Family Caregivers' Experiences of Caring for Patients with COVID-19: A Phenomenological Study

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Abstract

Background: Family caregivers of patients with COVID-19 face many challenges that affect their physical and mental health.

Aim: The aim of the present study was to explore the family caregivers' experiences of caring for patients with COVID-19.

Methods: This qualitative phenomenological study was performed based on 13 family caregivers who had experience in home caring for patients with COVID-19. Data were collected through purposive sampling with in-depth semi-structured interviews. The *Colaizzi's 7-step method* was used to determine themes. The MAXQDA10 software was used to manage qualitative data analysis.

Results: Five themes of (a) "nature of the disease" with 2 subcategories, including "fluctuating symptoms" and "emergent and unpredictable disease;" (b) "unmet needs" with 3 subcategories, including "lack of knowledge," "lack of health facilities," and "financial problems;" (c) "unpleasant physical, psychological, and social experiences" with 3 subcategories, including "unpleasant physical experiences," "unpleasant psychological experiences," and "unpleasant social experiences;" (d) "care facilitators" with 3 subcategories, including "social support," "adaptive mechanisms," and "intrinsic motivations;" and (e) "positive experiences" with 3 subcategories, including "promoting spirituality," "improving relationships," and "growth" were extracted.

Conclusion: Information and financial support for COVID-19 should be provided to family caregivers. Also, community members should embrace patients and family caregivers and reinforce the positive experiences of caregivers.

Background

Coronavirus disease (*COVID-19*) is a worldwide epidemic infection, which emerged initially in Wuhan, China, in December 2019, and it *rapidly became a growing public health concern with high transmission probability* [1]. *Based on the latest WHO statistics on November, 2020*, more than 51 million cases of COVID-19 had been confirmed, *which resulted in over 1 million deaths globally. The number of patients in the United States, India and Brazil is higher than other countries and Iran is ranked the fifteenth in the world* [2].

Although increased risk of severe illness and death has been more observed in the elderly and individuals with underlying medical conditions, current research evidences show that all ages are susceptible to coronavirus infection [3, 4]. The droplets generated by patients' coughing and sneezing and direct contact cause *infection in the hosts; in addition, asymptomatic carriers can transmit coronavirus* [4].

Covid-19 causes respiratory and digestive tract symptoms [5]. The symptoms of the disease may range from mild self-limited symptoms to severe pneumonia, septic shock, acute respiratory distress syndrome (ARDS), and multiple organ failure syndromes [6].

Since there is no specific cure for COVID-19, treatment is limited to symptomatic and supportive therapy [7]. Patients with severe COVID-19 need to be hospitalized and mild or some moderate patients without underlying chronic conditions can receive care by home-based informal caregivers [8].

Informal caregivers are usually family members, or close relatives who provide care, typically voluntarily to patients at home [9]. They provide significant support to individuals who are elder or have chronic disease, disabilities, mental health problems, and addiction. These caregivers are reducing increased pressure on health and social care systems [10]. *Assistance with performing activities of daily life, managing treatment-related conditions, communicating, educating, encouraging and empowering the patients to take care of themselves is known as responsibilities of home caregivers [10, 11]. The complexity of care provided by caregivers has increased, and almost half of caregivers have stated that they perform complex nursing and medical tasks and coordinate care [12].*

A collection of positive and negative experiences may be experienced when informal caregivers move into their caregiving role. They often expose to physical and psychological needs, such as caregiving overload and emotional stress [13]. Several factors are associated with caregiver distress, including incarceration, lack of leisure time, lack of assistance from other family members, poor care knowledge, caregiver age, and guilt over ignoring the patient's complaints [14-16]. Vagueness, stigma, discrimination, change in relationships with the patient and others, and compassion fatigue may also be experienced as negative experiences [17, 18]. Feeling good about themselves, compassion satisfaction, learning new skills, and strengthening family relationships are some of the positive experiences mentioned by family caregivers [18, 19]. Findings of scientific researches show that different experiences of family caregivers may be associated with their physical and mental health [10, 14, 19].

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. To date, most of studies have focused on the experiences of patients or health care staff. For example, death anxiety and fear, depression, stigma, ambiguity, decreased communication with family and society [20]. Moreover, anxiety, stress, fear, suffering and affliction, waiting for death, turmoil, and lack of support and equipment were experienced by nurses who cared for the patients with COVID-19 [21]. *However, to date, no study* has been conducted on family caregiving experiences of patients with COVID-19. Caregivers have many needs in different areas [22]. Since the consideration of caregivers' experience is necessary to plan services and support them [23], the present study was conducted to understand the experiences of family caregivers for patients with COVID-19 to explore their challenges regarding this novel disease.

Methods

Study Design

A qualitative descriptive phenomenological methodology was adopted to explore the family caregivers' experiences of caring for patients with COVID-19. The phenomenology is an approach that enables the researcher to explore the lived experiences of individuals as they occurred in life [24]. The openness to the phenomenon under study must be emphasized when researchers investigate lived experiences. *The openness emerged when researchers had questioned their preunderstanding, which means recognizing and becoming informed of preconceptions that might affect the analysis.* This is the same as bracketing, a generally used term in descriptive phenomenology [25]. The bracketing means to waive the researcher's prior knowledge about the study phenomenon. Bracketing helps to better understand the essence of the phenomenon from the participants' viewpoint [26]. In this study bracketing was considered in every part of study process, especially in analysis.

Sampling and Participants

The study was conducted in 2020 in Jiroft, which is located in the southeast of Iran. Purposive criterion sampling was used to identify participants who had experience in home caring for patients with COVID-19. This sampling method applies to generate a homogenous sample of participants that have all experienced the study phenomenon [27]. A sample of 13 family caregivers participated in this study. Sampling was continued until saturation of themes was achieved.

Data Collection

Data were collected from Jun to July 2020. First, a list of telephone number of patients diagnosed with Covid-19 disease was prepared from the city health center and then the contact information of home caregivers was obtained. The objectives of the study, the method of data collection, and the voluntary participation in the study were explained to participants. The time and place of the interviews were determined by the caregivers. All but one (at caregiver home) interview was conducted in the hospital. In-depth semi-structured face to face interviews was conducted to encourage the participants to discuss their experiences from caring for a patient with Covid-19.

The open-ended interview guide was designed and validated by the research team and included questions such as "Please describe your caring experience of patient with coronavirus disease in as much detail as possible." When necessary, probes and follow-up questions (eg, can you please explain more? can you give an example?) were added to encourage discussion and clarify answers. Every interview session ended with the question "Is there anything else you want to add, which I did not ask?" Interviews lasted 30 to 70 minutes, were digitally audio-recorded with participants' permission, and transcribed verbatim. To ensure data confidentiality, an ID number was assigned to each participant and the transcripts were without personal information.

Data were collected until data saturation was reached. After interviewing 11 participants, it was observed that no additional data could be obtained. To ensure that there was no other new information, the researchers conducted 2 more interviews.

Data Analysis

In this study, data were analyzed using *Colaizzi's 7-step method of data analysis* [28]. The steps to uncover components of the phenomenon of caring for caregivers of patients with Covid-19 were as follow: (1) data to achieve a general feel of data obtained; (2) extraction of significant statements related to the caring experience of patient with Covid-19; (3) formulation of meanings; (4) organization of the formulated meanings into theme clusters; (5) comprehensive description of the phenomenon described by participants; (6) identifying the fundamental structure of the study phenomenon; (7) and validation of the results with participants. The MAXQDA 10 software (VERBI GmbH, Germany, 2010) was used to analyze the text data.

Trustworthiness

Demonstrating trustworthiness is essential for qualitative studies, which are measured by criteria proposed by Lincoln and Guba, including *credibility, transferability, dependability, and confirmability* [29]. In this study, prolonged engagement, member checking, peer debriefing, thick contextual description, and enabling external audits were implemented as trustworthiness strategies.

Ethics

The study design and guideline interview was approved by the Scientific and Ethical Committee of Jiroft University of Medical Sciences (Ethics number IR.JMU.REC.1399.019). Written informed consent was obtained from all participants. To ensure anonymity and confidentiality, identifying information of family caregivers was not transcribed and all participants were given fictitious names and descriptions.

Results

The age of the participants ranged from 22 to 54 years. Twelve of the participants were female and 1 was male. Nine of the participants were married. All caregivers cared for their first-degree relatives (mother, father, child, sister, and spouse) at home. A total of 5 major themes emerged from the data: (a) Nature of the disease; (b) Unmet needs; (c) Unpleasant physical, psychological, and social experiences; (d) Care facilitators; and (e) Positive experiences.

Nature of the Disease: This theme referred to the caregivers' experience in relation with caring for a patient with the Covid-19. They stated that the experience of caring for a patient with Covid-19 was different from their previous caring experiences. This theme included 2 subthemes: "fluctuating symptoms" and "emergent and unpredictable disease."

Fluctuating Symptoms: This subtheme indicated the caregivers' experience of fluctuating symptoms of the disease. According to the caregivers, recurrence of the disease symptoms after partial relief, reversal of the symptoms, and appearance of unexpected symptoms caused them to feel hopelessness, fear, and stress. In this regard, one of the caregivers said,

"My husband's fever stopped for a few hours, but I did not know whether to help or not because the fever started again and this happened over and over again. Sometimes, he was feeling good and sometimes he was feeling bad; such fluctuating symptoms bothered me." (Caregiver 5)

Emergent and Unpredictable Disease: Most caregivers felt anxiety in dealing with this disease because COVID-19, as an emerging and unknown disease, has no definitive treatment and its course is unpredictable.

"This is an emergent disease; even physicians do not know much about it. It is evident that caring for these patients is difficult." (Caregiver 1, caring for a sister)

"It was a really difficult experience given that the disease is unknown; I did not know how the disease would progress." (Caregiver 4, taking care a husband)

Unmet Needs: This theme was about needs of caregivers that were not met and made the care experience challenging and difficult for caregivers. The subthemes were *lack of knowledge, lack of health facilities, and financial problems*.

Lack of Knowledge: All participants considered lack of knowledge and care skills as one of the main problems in caring for patients with COVID-19. Most caregivers expressed that they doubted their ability to care, their information needs were not met, and they feared that this lack of knowledge and skills would cause harm to the patient. One of the caregivers described her experience as follows:

"When my mother's shortness of breath got worse, I did not know what I was doing was right or not. I told myself 'I may endanger her life and make her worse.' It would have been great if I had a source to guide me." (Caregiver 2, Taking care of a mother)

Lack of Health Facilities: According to the caregivers, problems caused by lack of health facilities included lack of access to health care services, lack of access to physicians, lack of telemedicine, and lack of counseling center and psychological support.

One of the caregivers said, *"If there was a special care center for COVID-19 patients that provided 24-hour services, people did not have to spend a lot of time on visiting physicians. Consequently, stress and anxiety would have been reduced in caring for the patients."* (Caregiver 2, caring for a mother)

"Considering the quarantine situation, we do not want to leave the house. I wish some physicians visited the patients using WhatsApp or video calls." (Caregiver 9, caring for siblings)

Financial Problems: This subtheme was extracted from the statements of the caregivers who cared for male patients with nongovernmental jobs. These participants indicated that they had financial needs during the quarantine and mentioned that the government should support patients with financial and health packages. *"My husband is self-employed; he could not leave the house for almost 3 weeks due to*

the disease and we were in financial difficulties. The government should provide financial assistance to financially weak families.” (Caregiver 5, caring for a husband)

Unpleasant Physical, Psychological, and Social Experiences: Caregivers described experiences that were physically, psychologically, or socially unpleasant and even painful at time. This theme consisted of the following subthemes: unpleasant physical experiences, unpleasant psychological experiences, and unpleasant social experiences.

Unpleasant Physical Experiences: Some caregivers reported experiencing physical problems, such as sleep disturbances, anorexia, and allergies caused by overuse of disinfectants, and fatigue. *“I did not sleep until the wee hours of the morning because I was worried and anxious about my husband. I wanted to pay all my attention to him.”* (Caregiver 13, caring for a husband)

Unpleasant Psychological Experiences: All participants had unpleasant psychological experiences. They described this period as difficult and terrifying. These experiences varied, but the most common ones were fear, anxiety, worry, sadness, hopelessness, and mental preoccupation about the disease outcome. A caregiver mentioned,

“My mind was occupied by thinking about my mother. I thought she may get worse and die, God forbid! All these thoughts made me sad, upset, depressed, and frustrated.” (Caregiver 6, caring for a mother)

“I had a dark and sad period.” (Caregiver 10, caring for a 4-year-old child)

Unpleasant Social Experiences: Caregivers’ unpleasant social experiences, including experiences occurring when they encountered negative reactions from healthy people in the community. They felt socially rejected and deprived because their friends and family members avoided contacting them because they thought the caregivers may be disease carriers. Moreover, they were home alone with the patient, which made them feel lonely.

“Even after the quarantine period was over, others would distance themselves from me and shouted ‘Why did you come out?’ and I felt very upset.” (Caregiver 2, caring for a mother)

Care Facilitators: This theme included factors that facilitated the care process for caregivers and included subthemes of *social support, adaptive mechanisms, and intrinsic motivations*.

Social Support: According to the caregivers, social supports entailed practical supports, such as providing food and necessities of life and guidance for care as well as emotional support that encouraged them to continue caring with strength.

“My family members phoned and encouraged me. This reduced the loneliness and severity of the caring process.” (Caregiver 3, caring for a husband)

Adaptive Mechanisms: All caregivers used some mechanisms to reduce the care-related stress. They applied adaptive mechanisms, such as positive self-talking, distracting, seeking information from various

sources, as well as praying and trusting God.

"When my mind was occupied with illness and death and fear took me over, I immediately distracted myself by doing something or playing with children." (Caregiver 7, caring for a husband)

Intrinsic Motivation: Participants expressed a sense of responsibility regarding the patient and family health. The interest between caregiver and care recipient as well as observation of the healing process (as an internal driver) made the caregivers enjoy caring for the patient rather than *performing* a task that is imposed on them. A male caregiver who cared for his wife indicated, *"I accepted the responsibility to take care of my wife to protect our life and children. So, I took care of my wife with all my heart and soul."* (Caregiver 12, caring for a wife)

Positive Experiences: Based on the participants' statements, caring for patients with COVID-19 also had some positive outcomes for caregivers: promoting spirituality, improving relationships, and growth.

Promoting Spirituality: Most participants mentioned that caring for patients with COVID-19 showed them that life could be shorter than they thought. Thus, they realized that this world and its material gains were not worth the attachment. They concluded that human beings should not immerse themselves in materialism and luxury. Most of the participants also believed that this period strengthened their faith in God. In other words, they felt that their relationship with God got stronger and their appreciation increased for the blessings of life, especially the blessing of health. In this regard, one of the caregivers said, *"My faith in God have peaked during this period because I heard that some people, physically healthier than my husband, died due to COVID-19 but my husband survived. This was mere grace of God."* (Caregiver 7, caring for a husband)

Improving Relationships: Most participants reported that caring for a patient with COVID-19 improved their relationship with the patient. As they noted experience of living with and caring for someone for 2 weeks increased their interest in each other, and they appreciated each other during this period. Some caregivers stated that this experience increased their ability to forgive others, increased their tolerance threshold regarding the others' discouraging behaviors, and lowered their expectations of others, which improved their relationships with others.

"Now, I realized how important we are to each other, I feel we got closer." (Caregiver 7, caring for a husband)

Growth: Some caregivers, especially younger individuals, stated that the experience of caring for a critically ill patient made them stronger and more responsible and provided them with a sense of growth.

"I became much stronger, as I gained experience and learned how to protect myself from fear and stress." (Caregiver 9, caring for siblings)

Discussion

This phenomenological study explored how family caregivers experience and perceive caring for patients with COVID-19. Participants' experiences in the caregiving period cause them to have some perceptions about their roles, responsibilities, and challenges they faced. Five main obtained themes of this study included "nature of the disease", "unmet needs", "unpleasant physical, psychological and social experiences", "care facilitators," and "positive experiences" reflect experiences of family caregivers of patients with COVID-19.

According to the findings of the study, family caregivers described the nature of COVID-19 as unknown because of fluctuating symptoms and unpredictability of the disease. There is *limited* information regarding *the caring* challenges of family caregivers in patients with COVID-19, but *evidence shows formal caregivers, patients or the public community members experienced a wide range of concerns* about the nature of COVID-19. For example, Sun et al stated *nurses* participating in the study believe that COVID-19 is a new disease with an unpredictable condition that made them worry about secondary actions required if the patient's condition deteriorates [30]. Also, the results of a qualitative study on patients with COVID-19 indicated the disease appeared to manifest differently among the patients. The patients reported they had experienced *symptoms* of COVID-19 that sometimes got better and sometimes worse during different days of illness [31]. The result of a study revealed that unpredictability and uncontrollability of stressors are related to depression and anxiety [32]. We suggest conducting quantitative studies to survey the effect of caring of patients with COVID-19 on psychological status of caregivers.

In the current study, most of participants had needs that were not met, including lack of knowledge, lack of health facilities, and financial problems. Lack of public knowledge and awareness regarding various aspects of coronavirus have been reported in previous studies [30, 33]. To reduce mortality and morbidity caused by COVID-19, accurate and efficient information should be provided to the general population, especially high-risk groups, by and healthcare workers and social media.

With the onset of the outbreak of covid-19, the lack of medical facilities, equipment, and staff has affected health care systems and community members around the world. *The result of a study by Mohammadi et al* showed that lack of access to medical equipment for caregivers made caring for COVID-19 patients a challenge [34]. Also, *highcost* for *covid-19* treatment has affected families' financial stress and well-being, where the immediate and long-term effects of COVID-19 have led to occupational vulnerability of families because of unemployment, declining incomes, debt, and economic hardship [35].

Most of the respondents had experienced unpleasant physical, psychological, or social experiences while caregiving. *The result of a review showed that sleep disorders, fatigue, and inadequate self-care were recognized as common physical health problems in family caregivers [36].* Family caregivers may also *grapplewith* anxiety, depression, apathy, disappointment, loneliness, and isolation because of reduced social interactions and social exclusion while providing that care [19, 37]. All of these experiences may result in a poor quality of life among them. Therefore, implementing supportive interventions for family

caregivers is essential if the health care system aimed to reduce the cost of care through home caregiving.

Along with the experienced challenges and problems, our participants reported some personal facilitators, including social support, adaptive mechanisms, and intrinsic motivations that help them *to provide care for* COVID-19 patients. Research *findings have well established* the relationship between social support and increasing the quality of caregiving. In the presence of social support, *patient care* becomes a valuable experience for informal caregivers in addition to meeting patient needs. Also, emotional satisfaction, positive well-being, better relationships and stronger social bounds is more reported in caregivers who have received adequate social support from family members or others [38]. Moreover, *consistent with our findings*, various adaptive *strategies* have been employed to deal with home caregiving in other studies. Looking for distractions, resting, discussing experiences and emotions [39], talking to a spiritual person, attending religious services, and praying and meditating are some coping mechanisms that have been reported in the literature [40]. 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 [41]. In this study, participants stated a sense of responsibility and interest regarding the care of the patient. Similar to this finding, Zahed et al, reported that family caregivers considered caregiving as an honorable duty or a commitment to the love and care they shared as a spouse [42].

Promoting spirituality, improving relationships, and growth are positive experiences reported by participants, which are *similar to other studies* of family *caregivers* [43]. Caregivers, who perceive more positive experiences, are more likely to be satisfied and develop a close relationship with the patient; therefore, positive experiences, especially in the COVID-19 pandemic period, should be reinforced.

Conclusion

According to the results of the study, paying more attention to the problems and needs of home caregivers of COVID-19 patients is of paramount importance. The health care system should provide adequate information and financial support to patients' families. Also, the psychological atmosphere of the society should be friendly to patients and their families to create more empathy and facilitate the care of patients at home. Emphasis on positive experiences can also provide more satisfaction to caregivers to continue caring.

Declarations

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Authors' contributions

TR and FR, initiated and developed the proposal of study. FR and ND performed interviews and all authors participated in data analyze. TR, FR, and ND wrote the first draft of the manuscript and all authors approved the final draft of the manuscript.

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Availability of data and materials

All data analyzed during this study are included in this published article and its additional files.

Ethics approval and consent to participate

The proposal for the study was submitted for ethical approval to the Jiroft University of Medical Sciences Ethics Committee (Ethics number IR.JMU.REC.1399.019). Before starting the data collection process, the objective of the study was clearly explained to all home caregivers who participated in the study and informed consent were obtained. They were also assured of the data confidentiality and *the right of withdrawal from the study* at any time. One of the caregivers refused to participate in the study because of his busy schedule.

Consent for publication

Not applicable.

Competing interests

The authors declare no potential competing interests.

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