

Lived Experiences of Critically Ill COVID-19 Patients About Death and Dying: A Descriptive Phenomenology

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Abstract

Thinking about death is one of the most common problems of critically ill patients with COVID-19 in ICUs. Therefore, this study aims to explore the experiences of critically ill patients with COVID-19 about death and dying. This is a descriptive phenomenology approach. Participants in this study had 12 participants who were purposefully selected. The data collection method was semi-structured through interviews. Data were analyzed based on Colaizzi's approach. Data analysis generated two main themes, including personal, and non-personal; challenge thinking about death, and eight sub-themes. Thinking about the death of critically ill COVID-19 patients is a significant challenge that affects the patient's health and prolongs the treatment process. Therefore, it should be careful in the patient's treatment and care program.

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Since December 2019, when the SARS-CoV-2 was recognized from Wuhan, China, and soon became a pandemic, more than five million people have died worldwide ([Worldmeter, 2022](#)).

Human has always thought of death as one of their first and most enduring concerns. Death is the most undeniable reality that has effects on daily life. Death phenomenon is always considered by people throughout life and is the most certain reality of human life. Therefore, death is an integral part of human life, which preoccupied the mind and has been accompanied by fear and anxiety in people ([Anthony, 2013](#)).

Nowadays, more than 70% of human deaths in urban societies occur in hospitals. Therefore, the hospital is a place where critically ill patients should be admitted. In the context of the COVID-19 pandemic, hospitals are a frightening place for death in people minds. Even healthy people with no disease are afraid of death. ICUs with beds full of critically ill patients under mechanical ventilation, and overflowing corpses have become almost terrifying for sick and healthy people equally ([Wakam et al., 2020](#)).

Fear and anxiety of death are present in human beings, but during the COVID-19 pandemic, people have paid more attention to death. The current pandemic has not only resulted in uncertainty about health and safety, confusion, and chaos but has also put people in an indefinite period of fear of death ([Pradhan et al., 2020](#)).

Death anxiety refers to a great fear of dying or losing touch with the world or what happens after death. Death anxiety consists of four-factor including fear of the hereafter, fear of facing death, fear of short life, and fear of dying following an accident ([Templer et al., 2006](#)).

Patients who feel death is near having low adaptability during hospitalization and are exposed to many psychological issues. Therefore, many patients with COVID-19 face end-of-life challenges. They gradually experience physical, psychological, social deprivation, moral, and spiritual aspects that lead to fear and despair, and reveals many psychological needs ([Fernández & González-González, 2020](#)). Physical issues can be the onset of severe symptoms and progression of the secondary diseases, psychological aspects include stress, anxiety, depression, and fear of death; spiritual and religious aspects include turning to prayer and doing more religious rituals, and believing in healing. Ignoring any of these aspects lead to worsen the disease and greater fear of death ([Dubey et al., 2020](#)). Besides, fear of losing life is the most critical concern of patients after exposure to COVID-19 ([Galbadage et al., 2020](#)).

In addition, death anxiety due to the pandemic causes frustration, dissatisfaction, and a prolonging recovery process ([Liu et al., 2020](#)). Studies also show that critically ill patients with COVID-19 admitted to the ICU have a sense of near-death, fear of death, isolation, and depression. Spiritual issues are essential for these patients ([Galbadage et al., 2020](#); [Kotfis et al., 2020](#)).

As COVID-19 patients with respiratory problems admitted to ICUs have a greater sense of fear of death and need psychological support to regain their health. It seems necessary to increase our understanding of the patients' experiences with COVID-19 and consequently the clinical application of research findings in psychological and health interventions. In this regard, the present study aimed to explore the lived experiences of hospitalized patients with COVID-19 about death and dying. Assessing the challenges of these patients about death can be the basis for planning and implementing psychological interventions, social work, and nursing to help promote the physical, social, and psychological health of critically ill patients with COVID-19.

Methods

Design and Participant

The present study was conducted with a phenomenological approach. Phenomenological research answers the questions about a phenomenon structure and nature that people experience it. The main problem in applying phenomenology is the answer to the question "whether the phenomenon in question needs to be clarified or not." Practical contexts for the phenomenon of death from the perspective of COVID-19 critically ill patients, with all its importance, have not yet been sufficiently elucidated in previous studies. Participants in the present study were critically ill patients with COVID-19 admitted to the ICU in southeastern Iran. This study was performed from January to June 2021. Participants were recruited using a purposeful sampling method. Inclusion criteria were being affected by COVID-19, hospitalization in the ICU, having severe symptoms of COVID-19 disease, having respiratory problems and abnormal blood oxygen percentage at the time of admission, being discharged from the ICU after treatment, and having experienced death anxiety based on the "Templar Death Anxiety Checklist." The exclusion criterion was the unwillingness to participate in the study. Participants consisted of 12 critically ill patients from COVID-19. Participants were eligible with great diversity in terms of gender, age, marital status, COVID-19 symptoms, and days of hospitalization in the ICU.

Data gathering

The data was collected using a semi-structured interview in a private but well-ventilated area with coordination and willingness of the participants who were discharged from the hospital 1 month after a negative PCR test. Ethical principles were considered by providing oral and written consent. The participants were allowed to reject interviews at any time and were reassured of the confidentiality of data. The researchers provided their contact number and e-mail address to the participants if they had any questions or were willing to withdrawal from the study at any stage or to receive the study results. The exploratory questions were as "Please explain how you infected to COVID-19 and the symptoms that led to you being admitted to the ICU," and "Please talk about your

opinion or thoughts related to death and dying after being admitted to the ICU.” Next, clarification questions were asked if required such as “tell me more about that.” During the interviews, face and speech changes such as a change in voice tone, pauses, crying, and laughter was recorded as well. The duration of each interview was 30–45 minutes, and for some participants, two interview sessions were conducted. All interviews were recorded and immediately after each session transcribed word-for-word. Sampling was continued until data saturation. After 10 interviews, no new information was obtained, but two other interviews were conducted to ensure data saturation.

Data Analysis

After each interview data were analyzed simultaneously using Coliazzi’s (1978) method. This method provides clarity in the steps of analysis (Chien et al., 2020) as follow: First, reading and re-reading all the participants’ descriptions of the phenomenon under study; the second step, extracting significant statements from each description that directly relates to the phenomenon; the third step, formulating meanings from the significant statements; the fourth step, organizing the formulated meanings into themes; the fifth step, integrating the results of the data analysis into a description of the phenomenon under study; the sixth step, returning the results to the participants for validation; Finally, incorporating any new, relevant data into the fundamental structure of the phenomenon.

Trustworthiness

Goba and Lincoln criteria were applied for the study rigor as Credibility, Confirmability, Dependability, and Transferability (Krefting, 1991). Credibility and Confirmability were achieved via continuous engagement with the data, bracketing of ideas on the topic, and verification of the data by the participants, research team, and two faculty members outside the research team. To determine Dependability, two members of the research team coded the interviews, and there was a great deal of agreement between the opinions. Besides, the coefficient correlation of themes obtained from double coding by two researchers was 0.86, which was finally approved by the participants. Extreme care was also taken in collecting, implementing, and recording data, and allocating sufficient time for data collection. In terms of transferability, the information obtained by two faculty members outside the research group and the experts in the field of qualitative research was reviewed and confirmed the information.

Ethical Consideration

The ethical approval was achieved from the Ethics Committee of Zabol University of Medical Sciences (Ethics code: IR.ZBMU.REC.1399.021).

Table 1. Themes and Sub-Themes Identified in Interviews.

Themes	Sub-Themes
Personal challenges of death	Hospitalization in ICU and intubation as sources of death anxiety Death denial ICU as the end place of life Dying in presence of loved ones Dying without religious ceremony
Non-personal challenges of death	Concerns about family Social atmosphere concerns

Results

Participants were 12, 2 women and 10 men with a mean (range) age of 55.4 (42–76) years. Almost all participants had pulmonary involvement and severe symptoms. All participants experienced death anxiety at the time of admission. According to the “Templer’s Death Anxiety Scale,” 62% of patients experienced severe, 20% moderate, and 18% mild death anxiety at the time of admission to the ICUs. The average length of hospital stay in the ICU was 22 days. The analysis of data revealed two main themes and seven sub-themes (Table 1) as follows:

Personal Challenges of Death

People with critical conditions who were admitted to the ICU were more likely to be intubated and connected to artificial ventilators. Therefore, they encountered life challenges that shifted them to death anxiety when their health condition got worsen. Death anxiety in the results was confirmed using “Templer’s Death Anxiety Scale,” which consists of four components, including fear of the hereafter, fear of facing death, fear of short life, and the fear of death following an accident. This was an initial assessment to evaluate death anxiety in the participants before the interviews.

Hospitalization in ICU and Intubation as sources of death anxiety

Participants’ fear and anxiety increased in the ICU due to pulmonary problems and shortness of breath. The nightmare of imminent death occupied their minds and resulted in panic in them. Connecting to the artificial ventilator was considered a kind of death greetings, and they felt that there was no way to back life unless miracles save them.

“In the ICU, I saw patients who were connected to a device [ventilator] ... I felt that they were all fighting to the death ... I was so scared and I had nightmares of death.”

Participant 2

“I was in terrible due to my shortness of breath, I felt that I was dying, and I was always anxious about that ... I didn’t want to be connected to the device, because I thought I would lose all ways of connections with others.” Participant 4

Participants also thought that hospitalizing in ICU equals death.

“I heard that hospitalization in ICU and connection to device [ventilators] causes death, I was terrified that such a fate awaited me too when I was transferred to the ICU.” Participant 9

“I thought that if I were connected to the device [ventilator], it would be the end of the road ... I think people there [ICU] are expecting death at any moment.” Participant 10

Death Denial

Participants considered that confronting death as a difficult event and attempted to convince themselves it would not happen to them. They also attempted to reject or denial thinking about death through praying and distracting their mind from the disease such as not talking about the history of other patients who died and not looking at patients under resuscitation techniques.

“When I’d hospitalized I was so scared, I felt that I stepped more than 50 percent toward death, but I’ve tried to reject that I’m sick.” Participant 1

“Every time I thought about the future, I concerned what would happen to me here [hospital] ... I couldn’t accept death, and I tried not to think about it.” Participant 3

ICU as the end place of life

Participants described that being hospitalized in ICU due to shortness of breath and lung problems caused by COVID-19 as entering a one-way street with no return to life. Hospitalization in ICU was bad news for them.

“When the doctor visited me and said I have to be admitted to the ICU ... I felt that I had reached the end of the line.” Participant 4

“I had heard bad news about the special ward [ICU] that every patient who is hospitalized there dies. When they told me to be hospitalized there, the world just fell apart.” Participant 7

Dying in presence of Loved Ones

Although the participants had been recovered, they wished to die at home in presence of their family members or loved ones. They believed dying in hospital is suffering for

them and their families. They have to be connected to the artificial ventilators in ICU for a long time without any positive result. Besides, connection to the ventilator only expands their life length and sometimes if they improve weaning from the ventilators was difficult. They also believed that hospitalization might emerge new complications. Overall, they wished and expected a natural with an easy way of dying for themselves.

“I always wished to die in my house and visit my family members at the last moments of my life. ... but when I was hospitalized I felt my wishes are gone... Although I was afraid of dying in the hospital, I prayed for improvement.” Participant 5

“When I saw people in the ICU who are connected to a ventilator and die after a while ... their bodies were injured and smelled and they have been suffering for a long time, but for myself, I wished a fast and easy die ...” Participant 7

Dying Without Religious Ceremony

Participants were worried about religious rituals and ceremonies that were not performed for dead ones due to COVID-19 pandemic rule and regulations. Executing religious ceremonies indicates dignity for the dead and their families.

“Another problem that bothered me was dying under the device [ventilator] ... no rituals will be performed and that was painful thought for a religious person like me ...” Participant 1

“There are some religious ceremonies for dying people that must be done in the last moments of life ... but If I was died due to COVID-19 no religious ceremony would be done for me. That was a worrying condition in my mind.” Participant 9

Non-Personal Challenges of Death

In addition to personal challenges, the critically ill patients of COVID-19 have also had non-personal challenges on death. The non-personal challenges were concerned about family and social atmosphere concerns.

Concerns about family

Participants worried most about their families and relatives and what will happen to them if they die. They were worried about children and family incomes too.

“As I wasn’t well and I thought I might not leave the special ward [ICU] anymore ... I also saw worries on the faces of my family members ... I thought after my death, my children life will be difficult.” Participant 12

“I was sick and I was thinking about illness and my family matters ... I felt I was dying ... that time I was thinking about myself, but I was worried about my wife and children. They

didn't have a job and no one got married ... my mind was full of questions like what will happen to them if I die?" Participant 5

Social Atmosphere Concerns

Participants were concerned about their fate and burial rites if they die due to COVID-19. As the government restricted families for burial rites for COVID-19 victims, the participants believed that those limitations were dishonorable and disrespectful. Besides, dying due to COVID-19 was a social stigma, in which families attempted to hide the cause of death from others.

"One of my concerns was that if I died because of COVID-19 they would bury me without honorable ceremony. The government hasn't allowed the families to participate in burial ceremonies at first and people were buried in special conditions, and then everything ended." Participant 11

"During life, people respect and value you. If you die due to COVID-19, everything is gone at once, and you become a social stigma ... your family can't say why you died." Participant 9

Discussion

This study aimed to explore the experiences of critically ill patients with COVID-19 about death and dying. Data showed two main themes and seven sub-themes.

One of the main themes of the present study is the personal challenges of death. The critically ill patients with COVID-19 who were admitted to the ICU and intubated have had death anxiety. Therefore, hospitalizing in ICU and intubation were sources of death anxiety in COVID-19 patients. The results of studies show that the rate of death anxiety in patients with COVID-19 is very high, and the patient suffers from a high level of death anxiety. Death anxiety is a multi-factorial phenomenon that affects the recovery and severity of the disease. The factors contributing to the intensification of fear include the nature of the pandemic, ICU, inadequate knowledge about COVID-19 and its treatments, unknown prognosis of the disease, using protective equipment by doctors and medical staff, inadequate communication skills of medical staff (Meng et al., 2020; Menzies & Menzies, 2020; Mohammadpour et al., 2018). A previous study indicates patients in critical condition with severe pulmonary problems experience a higher level of anxiety due to imminent death during hospitalization in the ICU. In addition, the patients with COVID-19 who have underlying diseases such as cancer and diabetes may worsen due to anxiety and worry and if they will be overlooked, death will happen soon (Chochinov et al., 2020; Peteet, 2020).

Death denial of death was another sub-theme of the study. One of the concerns of critically ill patients who were admitted to ICU was thinking about death. They have attempted to reject death in their mind and to suppress threatened thoughts as a way to

protect themselves against death and to overcome the illness. The study results showed that COVID-19 patients face the reality of death that happens to many people every day. They understood that in severe conditions death might be happening; thus, they attempted to deny death for themselves to strengthen their morale. This result is in line with previous studies (Solomon et al., 2021; Jamili et al., 2021).

ICU as the end place of life was another sub-theme. Participants described hospitalization in ICUs as a one-way road that reaches the final stage of life and the recovery possibility is very low. A study indicates that COVID-19 patients who are hospitalized in the ICU feel that they will no longer be discharged and the death rate is very high due to the severity of their illness (Colonnello et al., 2020; Liu et al., 2020).

Wishing dying at home and in presence of loved ones was another sub-theme. As ICU is a ward where the families are not allowed to routinely visit their loved ones, the patients die alone without any presence of family members. Therefore, they requested to be discharged and wish to die at their home and in presence of their families or supporters. A study shows that patients with COVID-19, especially those who are hospitalized, expect poor quality mortality with physical problems, social isolation, and psychological problems without being supported (Carret et al., (2020). Another study also reports that death from COVID-19 is a form of solitary death. The dying people lose their social and family support. Although the presence of the family does not have a positive result for the patient, death in the presence of the family has become a symbol in the view of people that death seems more natural (Strang et al., 2020). Death as a stage of human life happens sooner or later. However, human beings believe a good death takes place at home, in peace, and presence of family. However, the COVID-19 pandemic has entirely changed what people expect about death (Menziez & Dar-Nimrod, 2017; Menziez et al., 2020). Besides, the pictures, movies, and news in media about the death of patients due to COVID-19 and the accumulation of corpses in morgues and cemeteries have shocked people minds (Miller, 2020).

Dying without religious ceremony is the other sub-theme that participants were concerned about it. Many human beings believe that religious rites are important for a peaceful death. Therefore, performing certain rituals based on their religion or beliefs at the time of death might enhance the quality of death and satisfy the family members as well. However, in COVID-19 pandemic preventive rules and restrictions limits performing religious services for dying patients as well as for their families. Studies reported the importance of religious rituals for peace dying and their family (Hamid & Jahangir, 2020; Simpson et al., 2021). Besides, elderly people are more likely willing to perform religious rites at the time of death to achieve peace during death. Therefore, they are more subject to cultural and religious rituals. COVID-19 pandemic has exacerbated these challenges and has turned them into significant concerns (Rababa et al., 2021).

The second main theme was the non-personal challenges of death in critically ill patients with COVID-19. Patients were concerned about their family and social atmosphere. Even the burial conditions for COVID-19 patients have changed. They have

been buried in a particular place with local conditions of hygiene principles and measures.

Another concern for critically ill patients before death is worrying about other family members who survive and they may face new challenges. They also have the challenge of losing their jobs, lives, and social status, and they may inadvertently die from COVID-19 and lose everything at once. In line with the results of the current study, the results of a study show that the patients feel who feel death is near also experience anxiety, depression, and emotional issues and other personal needs that are related to the family (Cook et al., 2021).

Social media is full of alarming stories of people who died of COVID-19. Families have been unable to see the loved one before death, and have not been able to hold a routine funeral. All these constitute negative images and experiences about death due to COVID-19 (Kozlov et al., 2019). Besides, the COVID-19 pandemic has challenged the viewpoints regarding life and death (Omonisi, 2020).

Given the social and cultural rituals, people actively participate in their funerals. COVID-19 patients expected an early death for themselves and also they are aware of the health restrictions for crowded funerals and corpus transportation to a favorite place or cemetery. A crowded funeral is prestigious for the late and their families. Besides, some families bury their relatives in a familial cemetery. Some people even testate where to be buried. Therefore, they were concerned about their funeral. If a funeral does not take place routinely it will be a social stigma for them.

Limitations

One of the limitations of the present study was that the participants were unable for a long interview due to the COVID-19 physical complications, though we have attempted to increase the number of interview sessions based on the participants' willingness and physical condition in a situation. Participants were also attempted to ignore the annoying memories of COVID-19, which may have affected the interviews.

Conclusion

The critically ill patients of COVID-19 are concerned about hospitalizing in ICU, dying place, dying rituals, and family members. Some of the concerns are real and healthcare providers should pay special attention to solving them. Some of the concerns such as intubation and hospitalization in ICU were misconceptions. As the media have a crucial role in broadcasting right and real information to audiences, they must offer information that reduces concerns about COVID-19 effects on societies. Besides, caregivers, health policymakers, and media must increase mass awareness through valid and reliable information about the pandemic effects. The cultural and religious ritual must be an inseparable part of life even in critical situations like the COVID-19 pandemic.

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