynamic conditions in such patients. Talking about her experience of in-home care for her father with COVID-19, a nurse said that:

"...My father had a history of an underlying disease. He was suffering from high blood pressure and had already undergone bypass surgery. It was very scary because I was working in the intensive care unit for COVID-19 patients. I had also seen patients who had failed to recover due to their previous heart bypass (Participant No. 3).

- ***Constant care***

Constant care for the COVID-19 patient was the other sub-category under Confusion and difficulty in care. During the in-home care delivery to such patients, caregivers were thus required to regularly monitor their health conditions and symptoms and even take them to the hospital in case of any problems. Caring for his wife 24 hours a day, a male participant stated that:

"...There has to be a vigilant caregiver or nurse. When there is no one, they cannot prepare food and juice, but my children and I were at her service round the clock because I was a taxi driver. I had much free time and I could do it easily and take care of my wife, but that would be a big problem if I was employed somewhere." (Participant No. 1)

Conflicting adaptation and moderation of psychological stress

Having positive styles to resolve conflicts and deal constructively with care problems and challenges could lead to adaptation in individuals and consequently moderate their psychological stress.

- ***Implementing positive emotion-focused coping strategies***

Adopting coping strategies, such as problem- and emotion-focused ones, could definitely help increase the knowledge and awareness of caregivers and their power of adaptation, and then result in stress-free acceptance and avoidance of withdrawal and despair. In this respect, a female participant, delineating the experience of caring for her brother, reiterated that:

"...The support and hope that my friend gave me was that they, too, were facing the same condition where in everyone had been infected and recovered." (Participant No. 8)

- ***Strengthening spiritual and religious beliefs in times of stress***

Although COVID-19 temporarily led to the cessation of religious rites and practices, it augmented spiritual beliefs in individuals and strengthened their religiosity. For example, a mother, experiencing the in-home care of her daughter, said that:

"...God is present in all things, and everything is unquestionably connected with Him. That was really helpful. The moments when I was feeling bad, that is, I had heart problems, only God saved my life. First and foremost, only God is everywhere. Our efforts are not fruitless, but nothing can happen without God's permission. The only strength was to reduce my anxiety." (Participant No. 7)

- ***Facing conflicts and tension and their role in family disruption***

Role conflicts and tension, especially in the case of the infection affecting several family members,

were inevitable challenges. Here, some roles could not be consistent with the other ones and might even disrupt the family's comfort due to the busy schedule. Delivering in-home care to his mother with COVID-19, a male participant declared that:

"...She was mothering the family and meeting the needs of all family members, but now there was a disturbance in the roles in our family due to her health conditions. The peace in our home was thus disturbed." (Participant No. 6)

Another participant described one's experience with COVID-19 affecting her parents as follows:

"...Two people in our family were infected at the same time, but one was getting worse, making it harder to take care of the other one. I did not know what to do on my own." (Participant No. 4)

- ***Self-sacrificing in care***

The patient-family relationship has been always a known factor in improving patient outcomes. Giving compassionate care to family members despite the fear of being infected could thus indicate a sense of sacrifice for the patient's recovery. Describing the compassionate care delivered to her child, a mother said that:

"...It did not even matter to me that I took care of him with every fiber of my being, even if I myself could get infected." (Participant No. 2).

Discussion

This study aimed to explain the experiences of in-home caregivers regarding care delivery to patients with COVID-19, whose results led to the emergence of the final theme, "vigilant care", with four main categories. Accordingly, in-home caregivers should be able to take care of COVID-19 patients in a wise and intelligent manner with sufficient knowledge and skills, and if necessary, benefit from advice and support from others. It is thus of importance to be a vigilant caregiver rather than an emotional one. COVID-19 is also a highly contagious disease; therefore, caregivers are required to protect themselves first once they deliver in-home care to such patients.

According to the Centers for Disease Control and Prevention, all caregivers should have vigilance in care for COVID-19 patients, provide them with physical and mental support, pay attention to the warning signs of the disease, and protect themselves to prevent the spread of the infection (20).

The use of quarantine/isolation strategies was thus one of the principles in the vigilant care of patients with COVID-19 from the perspective of the in-home caregivers. Like a fence, quarantine/isolation could keep the infected person to some extent away from contact with others and the surrounding environment but definitely prevent the spread of the disease (21). The WHO also declared that asymptomatic cases, as well as individuals under the age of 60 with underlying diseases, should stay in and receive care via consulting with physicians if they were tested positive for COVID-19. They could further benefit from home care provided that the principles of quarantine/isolation were met as far as possible (22).

Economic problems facing families were another challenge highlighted in the caregivers' experiences as a serious livelihood crisis that could overshadow all aspects of life. The economic burden, especially incurred to the heads of families with COVID-19, who had been already responsible for the household livelihood, could put much more psychological pressure on them and even affect their ability and performance, or their recovery from the disease. Verifying the results of the present study, Leer et al. had reported that the economic challenges arising during the COVID-19 pandemic had been multiplied among parents with school-age children and foster mothers (23). The result of a qualitative study in Iran showed that in the experience of living with COVID-19, economic worries about declining income and inability to make a living were among the subclasses of the negative emotion class that caused anxiety and worry in the individual (24).

The COVID-19 pandemic had also given rise to global economic disruption. Moreover, previous economic inequalities had increased, affecting female-headed households and low-income individuals. Many people, especially those living with lower income before the pandemic, had thus experienced significant reductions in their economic, physical, and mental well-being. Depression and anxiety among families had further escalated during this critical condition due to the economic problems (25).

Confusion in the treatment process was also another experience addressed by the in-home caregivers of the COVID-19 patients. Uncertainty and frustration in the treatment process, as well as incomplete

or even sometimes contradictory, ambiguous, and unreliable information, had accordingly triggered confusion in the treatment process. In this line, Koffman et al. had stated that the COVID-19 pandemic had many knowns and unknowns that could not be dismissed due to the uncertainty or the multiplicity of questions and ambiguities it had raised; however, it could be much better managed than it was now. Accordingly, some strategies could also improve the possibility of making decisions in the event of uncertainties (26).

Another challenge threatening the in-home caregivers of the patients with COVID-19 was confusion and difficulty in care even though the medical staff was also facing the same challenge. This was attributed to unstable patient conditions and some changes in the course of the disease that were unavoidable and unpredictable and even demanded vigilant care. Pazokian et al. had also stated that the difficulty of care among the medical staff was due to psychological distress, patients' critical conditions, treatment process, and inadequate training early in the pandemic (27).

Likewise, Amanda et al. had concluded that caring was more difficult for the caregivers of patients with chronic or debilitating conditions and required some improvements in the care process, such as providing emotional support or making changes in family life (28). Conflicting adaptation and moderation of psychological stress was another category associated with vigilant care. In fact, adaptation to the COVID-19 pandemic conditions was essential to control the related psychological issues. Accordingly, it was of importance to practice coping strategies wisely to meet some situational demands.

Morales et al. had further argued that gender and age were among the variables shaping the adaptation of individuals during the quarantine due to the COVID-19 pandemic. Indeed, women tended to feel more stressed out, have more gloomy attitudes, and show lower levels of self-esteem; however, older adults were better able to cope with the quarantine conditions. In general, quarantine was an effective way to control the spread of the disease; nonetheless, it could have unpleasant psychological consequences (29). Wu et al. had also stated that feeling at risk, being likely to be ill despite no symptoms, and worrying about infecting other family members necessitated some intervention strategies to adapt to the COVID-19 pandemic period (30). The limitation of this study was that it was not possible to interview the caregiver during the first period of Remdesivir injection due to anxiety and worry. We tried to reduce the level of anxiety by talking to the companion, establishing confidence and trust in the treatment process, and providing the possibility of an interview.

Implications for practice

Vigilant Care is a major challenge for the caregivers of patients with COVID-19 at home. Therefore, caregivers must have sufficient knowledge and awareness to care for patients. This requires caregivers to receive training support from the health team staff. Providing educational solutions or training booklets in outpatient wards during discharge and distance learning methods, such as telenursing, can partially resolve the ambiguities and be effective in improving care.

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Conflicts of interest

The authors have no conflict of interest.

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