

Lived Experiences and Challenges of the Families of COVID-19 Victims: A Qualitative Phenomenological Study in Tehran, Iran

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Abstract

Being COVID-19 positive and then dying causes a slew of personal, familial, and social issues for family members. Therefore, the current study was carried out to analyze the lived experiences and issues of COVID-19 victims' families in Tehran, Iran. The phenomenological approach was used in the qualitative analysis of 21 first-degree relatives of COVID-19 victims. From August 22 to October 21, 2020, data was gathered by phone (4 people) and in-person (17 people) using semi-structured interviews. The subjects were chosen through purposeful and snowball sampling. The MAXQDA-2018 program was used to organize the data, and the Colaizzi analytical technique was used to analyze it. Guba and Lincoln's criteria were also used to assess the findings' quality. After analyzing the data, 2 main categories and 14 subcategories were extracted, including (1) challenges in caring for a COVID-19 patient (being rejected, limited access to medical facilities, dissatisfaction with the behavior of medical staff, disruption of family life, the challenge of managing family members' behavior with the patient, and living with doubts and worries) (2) challenges after a COVID-19 patient's death (incomplete farewell to the corpse, unbelievability of the death, ambiguity and tension in the burial process, lonely burial, the twinge of conscience, worry about not respecting the deceased, incomplete condolences, and abandonment). The troubles of victims' families can be ameliorated by developing the skills of caring for COVID-19 patients at home, providing medical and psychological services to families before and after the patient's death, appropriately informing the families to guarantee them about dignity and respect and respect of the deceased at the interment, and developing a culture of virtual condolence to provide emotional support to survivors.

Keywords

COVID-19, coronavirus, patients' families, challenges, qualitative study, Iran

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What do we already know about this topic?

Being COVID-19 positive and subsequent death can cause a slew of personal, familial, and societal problems for family members.

How does your research contribute to the field?

Most of the studies in the field of COVID-19 have been conducted using quantitative and experimental approaches. Therefore, the need for qualitative research in Iran, which has a different social and cultural structure in the field of patient care and mourning after death, becomes more apparent. With qualitative research, the hidden layers of the subject can be examined in a better way.

What are your research's implications towards theory, practice, or policy?

To counteract the negative repercussions of COVID-19 infection, such as deaths, and to prevent a health crisis from becoming a societal disaster, appropriate measures must be implemented. Some steps must be taken to remove the disease's stigma through the media and public education, as well as to teach patients at home and provide wider access to medical counseling. In addition, developing a culture of virtual condolence by phone, video call, and sending a memento to provide emotional support to survivors, providing timely psychological services, and strengthening the morale of the victims' families all important in this regard.

Background

The new coronavirus (COVID-2019) first surfaced in December 2019 in Wuhan, China¹⁻³ and has since spread swiftly throughout the world. Thus, it has become the most serious health and medical concern in the world, and the World Health Organization has designated it a pandemic.^{4,5} COVID-19 has so far afflicted many individuals all across the world, and the number of people infected with the disease and dying as a result of it is fast growing.⁶⁻⁸ The total number of people infected with the virus globally as of January 8, 2021 was 89 080 882, with 1 916 020 deaths. The United States, India, and Brazil have the most cases of the infection, while Iran is one of the nations with the most cases of the sickness, with 1 274 514 people afflicted and 56 018 people killed.⁹ The number of patients admitted with COVID-19 in Iran at various eras fluctuated proportionally to the number of patients. At times, the number of COVID-19 hospitalized patients was so great that hospitals were unable to admit new patients. Therefore, attempts were made to admit only patients in need of critical care, while the remainder of the patients were referred home to be cared for by family members, for whom no data was available. Because, even when families were aware that their patient had COVID-19, they attempted to have their patient cared for at home due to worries about hospital fees or their patient's health.

People are concerned since this is the third lethal pandemic, following SARS and Mersin, and there is a lack of vaccination and clear therapy.^{2,10} COVID-19 has an impact on many facets of a person's life and has both physical and psychological implications. One of the concerns during the coronavirus outbreak is caring for patients infected with it. During these

crises, problems such as rejection, restricted access to medical facilities, interruption of life, mourning in solitude, respecting quarantine restrictions, mourning with no hugs, and sorrow for numerous deaths in a family are common.¹¹⁻¹⁴ The study of Robert et al (2020) revealed that the difficulty for families of COVID-19 patients in managing problems throughout the ailment, as well as the limitations of hospitals in seeing their loved ones, place a lot of mental burden on them.¹⁵

Furthermore, families confront a significant burden following the death of a COVID-19 patient. Despite the fact that death is unavoidable, COVID-19-related fatalities tend to have a more detrimental impact on families and acquaintances.^{11,16} Because the state of grief in the COVID-19 pandemic is fundamentally different. The psychological and emotional state of the family members is already engaged and fatigued, and with the extra emotional load of a loved one's death, tension and instability grow, making dealing with the other issues more difficult.^{16,17} For ages, Iranian culture has been used to holding funerals for the dead. During the COVID-19 outbreak, the death of loved ones is more painful and difficult in Iran and other countries with comparable cultural conditions, because performing social rituals for the departed is culturally and traditionally essential.^{17,18} According to Javadi and Sajadian (2020), one of the issues for families of COVID-19 victims is postponed mourning. Delayed grieving is defined as the failure to mourn in a timely manner or the suppression of an adequate emotional reaction. Delayed grieving leads to psychological issues such as depression, obsessive-compulsive disorder, sleep disorders, eating disorders, rage, guilt, suicide, drug addiction, and so on.¹⁸

Few studies have been undertaken worldwide to explore difficulties that families face while caring for COVID-19 patients and after their deaths. The majority of COVID-19 investigations have used quantitative and experimental methodologies, and have dealt with its prevalence and mortality as a result of it. Hence, the necessity for qualitative research in the field of patient care and bereavement after death becomes more obvious in Iran, which has a diverse social and cultural framework. Qualitative research allows for a more thorough examination of the subject's hidden layers. Consequently, the current study sought to analyze the lived experiences and obstacles of COVID-19 victims' families in Iran using a qualitative phenomenological technique.

Method

Design

The interpretative phenomenological approach was used to conduct this qualitative investigation. This technique examines the world through the eyes of a person. It seeks to investigate the meanings that the individual has encountered in everyday life and to arrive at a new view of the universe by uncovering new and overlooked meanings of these encounters.¹⁹ In other words, interpretative phenomenology places a greater focus on comprehending and interpreting a phenomenon or experience. This approach gives deeper data from individuals' latent and unseen experiences, which are less accessible through other methods.²⁰ In addition, in the current study, the interpretative phenomenological approach was employed to explore the situations and narratives of COVID-19 victims' family members in order to better expose the hidden experiences.

Participants

Residents of Tehran who had lost a first-degree relative owing to COVID-19 were included in the research population. Inclusion criteria included having cared for a COVID-19 patient at home, having witnessed a family member's death from COVID-19, and being willing to engage in the study. Interrupting the interview, refusing to record the interview,

and failing to finish the process of answering the interview questions were all exclusion criteria.

Data Collection

The information was gathered by phone (4 persons) and in-person (17 people) semi-structured interviews. Targeted and snowball sampling were used to choose participants. The researcher visited the hospitals where COVID-19 patients were being treated. Then he gathered the addresses and phone numbers of families whose COVID-19 patients had died in the past and called them. He invited them to join in the study after introducing himself and providing a brief summary of the necessity, purpose, and procedure of doing the research, and if they consented, the time, location, and mode of interviewing people were determined. The researcher then invited the participant to introduce someone else who satisfied the inclusion criteria after the interview. In all, 9 people were chosen through targeted sampling, while 12 people were chosen by snowball sampling.

The first author of the article, a PhD student in health promotion who is conversant with qualitative research and interviews, performed all of the interviews. Before conducting the interviews, all of the article's contributors collaborated in two meetings to create a guide to the interview questions. In addition, 3 trial interviews were carried out to check that the interview questions could elicit the needed information from the participants. The question guide was updated and finalized after coding and evaluating these 3 interviews [Table 1](#). All of the interview guide's questions were asked of all participants, although the sequence of the questions and the length of the interviews varied depending on the information and responses they provided. The interviews lasted an average of 45 min, with a minimum of 20 min and a maximum of 60 min. The majority of the interviews were performed in the morning and evening, and face-to-face interviews were conducted at the participants' residences in accordance with health guidelines. All interviews were taped with the participants' permission. The data collection period lasted from August 22, 2020 until October 21, 2020. The researchers kept collecting data until they achieved

Table 1. The Guide to General Questions about the Interviews.

No	Questions
1	How did you feel when someone in your family tested positive for COVID-19?
2	What problems and fears did you have while your patient was in the hospital?
3	How were you treated as a patient's family member by the medical staff?
4	What were the other family members' reactions when you brought the patient home for care? And what issues did you encounter?
5	What changes have occurred in your family since the patient was discharged?
6	How did you and your family members react when you learned of the patient's death?
7	What difficulties did you experience with burial? Please elaborate
8	How did you feel after your loved one died and was buried? And how did your family's bereavement go?
9	How did your relatives treat you after the patient's death?

theoretical saturation. That indicates the codes were repeating themselves, and no scientific findings were achieved.²¹ Thus, by interviewing 21 participants, theoretical saturation was attained.

Data Analysis

Data analysis was carried out by the first and corresponding authors using MAXQDA-2018 software and the 7-step Colaizzi approach.²² The investigators read and understand all of the participants' explanations and key findings. The researchers extracted crucial phrases and sentences related to the phenomenon, conceptualized the extracted meaningful sentences, regularly categorize participants' descriptions and common concepts, transformed all inferred ideas into comprehensive and complete descriptions, transformed complete descriptions of the phenomenon into an accurate, concise, and real description, and referred to the participants to clarify and validate the ideas obtained. In other words, the content of the interviews was carefully examined before identifying and recording key terms as code. The first examination of the codes was written independently, and the codes with conceptual similarities were placed in a subcategory and given a name. Main categories were developed by integrating subcategories based on common topics. Finally, a general and thorough explanation of the phenomena is developed and provided in the form of a concise statement.

Trustworthiness

The quality of the study was improved by adhering to the Guba and Lincoln criteria.²³ In addition, 32 items from Tong et al, (2007)'s qualitative research report (COREQ) were noticed.²⁴ Conformability was achieved by sharing the data analysis and coding process with 3 specialists (a sociologist, a health education specialist, and a psychologist) who were familiar with the qualitative research approach. Transferability was achieved through a thorough interpretation of the categories and subcategories, as well as explaining many direct quotations from participants and providing the research findings to four people who met the inclusion criteria but did not participate in the study in order to confirm the findings. Dependability was achieved by swiftly recording and documenting the interviews and providing a detailed explanation of all stages of the investigation. Furthermore, the whole study process was overseen by all of the authors. By investing adequate time in the data collection and analysis procedures, credibility was attained. The researchers also maintained proper communication with the interviewees, ensured diversity in the demographic characteristics of the participants, checked the overall perception of the participants' statements at the end of the interviews, and sent the data analysis and coding process to the participants for approval. The authors' experience with and expertise in qualitative research improves the overall quality of this study.

Ethical Considerations

Ethical approval was received from the Iran University of Medical Sciences in order to adhere to ethical principles in this research. Furthermore, the researcher adhered to the relevant health standards during the interviews (using masks and gloves and maintaining the appropriate distance). They also presented a brief summary of the research's need and aims. At the start of the interviews, the participants were given a brief biography of the researchers. Furthermore, the researchers received informed written and oral agreement from the participants, permitted the individuals to engage in or terminate the interview, and adhered to confidentiality rules throughout the research and publication of the findings.

Results

This study included 21 participants, the demographic information for whom is shown in Table 2. In addition, the interview data analysis was summarized in 165 major codes, 14 subcategories, and 2 main categories Table 3, which are listed below with explanations and quotations.

I- Challenges in Caring for a COVID-19 Patient

The first retrieved category of data contained the families' obstacles and issues in caring for a COVID-19 patient. Rejection, restricted access to medical facilities, displeasure

Table 2. Demographic Information of the Research Participants.

Variables	Dimensions	Frequency	Percentage
Age	Under 25	6	29
	25-50	12	57
	Over 50	3	14
Gender	Male	11	52
	Female	10	48
Marital status	Single	7	33.3
	Married	14	66.6
Relationship to the deceased	Parents	2	10
	Brother/Sister	3	14
	Spouse	4	19
	Children	12	57
Education	Illiterate	1	5
	Diploma and less than diploma	6	29
	Higher than diploma	14	66
Hospitalization duration of the patient in the hospital and at home ^a	Less than 1 week	5	24
	1-2 weeks	7	33
	Over 2 weeks	9	43

^aIt refers to the amount of time a patient was in the hospital or at home before passing away.

Table 3. Codes, Categories, and Subcategories Extracted From Interviews.

Categories	Subcategories	Codes
Challenges in caring for a COVID-19 patient	Being rejected	Avoidance of relatives' visit with families with a COVID-19 patient, inappropriate behavior of neighbors, avoidance of colleagues, tension with neighbors to clean the apartment building
	Limited access to medical facilities	Lack of medical equipment in the hospital, lack of ICU beds, etc., expensive oxygen devices, shortage and high cost of some drugs needed for COVID-19 patients, shortage and high cost of medical equipment needed to care for COVID-19 patients
	Dissatisfaction with medical staff behavior	Insufficient explanation about the patient's condition, early discharge from the hospital, impatience of nurses in responding to patients' families, insufficient guidance on how to deal with the patient after discharge from the hospital
	Disruption of family life	The difficulty of caring for a COVID-19 patient, the tension in sharing family responsibilities, keeping other family members away from home, lack of enough space to allocate to the infected person, cleaning the bathroom after each use of the patient, continuous cleaning of the patient's things
	Challenge of managing family members' behavior with the patient	Difficulty in managing and controlling other family members, especially children, for not communicating with the patient, emotional and irrational behavior of family members towards the patient, the contradiction of reason and feeling in the behavior of family members towards the patient
Challenges after a COVID-19 patient's death	Living with doubts and worries	Worry about the infection of other family members, worry about the infection of the caregiver, obsession with getting infected
	Incomplete farewell to the corpse	Not kissing the corpse, not touching the corpse, not seeing the corpse
	The unbelievability of death	Not seeing the last moments of the dying patient, not believing the patient's death, feeling sick and having nightmares about the patient's death, not seeing the moments of burial
	Ambiguity and tension in the burial process	Lack of a coherent and unified plan for burial, ambiguity in how to deliver the body, confusion in how to bury it, family tensions over how to hold a mourning ceremony
	Lonely burial	The solitude of the burial, separation from the family, the absence of the Qur'an, etc., the absence of some family members in the burial ceremony, the lack of funeral, not holding the ceremonies of the seventh day and fortieth day
	Twinge of conscience	The twinge of conscience about the inadequacy of mourning, the twinge of conscience about the inadequacy of care, the twinge of conscience about not observing the will of the deceased about burial
	Worry about not respecting the deceased	Concern about people's talk and sarcasm about the burial, mass burial of the dead, use of lime
	Incomplete condolence	Not hugging or kissing family members, not having all family members at home at the same time, and the absence of family elders with the deceased family incomplete condolence
	Abandonment	Lack of support and communication from the hospital with the family of the deceased, lack of support from relatives, lack of emotional support from governmental or non-governmental organizations

with the behavior of medical personnel, disturbance of family life, the issue of controlling family members' behavior with the patient, and living with doubts and fears were among the obstacles.

Being Rejected

When a person tested positive for COVID-19 in Iran, everybody abandoned him and tried to avoid him as much as possible. Many of the interviewees indicated that they had lost contact with the patient's family after their patient tested positive for COVID-19. Furthermore, because of their fears, the neighbors put a lot of pressure on the patient's family to clean and disinfect the building, believing that when the patient was moved, components of the building such as elevators and doors may be contaminated with virus, which is dangerous for residents. When a person's coworkers learn that he or she is caring for a COVID-19 patient at home, it might be embarrassing. Thus, the family of a COVID-19 patient is ostracized in Iranian society, and this issue might exacerbate the patient's and his family's psychological burden from the sickness.

"Our relatives' attitudes altered as soon as they found out we had a COVID-19 patient in our family." Even so, they no longer reply to our welcomes" (27-year-old guy, deceased's child).

"The neighbors' behavior was appalling. They were always calling and arguing with us, saying things like, "Why do you come and go in the building so much; why don't you take your patients somewhere else?" (32-year-old lady, deceased's child)

"Neighbors expected us to clean the entire building on a daily basis." We had a lot of disagreements with them. We were not permitted to use the elevator. Several times, it was on the verge of becoming a beating" (51-year-old lady, the deceased's widow).

"When my coworkers discovered that I was caring for a COVID-19 patient at home, they abandoned me. Their actions were much more heinous. At work, I followed all health and safety regulations, yet they were extremely disrespectful "(34-year-old male, the deceased's brother)

Limited Access to Medical Facilities

With the emergence of COVID-19 in Iran, there was a scarcity of health and medical equipment, both in hospitals and in public pharmacies in cities, causing issues for many families since they could not readily get the health equipment and hygiene supplies required to care for their patients.

"I had heard that the hospital was running low on medical supplies. So, nurses and physicians lacked the necessary medical and hygienic equipment to care for COVID-19 patients "(44-year-old lady, deceased's child)

"Our patient was admitted to a nearly full hospital. We were concerned about our patient's life since there was a dearth of

medical equipment, such as an ICU bed "(26-year-old guy, deceased's child)

"When we took our patient home, he required a variety of medications, which were sometimes only available at a small number of pharmacies, and we had to seek for them for a long time since we needed to clean the house all the time. There were few disinfectants available, and they were prohibitively expensive "(30-year-old male, child of the deceased).

Therefore, one of the primary worries of COVID-19 patients' families is a shortage of medical and health equipment. Families of these patients have had to seek all of the city's pharmacies for medical supplies, and they have also been compelled to buy from the black market, which is far more expensive.

Dissatisfaction With the Behavior of the Medical Staff

Some participants expressed unhappiness with the medical personnel because nurses and physicians did not offer enough explanations regarding the patient's condition or even how to care for the patient after release from the hospital. Others claimed that the hospital was in a rush to discharge patients and did not allow for complete healing.

"Whenever we inquired about our patient's health, they mentioned nothing extraordinary; they just stated, "It will get better." "Believe in God" (57-year-old guy, deceased's father).

"Some nurses do not have the patience to respond to us at all." I'm not sure, maybe it was weariness." (22-year-old male, the deceased's child).

"I believe our patient should have stayed in the hospital for a few more days before being discharged." I believe the physicians rushed to discharge him, and that in doing so, they did not adequately explain how to cope with him to us. Hence, I had to get information about it myself from the internet." (45-year-old lady, the deceased's sister).

In reality, it may be argued that by increasing the number of patients admitted to hospitals, as well as the working hours and duties of the medical team, they were weary and were unable to deliver information to patients' families as previously. However, due to a lack of hospital capacity, the medical team's inclination has been to accept patients with more acute problems and discharge other patients with comparatively better conditions, and these difficulties have prompted unhappiness with the medical team.

Disruption of Family Life

Meeting the needs of a COVID-19 patient places a lot of strain on the entire family since one person must be available at all times to serve the patient. A new division of labor had to

be established at home. Furthermore, the cleaning and washing of the patient's belongings exacerbated existing difficulties. Furthermore, some families living in small apartments did not have enough room to give to the patients, and as a result, some family members were forced to leave the house and relocate.

"It was difficult for us to bring our patient home. Someone had to look after him all the time. We occasionally split chores amongst ourselves, but some of my brothers felt less accountable, so I occasionally battled with them." (29-year-old male, child of the deceased)

"I was the only one who cared for our patient from the moment we brought her home." The remainder of the family was sent to my grandfather's residence by me. It was a really terrible time. I was disappointed that additional family members were not present" (49-year-old lady, the deceased's sister).

"Our house was small, we only had one room, therefore we had a lot of troubles" (30-year-old male, the deceased's child).

"We had to disinfect each time our patient went to the bathroom since we didn't have a separate bathroom and toilet. Our task was really difficult." (38-year-old lady, child of the deceased)

"It was really tough for us to wash and disinfect all the time, and I was occasionally dissatisfied" (32 years old, wife of the deceased's child).

The Challenge of Managing Family Members' Behavior With the Patient

The presence of a COVID-19 patient at home complicates communication between other family members and the patient. Therefore, most participants reported some level of conflict and dualism while interacting with the patient. On the one hand, they desired greater emotional contact and support for the patient, but they were unable to establish such a relationship owing to their fear of becoming ill. Others stated that family members occasionally became very enthusiastic, exhibited emotional behavior, and went too near to the patient, endangering their health. Families with children had additional challenges since their youngsters could not comprehend the sickness or how it spread. It caused them to be unable to comprehend the quarantine situation and to approach the ill individual on a regular basis.

"My mother had a hard time controlling herself sometimes. Despite the fact that she was well aware that if she came too near to my brother, she would take COVID-19. She, on the other hand, desired to embrace my brother." (34-year-old male, deceased's brother)

"I was irritated since I was the most educated and reasonable member of the family. I was always worried that one day my sister would be unable to control herself and would rush over to

embrace my mother. They wanted to do this several times, but I stopped them each time." (26-year-old male, the deceased's child)

"We had a five-year-old in the house. It was quite tough to keep him under control. Whatever we told him, he couldn't comprehend why he shouldn't approach our patient." (23 years old, woman, the deceased's child).

Life With Doubts and Worries

The majority of participants said that having a COVID-19 patient in their family raised their concerns and anxiety about infecting oneself and other family members, as well as an obsession with becoming ill. Indeed, due to the high occurrence of COVID-19, the presence of a COVID-19 patient has produced worry and anxiety in all family members' lives.

"The entire family was concerned that other members of the family had caught the sickness. We were all concerned when one of us coughed. It was quite difficult." (27-year-old man, deceased's child)

"I became obsessed. I felt ill whenever I got an ache someplace on my body. I couldn't sleep at all, day or night, since I was worried." (30-year-old male, child of the deceased).

"We were all concerned that my son might contract the sickness because he was caring for the patient" (51-year-old lady, the deceased's widow).

2- Challenges After the Death of a COVID-19 Patient

The second category comprises challenges that families faced following the death of the COVID-19 patient, such as an inadequate farewell to the corpse, the unfathomability of the death, ambiguity and stress in the burial procedure, lonely burial, a twinge of conscience, concern about not respecting the deceased, incomplete condolence, and abandonment.

Incomplete Farewell to the Corpse

It is typical in Iran for the deceased's relatives to keep him at home for a few hours after his death so that family members can say their final goodbyes, hug him, and chat to him. Because of the conditions that occurred following the death of COVID-19 patients, many families were unable to visit the patients and say their final goodbyes. As a result, the families felt they had given the patient an incomplete farewell and were disappointed with it.

"I was disappointed that I couldn't see his body. I wish I could see him after he's gone." (45-year-old female, deceased's sister)

“I really wanted to embrace and kiss him when he died, but I couldn’t even go near to him, which concerns me.” (61-year-old male, deceased’s mother)

“I wish I could have embraced and kissed her, but I couldn’t, and this is the most irritating sensation in the world” (26-year-old guy, deceased’s child).

Unbelievability Death

Family members are there from the beginning to the completion of the burial procedure in Iran, and they sometimes even help with things like digging graves, etc. This makes it simpler for them to accept their loved one’s death. Because the burial procedure was more varied than previously in the COVID-19 pandemic, and families could not observe the burial process up close, it was difficult for them to believe the death. Many people indicated they still could not believe their loved one had died.

“I can’t believe he’s dead since I couldn’t see how he was buried” (34-year-old male, deceased’s brother).

“I didn’t see him in his final moments, and I couldn’t see him after he died. So it’s difficult for me to comprehend” (44-year-old lady, deceased’s child)

“I was still struggling to come to terms with his passing. It was quite bizarre. Everything happened all at once. I have no knowledge of his death. I sometimes feel as if I’m having a nightmare” (27-year-old male, deceased’s child)

Ambiguity and Tension in the Burial Process

The majority of participants stated that once their patient died, they were left with many questions regarding how to receive and bury the corpse since hospital staff did not offer enough answers. There was also disagreement among family members on how to conduct the mourning service. Because of their diseases, individuals with COVID-19 were buried in a distinctive manner, but families were not adequately informed about the process. Furthermore, because holding ceremonies could jeopardize the health of other family members and relatives, there was a lot of stress in the families about how to hold them, and usually the older people who were more ambitious were more inclined to hold ceremonies and were in conflict with the younger people who were more aware of COVID-19 and less attached to social norms.

“We were stunned for several hours after learning of our patient’s death. We had no idea what to do, and we had no idea when or how the corpse would be delivered to us.” (45-year-old male, deceased’s brother)

“We had no idea how our patient would be laid to rest. Everyone said something, but no one from the hospital helped us.” (38-year-old lady, deceased’s child)

“Following our patient’s death, everyone in the family decided to see the relatives. Some members of the family proposed summoning relatives to the cemetery. Others advised us to do the ceremony at home. It was a dreadful experience. We were at a loss as to what we should do.” (30 years old, man, the deceased’s child).

Lonely Burial

In Iran, burial is done according to particular norms, which are followed even one year after death. Because of the development of COVID-19, families had to execute funeral and grief rituals in new ways. Therefore, several family members did not attend the funeral, and traditions such as funerals, burials, the seventh and forty-first days, which are traditional in Iranian society, were not held.

“We have a large number of friends and family, yet no one attended the burial. I had no idea why we had come to the funeral.” (32-year-old lady, deceased’s child)

“We were standing far away from the burial, which seemed unusual. It was so horrible that I can’t even explain it.” (35-year-old guy, deceased’s child)

“We did not perform celebrations on the seventh or forty-first days. I wish my father had not died in this manner. When I think of him, I still get a knot in my throat. It was unfamiliar to us; we were not used to this type of funeral” (23-year-old lady, deceased’s child)

“We were much more devastated since we were so far away from him when we buried his body. More than the loss of our loved one, the way of burial upset us” (51-year-old lady, deceased’s wife)

Twinge of Conscience

Families had a tinge of sadness about not being able to bury their loved ones properly, since the burial process during the COVID-19 pandemic was different than normal and several funeral traditions were not fulfilled. They were also unhappy since they could not be there to protect their patients in their final moments. Some participants reported that they had been unable to carry out their loved one’s wishes for the burial place, and as a result, they felt a pang of guilt.

“I’m sad when I think of the funeral. I’m tormented with guilt about why we didn’t have a proper funeral.” (27-year-old male, deceased’s child)

“It hurts me a lot that I didn’t try to be with our patient at the final minute. I sometimes feel bad for not taking care of him and for not being there for him” (32-year-old lady, deceased’s child)

“My father requested that he be buried in the hamlet where he was born, but we were unable to do so. We couldn’t carry him there because it was too far away, and we didn’t know how to

bury him there, so we buried him here. We have a nagging feeling that my father is displeased with us "(23-year-old lady, deceased's child)

Worry About Not Respecting the Deceased

In the early days of the COVID-19 outbreak in Iran, reports circulated that COVID-19 patients would be buried in mass graves or that common religious standards would not be applied to their burial, causing great worry among many families, the majority of whom feared disrespectful burial.

"I'd heard that COVID-19 victims were buried in bunches. This drove me insane. I had no idea what to do. I didn't want my brother's remains to be mistreated in any way. "(49-year-old female, deceased's sister)

"It was rumored in cyberspace that people who died from COVID-19 were not cleansed after death and that religious standards were not respected. This was a major source of anxiety for our family." (45-year-old lady, deceased's sister)

"It saddened me to learn that they were using lime to burn the flesh. When we learned of the death, these concerns arose in our heads and troubled us much more. "(30-year-old guy, the deceased's child).

Incomplete Condolence

Because they could not embrace one another after the patient died, family members could not comfort each other as normal for fear of becoming infected. It made dealing with the death of a loved one more difficult. In addition, quarantine restrictions prevented certain family members residing in other towns or countries from returning home to see other family members. The family's relatives and elders, who may always play a constructive role in comforting the grieving family, were also missing. It put a lot of pressure on the families.

"I wanted to embrace my mother and scream and cry, but my brother constantly told us not to since one of us may get COVID-19." (26-year-old male, deceased's child)

"We are a family of three sisters and two brothers. Only two of us made it back home. The others were unable to attend. The flights were rescheduled. It was quite inconvenient. We'd be able to settle down easier if everyone arrived." (44-year-old lady, deceased's child) "My uncle was usually with us in terrible circumstances and calmed us down, but this time he did not come. That is, none of my uncles came to our house at all. There was no one to console us." (38-year-old lady, deceased's child)

Abandonment

The majority of participants thought that after death, they had been ignored by families, friends, medical personnel,

governmental and non-governmental groups, and that no one had paid attention to their condition. Because the loss of relatives due to COVID-19 put a lot of pressure and challenges on families, they anticipated to get more help during this era, but this support was limited owing to the disease's state, and in some cases, there was none.

"I believe the hospital should have provided us with psychiatric treatment, but they did not even make a phone call. We were all psychologically wounded." (45-year-old female, deceased's sister)

"No one came to our house after my death. Some of our relatives phoned just now. I felt terrible. Our family had already endured the loss of a member. My brother was murdered in a vehicle accident two years ago, but the death of this brother, who died of COVID-19 in such circumstances, affected us a thousand times more "(49-year-old female, deceased's sister)

"My mother was a retired education ministry clerk. They didn't even put up a modest banner of condolences after her passing, which irritated us. We felt as if we were alone in the world. We were quite lonely "(44-year-old lady, deceased's child)

Discussion

The current research employed a qualitative technique to identify the lived experiences and problems of the families of COVID-19 victims in Tehran, Iran. The findings revealed that families faced issues such as exclusion, limited access to and satisfaction with medical facilities, disruption of life and difficulty in managing behavior with the patient and after the death of the patient, incomplete farewell with the corpse, unbelievability of the death, lonely burial, the twinge of conscience, incomplete condolence, and abandonment.

One of the experiences of COVID-19 victims' families is being rejected by others due to societal stigma. During epidemics, stigma, followed by social isolation, rises as a result of people's dread and anxiety about a sickness with an unknown source and a potentially lethal conclusion.²⁵ Several studies have found that stigma and rejection were common during the COVID-19 pandemic.²⁶⁻²⁸ According to the findings of Kim's (2020) study, nurses experienced social rejection and avoidance as a result of their direct interaction with COVID-19 patients.²⁹ The COVID-19 pandemic, according to Bhattacharya et al (2020), has resulted in societal stigma and discriminatory conduct among patients and their relatives.³⁰ So, in addition to people with COVID-19 who are rejected by society, their family and carers are also shunned. This rejection, which stems from the patient's dread of disease and death, as well as the prevalence of rumors, persists even after the patient heals or dies. While victims' families need help from family connections more than ever at this time, they are being rejected, which can make the process of adjusting to the death of relatives more challenging.

Another issue that the relatives of the COVID-19 victims faced was a lack of access to medical facilities. Other studies have found a lack of medical equipment during the COVID-19 pandemic.^{13,15,31,32} The disease's quick spread caused health-care facilities to be unprepared and resulted in a large inflow of patients seeking treatment. Therefore, access to medical facilities such as protective equipment, intensive care unit (ICU) facilities, and medical oxygen equipment is restricted.

In addition to limited access to medical equipment and facilities, the participants in this research were dissatisfied with the behavior of medical professionals. Expectations are one of the most significant variables influencing the quality of services provided to patients or their families, and a thorough grasp of these expectations is one of the cornerstones to providing high-quality services. Given the available resources, the health-care sector should perform the best in the case of a pandemic.³³ According to studies, the major worries of patients' relatives during hospitalization were to obtain honest, clear, and timely information, which they frequently did not receive.³⁴⁻³⁶ They also require companionship, comfort, closeness, and reassurance.^{35,37} Effective communication between medical personnel and families improves family satisfaction, trust in the intensive care unit, physicians, and family members' psychological well-being. However, during the outbreak of diseases, particularly epidemic diseases, when the number of hospitalizations rises, the staff, for reasons such as inadequate facilities, fatigue, work pressure, and so on, contribute to families' dissatisfaction by failing to interact with and respond to them properly.

Another problem for the families of COVID-19 victims was the disruption of family life. According to the Fuchs research (2020), when a person in the family becomes infected with COVID-19, family members must do numerous chores such as caring, cleaning, cooking, teaching, shopping, and so on, which eventually impacts physical and mental health, family relationships, and life in general.³⁸ The World Health Organization recommends some strategies for effective care for COVID-19 patients at home, such as isolating the patient in a place away from friends and family members, or at least maintaining a safe distance, cleaning and disinfecting goods frequently, and disinfecting the house, particularly the patient's bathroom. In general, these tactics interrupt the lives of family members.³⁹ Because of the tiny size of the house, measures made by family members to care for the sick may cause other family members to be separated from the household or disturb family life. It puts additional strain on the patient's family members, particularly carers, owing to social conditions, limits imposed by the breakout of disease, the closure of schools and some occupations, and the continuous attendance of family members at home.

Another issue stated by survey participants was managing the conduct and disagreement of family members with the ill individual. According to COVID-19 research, addressing these situations and disagreements is tough for the patient's

family members and places a lot of stress and emotional strain on them.^{15,16} In fact, the need for emotional support led family members to have an emotionally intimate relationship with the patient, but at the same time, the warnings and worries about the potential of spreading the virus through close contact with patients ended up causing fear and anxiety, and family members displayed contradictory and inappropriate behaviors. Another outcome of the current study was this way of living, together with uncertainties and fears of becoming ill. According to the findings of Nickell (2020) and Mo (2020) research, one of the primary concerns of nurses caring for COVID-19 patients was anxiety and uncertainty about the disease.^{40,41} With a COVID-19 patient at home and knowledge of the disease's highly communicable nature, members of the patient's family were always afraid of being infected, which added to their stress.

Families of COVID-19 patients encountered additional obstacles following the patient's death. One of these difficulties was the unfinished farewell to the corpse, which caused enormous grief to the relatives of COVID-19 victims. Social media is rife with heartbreaking stories of families who either did not say goodbye to their loved ones before their deaths or said their last goodbyes over the phone or video chats.¹⁶ The amount of quantitative and qualitative information on the impact of funeral practices on the mental health of people impacted by the COVID-19 pandemic varies. Burrell and Selman (2020) conducted a comprehensive review that demonstrated the influence of funeral rituals on the mental health of bereaved relatives while emphasizing that there is no effect of grieving on the mental health of survivors.⁴² A study on the relatives of dead cancer patients done by Otani et al (2017) found a substantial association between saying goodbye to the patient before death and the depressed condition and complicated suffering of the deceased's family members.⁴³ Other research' findings support the necessity of saying good-bye to the dead.^{44,45} Consequently, the influence of this variable on the mental health of survivors is dependent on cultural sensitivities, the relevance of mourning rites for survivors, as well as mourners' ability to perform this ritual and their meaningful farewell.⁴²

Another result mentioned by study participants was the incredulity of a family member's death. The short time between illness and death, the difficulties of meeting patients before death, and burial in a different manner were all effective factors in not believing COVID-19 patients' deaths. Mohammadi et al⁴⁶ (2021) show that the relatives of COVID-19 victims have been impacted by a variety of psychological crises that have exposed them to significant feelings of loss and emotional shock, and in order to alleviate this, they deny and refuse to accept death.⁴⁶ Lobb et al's study also shows the difficulties of accepting the death of close ones (2010).⁴⁷ In this study, the person's unpreparedness to embrace the loss of loved ones was influenced by the deceased's relationship type and the quality of care experience.

Another issue that families of COVID-19 patients had when their loved ones died was the uncertainty and stress of the funeral procedure. Because the corpse had to be prepared in different ways than in the past, families in those difficult situations required comprehensive assistance and counsel from doctors and health facilities. However, due to overcrowding in hospitals and the large number of deaths, these steps for patients' relatives were not implemented in the majority of cases.

In response to these challenges, customs derived from Iranian-Islamic culture, such as respect for the deceased, possessing funeral prayers in the presence of family members and friends of the dearly departed, and the appearance of all relatives at the funeral as a gesture of respect and farewell to the deceased,^{17,18} are suddenly ruled out under the pressure of the current outbreak, leading to resistance from some members of the deceased family and creating tension among family members. Also, the deceased's family members attempted to perform the burial ritual in the traditional manner and with the participation of relatives, which in the midst of the pandemic was regarded as an abnormality and a risk to the health of the participants, raising tensions in the deceased's family.

Another conclusion of the study on COVID-19 victims was the deceased's lonely burial. Morris et al (2020) discovered that one of the most important worries of the family was the lack of rituals and customary funeral ceremonies in the presence of friends and relatives of the dead^{11,48}. In the instance of the COVID-19 outbreak, in addition to burial without the presence of relatives, the seventh and forty-first rites done for the departed in Iranian-Islamic tradition were prohibited, putting a lot of psychological burden on family members. The presence of relatives on such a day, together with the family of the deceased, consoles them and creates a form of emotional support, allowing individuals to progressively cope with this catastrophe. Virtual connection with the bereaved family, as well as phone calls from relatives and friends, can give some of this support for the individuals.

Another difficulty experienced by the relatives of those who died as a result of COVID-19 was feeling a pang of conscience. Several studies have demonstrated feelings of guilt and sadness following the loss of a family member.⁴⁹⁻⁵¹ The reasons for this emotion among family members have been documented as a lack of suitable burial, the standard of healthcare for the sick person at the end of life, and failure to see him before death, as well as a rapid transition from disease to death in previously healthy people.^{47,52} This sort of death leaves families bereaved and suffering from post-traumatic stress disorder.

A noteworthy and novel finding of the current study was the relatives of COVID-19 victims' concern over not honoring the departed. In mass burials, among the concerns of the relatives of the deceased were not washing the corpse before burial or burial without completing the rites and prayers, and its source was mostly hearsay that had circulated on social

media. This might be acceptable if, during the COVID-19 pandemic, several funeral homes limited each person and workers at each service to a physical distance,⁵³ while disease mortality soared considerably. Because the significance of preserving the dignity of the departed is emphasized in Iranian societal teachings, the failure to observe and execute burial rituals was heartbreaking for relatives and family members, putting them under further strain.

Another concern that relatives of COVID-19 victims experience that has not been addressed in previous research is incomplete condolence. Everyone goes through the experience of losing a loved one at some point in their lives. The attention of others allows the grief stricken family to go through this mental anguish and adversity naturally and with more patience, but social distancing, difficulties in holding burial rites, and the nonattendance of friends and comforters during the COVID-19 outbreak prevented grieving families from going through the normal grieving process, increasing the risk of depression and anxiety among them.⁴⁸ These implications were felt more acutely by families in the case of untimely death, which may have been foreseen during the COVID-19 pandemic. In this scenario, consoling others, even online, can help to lessen the depth of their grief. Mortazavi et al⁴⁸ (2021) demonstrated that during the COVID-19 pandemic, the inability to perform routine mourning ceremonies, as well as a lack of necessary social and emotional support, left the deceased's relatives with a variety of conditions that interrupted the mourning process and, in the future, may lead to emotional and psychological difficulties for the survivors, compounding their grief.⁴⁸ These measures will have a stronger influence on the mental health of the deceased's family, especially in Iranian society, which has a rather strong kinship system. Again, the media plays an important role in communicating these ideas to society.

Another difficulty identified by the participants was a sense of abandonment. This sentiment was generated in the deceased's family by a lack of emotional and social support from friends, relatives, and institutions such as hospitals and associated organizations. According to Romero et al⁴⁴ (2014), there is minimal evidence that paying attention to patients' survivors and providing social assistance to them diminishes the grief caused by the loss of loved ones.⁴⁴ Mittelman et al (2004) stressed the need of social support and supportive therapy for bereaved families in preventing depression and complicated suffering, as well as the importance of paying attention to the patient's survivors after death.⁴⁵

Limitations and Strengths

This is one of the few studies that has looked at the experiences and hardships of the relatives of COVID-19 victims in Iran in depth. Therefore, it may give first-hand knowledge to policymakers, psychologists, social workers, and public health officials to help them find

answers to these problems. Furthermore, two of the article's authors had prior experience caring for COVID-19 patients, and one of the authors' family members died. They had a better knowledge of the problem and could work more effectively in coding and data analysis. Nevertheless, this study, like most qualitative studies in the field of COVID-19, encountered challenges such as some participants' unwillingness to talk in person, psychological problems of respondents due to the loss of loved ones, and the need to work hard to acquire appropriate information and data, difficulty in commuting for researchers to conduct interviews due to the city's reduced traffic hours, and challenging availability of healthcare equipment needed. Other limitations of the study were strategy, sample size, and cultural context, all of which precluded the study's findings from being generalized.

Conclusion

According to the findings of the study, the families of COVID-19 victims faced a number of challenges, including alienation, restricted access to medical services, and disruption of family life. After the patients died, their obstacles persisted, and the inadequate farewell to the corpse, the unfathomability of the death, the lonesome funeral, the pang of conscience, and abandonment exacerbated the difficulties. Therefore, in order to minimize the negative repercussions of COVID-19 infection and death and prevent a health crisis from becoming a social crisis, proper action must be taken to remove the disease's stigma through the media and public education, training skills and treat patients at home through mainstream press, and offering more access to medical counseling, care, and facilities. There are some other critical problems for the period following the patient's death, such as delivering correct information by relevant agencies such as the media and health centers to assure families to respect and reverence the deceased while also following health guidelines for burial, developing a culture of virtual condolence by phone, video call, and sending a message to provide emotional support to the survivors, and providing timely psychological services to prevent suicide.

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Authors' Contributions

All authors participated and approved the study design. JYL and SFI and SA contributed to designing the study. GS, ASH, and TX collected the data and analyzed it by HS, FEFA, and SFI. The final report and article were written by SFI, JYL, NF and SA. All authors read and approved the final manuscript.

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Ethics Approval and Consent to Participate

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approval was obtained from the Ethical Review Committee of IUMS (IR.IUMS.REC.1399.500), written informed consent was obtained from all participants

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