

# Complicated Grief: The Lived Experiences of Those Bereaved By COVID-19

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## Abstract

The morbidity and mortality rates of COVID-19 pandemic are increasing, and many families have lost their loved ones. This study explored the experiences of families living in Iran who lost a loved one to COVID-19. The researchers apply a descriptive phenomenological approach and draw on in-depth interviews with 18 family members who had lost at least one family member because of COVID-19. Data were analyzed using Colaizzi's method. After reviewing and comparing the consistency of the codes, crisis in crisis, circumstances of death and its consequences, and lack of preservation of patient dignity were extracted as main categories. Neglecting grieving families and related issues can lead to delays and difficulties in the process of recovery and intensification of their psychosocial pressures. Acquiring more knowledge about different impacts of COVID-19 will be helpful for providing timely and better rehabilitation.

## Keywords

COVID-19, bereaved families, psychosocial challenges, complicated grief

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On February 19, 2020, Iran confirmed the first two deaths from the COVID-19. Since then, the disease has spread rapidly in Tehran and other cities (Mortazavi et al., 2020). Despite preventive policies, reports from the Ministry of Health and Medical Education of Iran indicated high rates of incidence and mortality of COVID-19 (WHO, 2020). On Oct 7, 2021, about 5,660,000 cases of COVID-19 were confirmed in Iran since the outbreak of the disease, and more than 122,000 deaths from COVID-19 were reported (Worldometers.info, 2021).

The dominant religion in Iran is Islam, under the normal circumstances, numerous mourning ceremonies are held publicly and at different times after death (funeral ceremony, third, seventh, 40th day and anniversaries ceremonies). These memorial ceremonies are usually held at mosques or cemeteries and participants express their condolences to the families of the survivors. In addition, there are special rites and rituals for bathing and burying the dead bodies which are very important for survivors. The rapid progression of COVID-19 and restrictions led to the disruptions in this mourning process. Due to the need to follow health protocols, most of these ceremonies were not performed and this causes the emotional and psychological suffering of the survivors.

The experience of grief and loss due to COVID-19 is more complex and difficult for families and there is limited evidence related to death and mourning in COVID-19 (Stroebe & Schut, 2021). Some studies have reported signs of complicated grief, low levels of social support, unpreparedness for death, and feeling guilty in the death of a patient (Wallace et al., 2020). Also, some of studies have examined different aspects related to mortality of COVID-19, its epidemiological aspects (Lake, 2020), and recommendations for end-of-life care, palliative care, and mourning interventions caused by COVID-19 (Wallace et al., 2020).

Although numerous studies have examined the quantitative impact of covid-19, few have looked at the lived experiences of grieving families. A deep understanding of the lived experiences of families who lost a loved one to COVID-19 is essential because of the special characteristics and circumstances resulting from the COVID-19 outbreak. Failure to gain a deeper understanding of their experiences can delay the timely and effective return of these people to normal life and may have various long-term consequences. Therefore, this study was conducted to better understand the lived experiences of the COVID-19 survivors living in Tehran.

## Method

This study was a qualitative study that used a descriptive phenomenological approach. Descriptive phenomenology explores participants' point of views and meaning of their lived experience by describing the phenomenon under investigation with the words of the participants (Morrow et al., 2015). In this study, researchers used bracketing to mitigate the potential effects of unacknowledged preconceptions related to the research and thereby to increase the rigor of the study.

## *Setting and Participants*

The research was carried out in Tehran city. Tehran city is the capital and largest city of Iran with a population of 13.2 million people. It is home to diverse ethnic and linguistic groups from people all over the country but almost all its residents understand and speak Persian. The majority of Tehran is officially Muslim. According to statistics published by the Ministry of Health and Medical Education, since the beginning of the COVID-19 pandemic in Iran, Tehran is one of the cities with the highest rate of infection and death.

The participants in the study were recruited using purposive sampling. Researchers recruited participants using a list of COVID deceased. This list was compiled from several hospitals in Tehran. The aim of the purposive sampling was to select participants representing a range of perspectives on loss of the closest family member due to COVID-19. The diversity of experiences was based on various family members, gender, age, ethnic and racial group. Respondents were qualified for inclusion in this study if they were Persian speaking adults over the age of 18 and a member of one of the four major ethnic and racial groups (Fars, Turk, Kurd, or Lor). In order to understand how Covid-19 related grief effects multiple relationships, participants were not excluded based on their relationship to the deceased. Study respondents were excluded from data collection and analysis if they identified themselves as being emotionally unstable. Participants were recruited into this study, until data saturation (no new information is discovered in data analysis) was reached.

## *Data Collection*

Data were collected between September and December 2020, using in-depth semi-structured face to face interviews, virtual interviews, and field notes. Before starting the interview, the aims of the present study were clarified to the participants. The time and place of the interviews were determined with the consent of the subjects. The IRB approval was acquired by (anonymity). The majority of them asked to be interviewed in their homes. The interviews ranged from 40 to 70 minutes in length. Because of pandemic, some interviews were conducted virtually. Other interviews conducted face to face with the use of personal protective equipment (PPE), and 2-meter distance. The interview began with an opening question. The question focused on lived experiences of loss and bereavement: "Tell me about your experience of losing your ...?" then probing questions such as: "Tell me more about....?" "What was that like?" were asked to gain deeper understanding on various aspects of experiences.

18 participants who had lost at least one family member because of COVID-19 participated in this study. The demographic characteristics of them are listed in [Table 1](#).

**Table I.** Participant Characteristics.

Participants	Gender	Age	Education	Job	Relationship with the deceased
1	Male	45	Diploma	Self-employment	Father
3	Female	36	BA	House wife	Wife
2	Female	48	MA	Employee	Daughter
4	Female	55	Diploma	House wife	Wife
5	Male	41	MA	Employee	Son
6	Male	51	PHD	Employee	Son
7	Male	78	PE	Retired	Husband
8	Female	30	BA	Student	Daughter
9	Male	63	Diploma	Retired	Husband
10	Female	54	Diploma	House wife	Daughter
11	Female	53	BA	Retired	Mother
12	Male	52	Diploma	Self-employment	Son
13	Male	50	PHD	Employee	Son
14	Male	48	BA	Unemployed	Husband
15	Female	33	Diploma	Employee	Daughter
16	Male	58	PE	Retired	Father
17	Male	63	PE	Self-employment	Father
18	Female	47	BA	Employee	Sister

### Data Analysis

Data analysis process and coding were performed simultaneously by Colaizzi's method (Morrow et al., 2015). At the first step researchers read the transcribed interviews after listening several times to acquire a feeling for the participants and their responses. Then, researchers identified significant statements from the transcripts that were related to the experiences of losing a closed family member by COVID-19. In the third step, researchers formulated and wrote the meanings of each significant statement. Researchers clustered the identified meanings into themes that are common across all transcripts in the fourth step. To validate clusters or themes, researchers compared them with the original interviews and refined them in order to reflect the intent of the subjects. Then, researchers wrote a full and inclusive description of the phenomenon under study which helped to determine the fundamental structure of the experience. In the sixth step, researchers summarized the exhaustive description which were essential to the structure of the phenomenon. Finally, in the last step, researchers returned the fundamental structure statement to available participants to ensure that it represented their experiences. This was done as a measure of credibility and validity of research findings.

**Table 2.** Categories and Subcategories.

Categories	Subcategories
Economic challenges	Crisis in crisis psychosocial consequences of COVID-19
Lack of preservation of patient dignity	Death stigma due to COVID-19 Denial of dignified death rituals and customs Defect in care along with dignity The un-believability and unexpectedness of death Death without farewell
Circumstances of death and its consequences	Lack of perceived psychosocial support Psychological and physical complications

### *Trustworthiness*

The rigor of the study was assessed throughout the process of data collection and analysis (Morrow et al., 2015). Credibility ensures that the phenomenon was accurately identified and described, which was done through triangulation, member checks (participant or respondent validation) and peer checks (researchers). Dependability refers to the stability of data over time and under different conditions, which was achieved by using the code–recode procedure for analyzing interviews and through examination of data by an external reviewer. Confirmability indicates confirmation of results by others, which was achieved through explication of study methods, double checking of results by researchers, and bracketing of ideas, thoughts, and pre-assumptions on the research topic. Transferability refers to the generalization of findings to other settings or contexts; in this case, researchers attempted to include participants with different types of cancer though the transferability of data was questionable due to a limited context. In this regards, returning data to available participants to verify the validity of extracted themes and sub-themes, using several data collection methods, and coding by two researchers were main techniques which used for enhancing the rigor of study.

## **Results**

Three main categories of non-preservation of patient dignity, circumstances of death and its consequences, and crisis in crisis were extracted (Table 2).

### *Crisis in Crisis*

COVID-19 has caused many changes in society. Numerous lifestyle changes, such as changes in business, family and social relationships, have increased individual tensions in the community. Because society was in a critical situation, the death of loved one and the individual's accompanying grief increased the difficulty on the already difficult situation, causing a crisis to emerge within a crisis.

**Economic Challenges.** The participants' experiences showed that the loss of a family member was compounded by an unfavorable economic situation. Increasing living costs and insufficient income exacerbated the economic problems caused by Iran's economic sanctions. Unemployment, job loss instability, and insufficient government financial support followed the COVID-19 outbreak were the cases mentioned by participants. In this economic crisis, the addition of mourning for loved ones was a crisis in the economic crisis and doubled the difficulty of the situation. In this regards one of the participants said:

*"I had rented a shop. I could not afford to pay the rent because of lockdown followed by COVID-19 outbreak and I became unemployed. I was under a lot of pressure. I had no other income. The situation was very difficult for me, and my mother's death, along with unemployment and severe financial pressure, was like rubble falling on my head and I felt crushed."*

**Psychosocial Consequences of COVID-19.** Participants noted that with the advent of the COVID-19, they experienced mental occupation, psychological fear of spreading the disease to themselves and other family members, reduced social relationships, and social isolation. Further, the rate of interpersonal conflicts in families had increased due to long stays in the home, increasing economic problems, and personal tensions. The experience of the death of a beloved one was a crisis that had formed in the heart of the COVID-19 crisis and had led to intensified feelings of despair and helplessness, stress, and psychological instability. A participant said that:

*"With the COVID-19 outbreak, we were more at home and the verbal conflicts and marital disputes between me and my spouse had increased. I myself had become very aggressive. I became angry very quickly and there were many arguments in our house during the day. When we found out my father got sick and then died, I felt like I lost everything together."*

### **Lack of Preservation of Patient Dignity**

One of the common experiences that most participants mentioned was the lack of preservation of patients' dignity both at the time of hospitalization and at the time of their death. According to the findings, the lack of preservation of patients' dignity included the stigma of death due to COVID-19, deprivation of dignified rituals and customs was defect in care and dignity.

**Death Stigma Due to COVID-19.** Discriminatory behaviors with participants and those around them and their kinship network to avoid communication was experienced by participants. Participants sometimes tried to obtain a death certificate for a beloved one for a non-COVID-19 reason. According to protocols, COVID-19 affected houses had to be disinfected, but in some cases, families refused to do so for fear that neighbors

would become aware of the COVID-19 disease, and they refused to say that a family member had a COVID-19.

*"I could accept anything except dying from COVID-19. The first night we found out that the neighbors had walked behind us and disinfected the whole building. Even one of the neighbors came forward when she/he saw that I was speaking with her/his little boy, took his hand and walked away quickly. I went home and cried alone. We were being treated as if we had leprosy"* (Participant No. 5)

**Denial of Dignified Death Rituals and Customs.** According to the participants, the mourning and burial ceremonies were not performed in the dignity of the deceased due to the conditions caused by the COVID-19. Also, funerals were attended by a small number of people. Participants felt the deceased was not valued enough and that her/his services were not appreciated because they had died from COVID-19. Most of them also were not satisfied about the funeral ceremony. Because they hold ceremonies in isolation without social support.

*"The least thing had to be done for my father was a dignified and worthy funeral and burial ceremony, which was not possible. There was neither a eulogy, no memorial, no ceremony."*

In this regard, some participants pointed out the inappropriate treatment of the patient's body:

*"What bothers us forever is whether the corpse was washed properly or not? We do not even dare to ask whether the corpse was bathed or not? Because it is very unlikely. In fact, we are more confident that the corpse would not be washed. These are the facts from which we escape, we do not even ask and we do not seek the answer."*

**Defect in Care Along with Dignity.** According to the experiences of the participants, one of the most important needs of patients and their families was to provide respectful care and respect for human dignity. The families felt their loved ones had been neglected and had not received adequate care during their hospital stay. According to the families' perception, medical staff considered their own health to have priority over the patient's health and refused to provide necessary and appropriate services to patients due to fear of being infected. Participants also noted the lack of proper and timely information to the family about the patient's condition, inadequate communication of staff, waiting for patients to receive care for a long time and not providing services in their honor.

*"The nurses did not come too close to her/him because they understood that she/he was a COVID-19 patient. Earlier, when we could see her/him, she was sighing and moaning and she/he was upset. I told her/him to tell the doctor or nurse, she/he said they are afraid of getting sick, no one comes here and I do not see anyone. The food she/he was given was not suitable for her/him at all. Food was not soft. The hospital did not take care of them. They*

*gave them rice, while these patients needed hot soup. She/he looked at the food and did not eat at all. She/he was malnourished because she/he did not eat” (Participant No. 6).*

### **Circumstances of Death and Its Consequences**

According to the participants’ experiences, the death from COVID-19 was unexpected. Since one of the most important means of COVID-19 transmission is physical contact, it was not possible to accompany the deceased at the time of illness or to say goodbye to him or her for the last time at the time of burial. Due to the need for social distance, it was not possible to hold a funeral ceremony for the deceased and receive psychological and social support from friends and acquaintances and relieve the survivor. Participants pointed to psychological and physical problems caused by the mental state of the deceased’s death.

**The Un-Believability and Unexpectedness of Death.** The findings of the study showed that, there was no expectation of the patient’s death and the family thought that the disease was not fatal. Therefore, their encounter with death was sudden. Participants’ experiences showed that it was difficult to accept this death, because they lost their loved ones in a very short time, within a week to 10 days after morbidity to COVID\_19. It even led to frustration with previous religion beliefs, appeals, and religious crises.

*“I cannot believe that she is not here anymore. When I go home, I still go straight to her room and look for her after 3 months. Our mother had a cough and fever for a few days and we thought she had flu. After a few days, her condition worsened. We took her to the hospital in an emergency van. They did not allow family members to meet her. After a few days, they informed us on the phone that my mother died. I wondered why this happened to my mother, and I said to myself, ‘God, where were you when my dear one was in pain?’”*

**Death Without Farewell.** Participants’ experiences showed that certain COVID-19 conditions prevented them from accompanying the patient at hospital. They said that if they could accompany and help the patient in times of suffering, they would feel that they had done their duty and that it would be a kind of relief and farewell for them. Prior to burial, observing and contacting the patient’s lifeless body could help to accept his death, which was not possible due to health protocols. Therefore, they feel that they have not succeeded in saying goodbye to their lost beloved one.

*“I lost my brother due to COVID-19 four months ago. We were all quarantined, we could not be with him in the hospital, they did not even allow me to touch his face for the last time and say goodbye to him.”*

**Lack of Perceived Psychosocial Support.** The findings showed that not only it not possible to relieve the family through mourning due to COVID-19 but also mourning was mainly performed in quarantine without the support and sympathy of relatives, which



caused loneliness and more emotional pressure. In addition, some family members refused adequate support for fear of being infected by themselves and those around them both at the time of the illness and at the time of death. This issue had put double psychological pressure on the other members. Overall, the mourning period was more intense, shorter, and inadequate for the family of a COVID-19 patient. One of the participants, who lost his father, said:

*“I also experienced the death of my mother; it was very painful but it was very different for my father. My father’s death from COVID-19 caused us to experience a strange loneliness. Mass mourning keeps one away from fear, but the participants stood far apart at my father’s funeral because of COVID-19 and no one could hug another or express sympathy. “My job is to cry with my grandmother and aunt from behind the phone ...”*

**Psychological and Physical Complications.** After the patient’s death, the family experienced a variety of psychological and physical complications and problems, including anxiety and depression, insomnia, weight loss or gain, fatigue, headache, palpitations, digestive problems, etc.:

*“Ever since this happened, my sleep and wakefulness have been disrupted. Sometimes I stay up at night until almost in the morning and during the day I am completely tired and have strange headaches. I am often anxious and I think that I am infected, like my brother.”*

## Discussion

The purpose of this research was to develop a deep understanding of the lived experiences of the families of the deceased COVID-19 in Tehran. These experiences were divided into three main categories such as crisis in crisis, lack of preservation of patient dignity, and circumstances of death and its consequences.

The results of the study showed that the economic, psychological, and social consequences of the COVID-19 outbreak had provided a critical context and the crisis of losing the patient in these pre-existing conditions had made the situation more difficult. Families were in a difficult economic situation due to lockdowns and some were in a critical economic situation. They were more in financial difficulties especially in cases where the deceased was the head of the family.

The results of many studies indicate the intensification of economic problems of communities and people during the COVID-19 pandemic (Zhu et al., 2020). Noorbala and colleagues (2018) suggested that Tehran people’s concern about the future has been one of their most important tensions in the recent years and a significant part of these stresses has been related to financial and economic concerns (Noorbala et al., 2018). Alipour and colleagues (2020) also showed that the lockdown of small and large financial businesses, unemployment, rising living costs and health expenditures of the people of Tehran have been their most important challenges during the COVID-19 outbreak (Alipour et al., 2020).

Psychological and social consequences after the COVID-19 pandemic has created adverse conditions for families. The situation has become more difficult and in some cases led to the emotional and mental despair of families with the addition of the death of a family member as mentioned in previous studies (Ahmadi et al., 2018; Bertuccio & Runion, 2020; Eisma & Tamminga, 2020).

Family members pointed out that the patient's dignity was not preserved in various cases, including hospitals and care centers during the care of the patient by the medical staff and at the time of the patient's death in the form of deprivation of dignified mourning rituals and social stigma both during the patient's life and death. Participants also reported socially discriminatory behaviors and rejection by relatives, neighbors, and loved ones after informing of the cause of their patient's death. Therefore, a number of participants in their experiences mentioned that they were trying to get a death certificate for reasons other than Covid 19 for deceased or they tried to hide the cause of death from acquaintances and relatives. On the other hand, social stigma and COVID-19 limitations prevented their families to hold appropriate funeral ceremonies conformed to values and norms. This situation was even more complicated in the Iranian society, where the ceremony of honoring the deceased is held collectively and is a kind of preserving the dignity of the deceased. The families felt that they had not been able to hold a proper and dignified ceremony for the deceased, and interpreted their patient's death loneliest and without dignity. They also failed to perform the religious rites associated with the burial. In this regard, Alipour and colleagues (2020) have introduced social stigma as one of the psychosocial consequences of the COVID-19 pandemic in Tehran. Consistent with the results of this study, the findings of related studies in other countries have also reported to the stigma associated with loss due to COVID-19 (Bhanot et al., 2020). The social stigma of COVID-19 has not even shown mercy to the dead bodies of the patients in India. There have been violent disruptions or prohibitions of funeral ceremonies and burials of COVID-related deaths.

In this study, the families believed that the dignity of the deceased had not been respected by the medical staff in proportion to her/his dignity. In many cases, fear of disease transmission and fatigue seems to be the main obstacle to providing care along with maintaining the patient's dignity.

Some other studies showed similar results, including the studies that focused on reasons such as anxiety, fatigue, and insomnia, and lack of adequate support, declining quality of care and inadequate patient care by hospital staff for treating patients with SARS, Ebola, and COVID-19 (Rubin & Wessely, 2020; Vizheh et al., 2020).

Further, COVID-19 restrictions led to disruption in the process of patient admission and treatments. This normal process was not implemented for a person who was hospitalized for COVID-19. In many cases, the family was suddenly informed that the patient was in critical condition and was transferred to the intensive care unit and was dying. Therefore, the family had unexpectedly faced the death of their beloved one in a short period of time and did not expect his/her death. Other related studies have shown that unpreparedness for death from COVID-19 has been associated with complex mourning and severe grief (Wallace et al., 2020).

People felt that the farewell to the deceased had not taken place due to COVID-19 conditions and the impossibility of accompanying the patient during the illness and saying goodbye to the deceased at the time of death and holding a ceremony. [Mortazavi et al. \(2020\)](#) and [Wallace et al. \(2020\)](#) also showed that the families of COVID-19 deceased did not have the opportunity to say goodbye to their beloved ones before their death even with phone or video call, while they were not sure that their last contact was with the deceased, and this may have led to a complex mourning for them. ([Mortazavi et al., 2020](#); [Wallace et al., 2020](#)).

According to the findings, relevant evidences in other countries also shows that funerals and burials are usually delayed in the COVID-19 pandemic, or it was held in the presence of a small number of relatives. The family was not able to gather at the funeral and relieve the survivor ([Izadi-Mazidi & Riahi, 2020](#)). Other family experiences include psychological and physical problems associated with grief.

Other studies have reported the experience of losing a beloved one as one of the most stressful events in a person's life, which can lead to negative health consequences such as chronic headaches, anxiety, depression, cognitive disorders, loneliness and boredom, social isolation and post-traumatic stress disorder, and other physical problems ([Toftthagen et al., 2017](#); [Wang et al., 2020](#)).

### ***Study Limitations***

There are some limitations in this study that need to be considered. Since there are not many studies on family experiences of COVID-19 deceased, there was no strong research background in this area, and researchers sought to fill this gap to some extent by using the most relevant study texts. The stress of pandemic was another limitation which controlled by adherence of health protocols of Covid-19.

### ***Future Research***

Given that the experiences of COVID-19 deceased families are highly dependent on context and culture, more extensive studies are suggested to better understand the experiences of family mourning in other cultures and societies. Paying attention to the needs of this group and formulating related policies in the field of end-of-life care and mourning interventions is necessary and enforceable given the unique experience and difficulty of COVID-19 mourning for the family. The results of the present study can be used in prevention and support programs as well as in the treatment of grief.

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## Ethical Considerations

The procedures followed in the present study caused no physical or psychological harm to the subjects. At the beginning of the interview, the purpose of the study, and data confidentiality were explained to the participants and written consent was given. The subjects had the right to withdraw from the study at any time. The study has been approved by research committee of University of Social Welfare and Rehabilitation Sciences (code: IR.USWR.REC.1399.029).

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