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Adaptation to the New World: Experiences of Bereaved Families of the Patients with Coronavirus Disease 2019

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Abstract

Background: Acceptance of others' death is inherently difficult; therefore, throughout history, humans have avoided facing the reality of death. Mourning is a difficult experience in itself, and with Coronavirus 2019 (COVID-19), it may become more complicated.

Aim: This study aimed to explain the experience of bereaved families of patients with COVID-19.

Method: This qualitative descriptive study used the conventional content analysis method. In total, 20 participants were purposefully selected and included in the study. The data were obtained through in-depth semi-structured interviews. Participants' contact numbers were extracted from the archives of deceased COVID-19 patients hospitalized in the COVID-19 wards of educational hospitals of Shahid Beheshti University of Medical Sciences from August 22, 2020, to May 21, 2021, Tehran, Iran. The interviews continued until the data saturation. The interview lasted between 35 and 40 minutes. MAXQDA software (version 10) was used to analyze information.

Results: The final theme of adaptation to the new world includes psychological symptoms (disbelief mourning and disease, and social stigma), role conflict (threatening context of multiple roles, bottleneck of mental and work hazards, and uncertain future), and miracle of belief and faith (inner peace with praying and distraction of thoughts).

Implications for Practice: Given that one of the main concerns of the world following the COVID-19 pandemic is incomplete mourning and the resulting psychological disorders in the family, it is important to find a solution to support bereaved families to adapt to the new world without the deceased.

Keywords: Adaption, COVID-19, Family of patient, Mourning, Qualitative study

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Introduction

The Coronavirus Disease 2019 (COVID-19) originates from a new virus that has been encountered by many countries since 2019, including Iran (1). The number of sufferers worldwide until July 26 was 195,344,744; moreover, the total number of patients with COVID-19 in Iran reached 3,723,246 cases of which 89,122 people died (2). About 16 months from the outbreak of the COVID-19 virus has passed, and Iran has entered the 5th COVID-19 wave. Despite the restrictions and start of vaccination in the country, due to the rising trend in the incidence and mortality of COVID-19 and daily statistics announced by the Ministry of Health, this disease will not be eradicated in the country soon (3). In most societies, thinking about death from COVID-19 causes anxiety and fear in people. One of the symptoms that sufferers and their families experience after infection with the COVID-19 virus is death anxiety (4).

Since mourning is an inevitable phenomenon that a person experiences in life when losing a loved one, many bereaved people experience mourning as a fact of life; however, may experience problems, such as sleep, nutrition, and emotional disorders (loneliness, depression, shock, anger, and isolation) during this period (5). The severity and duration of mourning depend on factors, including personal and cultural characteristics and whether death is expected or not. In Iran, according to the prevailing Islamic culture and religion, people go through the process of mourning by not wearing bright clothes, not attending parties and entertainment, and doing activities, such as charity and vows. In many areas, relatives visit the bereaved after the burial, pray, and ask for blessings from God. The grief caused by the loss of a person is relieved a little by holding group mourning ceremonies, going to the cemetery, talking to friends based on the mourning ritual during the attendance ceremony. However, during the COVID-19 pandemic, the support of friends and dear ones during the mourning ceremony is not possible due to the necessity of observing the principles of quarantine, and no option can replace the customary ceremony (6).

Furthermore, due to the COVID-19 pandemic, the cycle of rational grief is not created according to psychologists and allows people to adapt quickly to the situation. Lack of a comprehensive and appropriate response can lead to complex grief and predictable death, such as suicidal behaviors and substance abuse. This pandemic has affected the stages of grief from Kobler Ross's point of view, making adapting a little difficult in five stages as follows:

1) Denial: Establishing a mourning ceremony facilitates non-denial and is not possible with the COVID-19 pandemic conditions that provide grounds for denial to remain, 2) Anger: Feelings of guilt and anger over the inability to accompany patients in the last days of life due to the outbreak and transmission of COVID-19 is a complex issue that may provoke anger, 3) Bargaining: Survivors blame the death on COVID-19 due to members' failure to adhere to health protocols, which leads to a recurrence of thoughts among survivors about what principles to follow to prevent the death of a loved one, 4) Depression: Lack of social support and inability to hold ceremonies leads to depression, and 5) Acceptance: This makes acceptance which lasts about 4-6 weeks to several months a little difficult (7).

A cross-sectional online survey conducted by Tang and Xiang in 2021 showed that the prevalence of prolonged grief caused by COVID-19 was 8.37%. There was no difference in the type of grief symptoms in participants who lost a loved one for more than six months and those who lost someone less than this period. Nonetheless, the symptoms of long-term grief were more severe in people who lost a loved one due to COVID-19 (8). Moreover, Javadi and Sajjadian in 2020 stated that the COVID-19 pandemic was an important factor in prolonging the mourning period of the bereaved family. The main feature of a retarded mourning is the long-term denial of the subject. In other words, when these people lose their loved ones, those around them and the society prevent their grief and anxiety and do not allow them to mourn. They form delayed mourning. Delay causes psychological problems, such as depression, anxiety, bipolar disorder, obsessive-compulsive disorder, sleep disorders, eating disorders, anger, guilt, suicide, and drug addiction (9). Another study revealed that in COVID-19-related death, between 47% and 71% of the mourners experienced grief, while only 20% of them experience complex grief, and if they feel the death process is traumatic and unexpected, they may experience more grief (10).

In addition, the results of a study conducted by Cardoso et al. in Brazil during 2020 showed the effect of not holding mourning in the bereaved families of COVID-19 and indicated that the shared experiences reflected the pain of sudden death for a family. Suppression of funeral rites and failure to pay the last respects to the loved one cause feelings of disbelief and anger in the family (11).

Ingravallo in 2020 mentioned that behavioral and social interventions adopted during the COVID-19 pandemic have greatly affected the way of dying in many countries. Lack of contact, mourning ceremonies, and support for humanity at the end of life is debilitating and emotionally exhausting. A live funeral may at least compensate for the grief. In the 21st century, our ability to respond to epidemics will be tested by how we can maintain the social dimension of death and dying (12).

Deaths from COVID-19 have no limitation and affect all people at any age. Moreover, quarantine caused by COVID-19 limits the performance of mourning rituals, and death due to this disease is unexpected. It may have various effects on the survivors. Accordingly, the identification of the experiences faced by bereaved families helps policy-makers and health system administrators to plan and implement psychological interventions and social work to promote physical, psychological, and social health, thereby improving the quality of life.

On the other hand, the provision of recommendations about the approach to mourning to the families of those who died by COVID-19 can prevent complex grief. Mourning is a state of intense and inner sadness, behaviors, motivations, emotions, and feelings that can only be achieved through the experience of people who have realized this fact. Therefore, the present qualitative study was conducted to perceive the experience of bereaved families of patients with COVID-19 in Iran.

Methods

This qualitative descriptive study was conducted based on a conventional content analysis method. The study protocol was approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences, Tehran, Iran (IR.SBMU.RETECH.REC.1400.051). After obtaining the required permission, the researcher extracted a list of 100 families' contact numbers from the archives of deceased COVID-19 patients that hospitalized in the COVID-19 wards of educational hospitals of Shahid Beheshti University of Medical Sciences, Tehran, Iran, from August 22, 2020, to May 21, 2021.

Subsequently, the researcher made telephone calls to the family members and explained the research objectives and procedure. In case of willingness, an appropriate time was determined for a telephone interview, and the participant was contacted at a specific time. The participants were purposefully selected and entered into the study according to the following inclusion criteria. The required data were obtained through in-depth semi-structured interviews conducted by the researcher.

At the beginning of the interview, participants were assured that the recorded voices would remain confidential by encrypting the files. Furthermore, due to the loss of a loved one, they could interrupt the interview whenever they did not want to and cancel the continuation of the research. The inclusion criteria were: 1) being the first-degree relatives of the deceased person (spouse, parents, siblings, and children), and 2) a minimum of four-month time interval since the deceased was buried.

The sample interview questions included: "What does mourning mean?", "Describe the experience of mourning the loss of a loved one?", and "Describe the impact of losing a loved one on your life?". During the interview, open clarifying questions, such as "Please explain more and please give an example", were used to clarify and understand the problem better. Interviews continued until data saturation (i.e., until the end of gathering new information; n=20 participants). The interview lasted between 35 and 40 min. MAXQDA software (version 10) was used to analyze information.

Furthermore, the data analysis was performed by the conventional content analysis method according to the approach of Granheim and Landman 2004 (13). In this study, the following steps were performed using this approach:

Immediately, after the end of each interview, the recorded information was carefully listened to, and then each word was written in Word 2016 software. The texts obtained from the interview were then checked by the researcher with the recorded tapes, and after ensuring their accuracy, the written texts were read several times to create a general and new idea by immersing in data. Each interview was considered a unit of analysis. The semantic units of each text were specified and then converted to the initial code. Afterward, the initial codes, which had the same meaning and concept, became a summary code. Codes were accrued to subcategories based on common features, and subcategories formed original categories or themes based on their common features. Lincoln and Guba's criteria (2005) including credibility, dependability, conformability, and transferability were used in order to assure the data's trustworthiness (14). The researcher was involved in the data collection and analysis process for four months and immersed in it. The research team continuously reviewed the interviews, transcribed them, and reviewed the notes in the field; moreover, they constantly compared the

information and discussed the categories, subcategories, and the extracted codes.
For data dependability, the extracted data, codes, and themes were reviewed and approved by six participants and two experts. In addition, three professors in qualitative research methods examined them, and the accuracy, as well as the proportion of the codes, were compared with their opinion, and the required revisions were applied. In the present study, for data conformability, all stages of the study were described in such a way that other people could judge by reading them, as well as participants with maximum diversity were included (meaning interviews with different people in terms of age, gender, the duration that passed from the death of the loved one, and different roles of the deceased). Following that, the ability to transfer data was achieved by transcribing the interviews immediately after the interview, describing statements and objective experiences accurately, and providing examples as well as quotes of the participants.

Results

The findings of this study were obtained from 20 interviews. It is worth mentioning that the majority (75%) of the participants were male. The mean±SD age of the respondents was 43.20±7.33 years. Other demographic characteristics are listed in Table 1. The final theme was the adaptation to the new world with three categories (Table 2).

Psychological symptoms

In the experience of mourning after the death of a loved one, the individual suffers disbelief and does not accept the death of the loved one and may show different physiological and psychological reactions. These symptoms may change permanently, especially if the sudden death is due to COVID-19 disease.

Disbelief mourning

Disbelief mourning was the first subcategory of the psychological symptoms category. The experience of natural death is quite different from the death caused by COVID-19. Old age provides many diseases with a dreamy background to death and reduces anxiety and its complications, while death due to COVID-19 occurs unexpectedly and at different and complete disbelief, a loved person is lost. After the death of a loved one, the individuals think that wherever they go, they see the lost dear person. Moreover, whenever they spend time together, some family members start criticizing the doctors and nurses who could not prevent death and assume that they were culpable for the loved one's death.

A woman stated that her husband's death caused by COVID-19 was as following:

"...When they told me about my husband's death, I kept thinking that it's just a dream or a nightmare

Table 1. Demographic characteristics of the participants

variable		Frequency
Gender	Female	7
	Male	13
Role in the family	Child	7
	Sister	2
	Brother	1
	Mother	1
	Spouse	9
Duration passed from the funeral of the deceased (months)	Less than 4	6
	4-8	13
	8-12	1
Age (year)	20-30	1
	30-40	6
	40-50	9
	50-60	4
Interview time (min)	Average	35-40

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

Final theme	Categories	Subcategories
Adaptation to the new world	Psychological symptoms	-Disbelief mourning -Disease and social stigma
	Role conflict	-Threatening context of multiple roles -Bottleneck of mental and work hazards -Uncertain future
	Miracle of belief and faith	-Inner peace with praying -Distraction of thoughts

and he is traveling and will come back soon, and it was unbelievable to me totally, and after 6 months, I still have not believed it. I am angry with those around me because I wonder why this happened just for my husband and I feel apathetic from now on to everyone and I will not get sad about anyone's death anymore. Life has become worthless nothing matters to me". (Interview 11)

Disease and social stigma

Disease and social stigma have embarrassed bereaved families who considered COVID-19 and its labels a barrier to accepting treatment and adapting to the death of a loved one. A man expresses the experience of his mother's mourning:

"...How hard it was that no one came to see my mother, everyone was afraid of getting infected, and at work, I was treated like a hated and rejected person, I heard myself that my co-workers say that I have COVID-19". (Interview 6)

Role conflictions

The role conflict was on the second category of the final theme, which is experienced by people who occupy certain roles. Changes in circumstances may cause role conflict, while role conflict is challenging for people. Often a person must resolve the role conflict on her/his own.

Threatening context of multiple roles

The threatening context of multiple roles was the first subcategory of role conflict. Hospitalization stress and eventual death challenge a person's roles, and multiple roles may threaten the mourners' health. When a person loses a loved one, friends and family's supports can help her/him to get back on the normal life.

A man explains the threatening context of multiple roles that has experienced after the death of his spouse due to COVID-19 as follows:

"...When a family member dies, I think half of my life is lost. This incident caused me to lose my job because my mother was disabled, and I was responsible for taking care of her, and because my mother was dependent on her, she became more disabled". (Interview 7)

Moreover, a son described the experience of losing his father in this way:

"...Because my mother was not in a good mood, I was worried at first, but I tried not to lose myself so that I could help her. After my father's death, I was given his responsibility and I do his work and I do not let her feel lonely and I am always by her side. I was afraid of losing my job but I tried not to create any problems in my work environment, and according to my situation, my co-worker encouraged me, and my wife helped me in this situation". (Interview 10)

Bottleneck of mental and work hazards

The bottleneck of mental and work hazards was the second subcategory of role conflict. It is an experience that also occurs in unrelated COVID-19 death. The involvement of mind, thinking about the lost loved one, and denying death are obstacles to returning to normal life, as well as resuming work, education, and constructive activities after a period of mourning. This puts a person in a bottleneck that is difficult to get rid of. Complementary activities, such as participating in charity events, can help you feel positive about yourself and the world, thereby helping return to normal life and overcoming mental and work hazards.

A man expressed his experience in this field as follows:

"... After my wife died, I was given all the responsibilities of life. I returned to work after 20 days, I tried to continue my work, I talked to others in the workplace so that I would feel better. I would go home to my children, I would not cry and be upset, and I would not worry". (Interview 8)

A woman described the experience of her husband's death as follows:
"...After the death of my husband, I felt that the world was over and I felt emptiness and fear, fear of living alone, and I thought I could no longer live after him, and all the life affairs were on my shoulder. After his death, life was very much hard, as if I was trapped in a swamp and afraid to do anything alone". (Interview 12)
Uncertain future
Getting used to life after the initial shock of a loved one's death appears to most people; however, it is different for each person. Inability to work due to that loss is normal but over time, mental involvement with this loss will decrease.
A woman described the loss of her husband by COVID-19 as follows:
"...I used to think that I mostly live for myself, but now the form of my dreams has changed and I no longer look to the future and I try my best to play the role of a father for my children well. Sometimes, when my responsibilities increase I get angry with my husband for leaving me alone, what will happen to the future of these children?". (Interview 5)

Miracle of belief and faith
Miracle of belief and faith was the third category of the final theme. Emotional and internal discharge in people when they lose a loved one is one of the most important ways to relieve pain and grief. In these COVID-19-related days, the loss of a loved one due to this pandemic and the impossibility of holding a mourning ceremony in the previous form has made it harder to bear the loss of a loved one. Activities, such as praying and averting the mind in lonely times are helpful depending on the culture and beliefs.
Inner peace with praying
Communication with God and the caress of the bereaved person leads to peace of mind. It is an experience that also occurs in unrelated COVID-19 death. Reading Quran, as well as saying the prayer and this verse*: "Indeed we belong to Allah and to Him we indeed return"* calm the hearts.
A woman stated her experiences of the death of her husband due to COVID-19 in this regard as follows:
"...I cried all the time in my privacy and I kept caress with my God and asked him why this happened and why I should be left alone, and it is sad for me to go through his memories and the pain he endured during his illness. I became depressed after my husband died and there is no day that I do not remember my spouse. Under any circumstances, I have to go to Behesht Zahra to get some peace".(Interview 1)
Distraction of thoughts
Distraction is an adaptive mechanism that leads to controlling a person's pain, fear, and anxiety. The bereaved person described his experience after the death of her spouse due to COVID-19 as follows:
"...When I was alone, I read Quran from night to morning and cried. I missed him a lot. On the first days of his death, I was constantly thinking and dreaming. I had sleep disorders. I was very irritable, but I tried to distract my mind by talking to others and do charity for him, and now I feel better". (Interview 9)

Discussion
This study aimed to evaluate the grief experience of the bereaved families of patients with COVID-19 in Iran. The result of this qualitative study can be summarized into a theme called "Adaptation to the New World" with three categories. It is noteworthy that some of the extracted experiences were similar to non-COVID-19 death, and this may be due to the fact that most participants shared their experiences at a time between 4 and 8 months after the death of their loved one, and they adapted to the circumstances.
In fact, they had gone through the initial crisis. Denial of death, the need to continue living under any circumstances, the inevitability of death, and the conflict between death and life may affect people's adaptation, especially when it happens unexpectedly. Although the observation of deaths due to COVID-19 is much more painful and impressive, and the family unexpectedly faces the death of a loved one and a crisis. According to Kobler Ross, adaptation is the same as the general experience of death between 4 and 6 months, followed by five stages with a little difference in steps (15).
The disbelief of mourning and disease, as well as social stigma, were psychological symptoms of grief

in bereaved families. The results of a study showed that women and young people aged 16-25 years were more prone to fear, anxiety, and depression caused by COVID-19. Moreover, fear, anxiety, and depression showed a significant relationship with attention to vulnerable groups to minimize psychological problems during an epidemic (16). Other studies were conducted to evaluate the underlying factors, such as race, age, and sick leave; moreover, they recommended preventive behaviors and showed that the association of COVID-19 with death predicted reluctance and discouragement of life and unwillingness with preventive behaviors (17).

Hagen's experience of the death of his grandmother with whom he had regular visits before COVID-19 and very few in recent months due to this pandemic, followed by a limited funeral and lack of soothing rites, became the norm. It was unusual mourning to feel like it was a funeral; however, it was not a real funeral feeling, and he no longer had a chance to share fond memories, and he lost his grandmother in disbelief (18).

Stigma is more dangerous and harmful than the disease itself and is an obstacle to improvement and acceptance. The media can play an important and special role in increasing or decreasing stigmatizing behaviors. The World Health Organization in its 2020 guideline for the prevention and control of social stigma caused by COVID-19 noted that people who were not infected but had been exposed to the virus felt social stigma and discriminatory behavior. Collectively, they play an important role in controlling and preventing this social stigma, which can be achieved by knowing the facts about how the disease is transmitted (19).

Role conflict was another category of the final theme, and those who lost their spouses had a role conflict because they had to play the role of the lost spouse in addition to their own role. Role conflict due to multiple roles after a person's death in the family and a threatening context for individual's health, make it difficult for the person to take on responsibilities. On the other hand, the conflict of the role placed the individual in bottlenecks of the work and mental hazards, which necessitates the adaptation to them.

Kristin et al. (2013) showed that the contextual threat by the sibling of a child with cancer was independent of age, gender, and order of birth. Moreover, the child's deteriorating condition provides the contextual threat for sibling distress (20). Ghebrat et al. (2008) in a descriptive study entitled "bottlenecks in providing quality mental health services" showed no comprehensive mental health policies and laws in Eritrea. Furthermore, shortages in providing cost-effective services limited human resource capacity and inadequate mental health services in primary health care (21).

Zainal Badri and Mohd Yunus conducted a study on the relationship of conflict of academic, family, and personal roles with the mental health of Malaysian students during the COVID-19 crisis. The results showed that the experience of the first conflict (e.g., academic work weakens family roles) predicted higher levels of stress, anxiety, depression, social dysfunction, and loss of self-confidence, while the second type of conflict (that is when the family roles undermine college work) was associated with increased stress, anxiety, depression, loss of self-confidence, and unhappiness; however, it was not associated with impaired social functioning (22).

The COVID-19 virus poses a unique challenge that requires finding ways to work and interact while maintaining mental health and social well-being. Therefore, it is critical to have a regular schedule, maintain interaction with family and friends, use new technologies, strengthen the immune system and personal hygiene, limit contact with others, breathe fresh air, and gain up-to-date information about the disease (23).

Sadness, frustration, and anger were the experiences of grieving families, and videotaping created a dichotomy. The presence of doctors at the time of his/her death was a consolation to the families. Anger, frustration, and shame resulted from the recklessness of the government and people, lack of saying goodbye arbitrarily, as well as social support and post-mortem ceremonies (24). Following the COVID-19 epidemic, sudden and noticeable changes in job and family roles were experienced, especially when the family experienced the death of a family member. This negative consequence has devastating effects on people's mental health, which affects their ability to adapt to crises (25).

Miracle of belief and faith played an important role in adapting to the death of a loved one during the COVID-19 pandemic, which is the same as death unrelated to the COVID-19; accordingly, in the Iranian-Islamic culture, communication with God (Quran verses, such as *"To Allah, ˹alone˺ belongs the kingdom of the heavens and the earth and everything within"* and *"He is the Most Capable of everything". [Al-Ma'idah:120])*, and the caress with the creatures and diversion of thoughts could be

very helpful for inner peace.
The results of a study conducted by Cardoso et al. in Brazil during 2020 showed that the shared experiences in the reports indicated the misery that was inflicted by the sudden death, which was reinforced by the absence or inhibition of a familial farewell ceremony. Failure to perform funeral ceremonies is a traumatic experience because family members are prevented from paying their last respects to a loved one who has died suddenly and caused feelings of disbelief and anger (11). The limitation of the present study was that due to the COVID-19 pandemic, it was not possible to use different data collection methods, such as face-to-face interviews, observation, and focus groups. On the other hand, it was attempted to gain the experiences of bereaved families by in-depth telephone interviews with probing questions.

Implications for Practice
The level of adaptation and acceptance of the bereaved in the COVID-19 crisis varies based on the different ages of death. Form of mourning, the way of expressing emotions, the importance of the role of others, as well as mourning in the community and with family members are of significant importance. Even in the current situation that mourning ceremonies cannot be held due to the outbreak of COVID-19, mourning among even a small number of family members and close friends, talking on the phone or internet with friends and acquaintances, as well as expressing emotions while talking to others are very important for compatibility. Therefore, it is essential to find a solution to support bereaved families to adapt to the new world without the deceased.

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Conflicts of Interest
The authors have no conflict of interest.

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