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Prolonged grief disorder in the families of COVID-19 pandemic victims: A phenomenological study

Narges Kheirollahi¹⁰, Nasrollah Alimohammadi¹⁰, Mohammad Sadegh Abotalebi¹⁰, Hassan Babamohamadi^{2,3*0}

¹Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

²Nursing Care Research Center, Semnan University of Medical Sciences, Semnan, Iran

³Department of Nursing, School of Nursing and Midwifery, Semnan University of Medical Sciences, Semnan, Iran

Abstract

Background and aims: The COVID-19 pandemic has had a major impact on the human grief experience, putting bereaved people in difficult, complex, and unprecedented conditions. This study explored complicated grief (CG) experiences in the families of victims of the COVID-19 pandemic.

Methods: A qualitative study with a phenomenological approach was conducted in 2021 in Isfahan, Iran. Purposive sampling was used in this study. Data were collected by in-depth and semi-structured interviews with 14 family members of COVID-19 victims and analyzed using Colaizzi's method.

Results: Findings include 260 primary codes extracted according to the purpose and research question in 5 main categories and 15 subcategories. Incompatibility, helplessness, untimely death, inconsolable grief, and neuroticism are the themes of the main categories.

Conclusion: Many painful physical, mental, social, and spiritual experiences lead to complicated grief in the families of the COVID-19 victims. Awareness of health providers of this helps reduce the experience of incompatibility, helplessness, untimely death, inconsolable grief, and neuroticism in order to manage behavior and reduce negative emotions through specific psychological interventions. It also helps them cope with grief and the resulting psychological suffering.

Keywords: Grief disorder, Complicated grief, COVID-19, Victims, Family, Phenomenology

*Corresponding Author:

Hassan Babamohamadi, Email: babamohamadi@ semums.ac.ir

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Introduction

The COVID-19 pandemic is one of the worst public health crises of the last century, and because of that, millions of people around the world have lost their lives and have experienced grief (1). Although the consequences of this crisis are still unknown, the multiplicity of deaths caused by it has a profound effect on cultural norms, rituals, and common social practices related to death, grief, and the experience of bereavement of individuals and communities. It could potentially lead to complicated grief (CG) (=(2).

CG in the DSM-5 (3) is a mental disorder consisting of a distinct set of symptoms following the death of a family member or close friend (i.e., bereavement). People with CG are preoccupied with grief and feelings of loss to the point of clinically significant distress and impairment, which can manifest in a variety of symptoms, including depression, emotional pain, emotional numbness, loneliness, identity disturbance, and difficulty in managing interpersonal relationships (4).

Normally, the symptoms of grief decrease and should not last more than two months. However, in CG, a longer duration lasts more than six months and leads to a debilitating mental condition that requires serious psychiatric intervention (5).

Risk factors for CG include 1. the nature of death, for example, Sudden, traumatic, unpredictable deaths; 2. Limiting the opportunity to "say goodbye"; 3. The environment in which the death took place; 4. Low level of social and family support; 5. Cultural background; and 6. Mental health of the bereaved (6-8). Deaths from COVID-19 also have a set of risk factors, including rapid and unexpected death, social isolation due to conditions such as quarantine, social distance, preventing gatherings and grief, and preventing sensitive and necessary communication due to the contagious nature of this disease and not giving the opportunity to "say goodbye." Therefore, this set of risk factors may lead people to experience CG (2).

The effective contexts for the experience of CG in the family members of the COVID-19 victims, with all its importance, have not yet been studied in previous studies. Therefore, considering the importance of the CG experience and its consequences, on the aspects of the

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grief experience and the lack of qualitative studies on the experience of CG following the deaths of COVID-19, the main question of this study is: How do the survivors and family members of the COVID-19 victims experience the CG?

Phenomenological research seeks the answer to the question, "What is the structure and nature of the experience of a phenomenon by humans? Moreover, the main issue in phenomenological studies is the answer to the question of whether that phenomenon needs to be clarified or not?"(9). Therefore, the present study was conducted with a descriptive phenomenological approach to understand better the experiences of the COVID-19 survivors living in Isfahan.

Methods

The participants were the family members of the victims of COVID-19 in Isfahan in 2021. After receiving permission, their information from the files of the deceased COVID-19 patients who had died more than six months ago from two COVID-19 referral hospital centers in Isfahan was obtained.

Participants were selected using purposive sampling. Sample selection criteria were: Participants experienced the death of a family member following COVID-19, had at least six months of grief, were interested in sharing their experiences, and they had the minimum literacy to conduct the interview. At first, a preliminary interview was conducted by a clinical psychologist (20–30-minute phone call) with 200 family members of the victims of COVID-19 who were on the list. After an initial assessment, 23 people with symptoms of CG were diagnosed by a clinical psychologist, and 14 of them agreed to participate in the study.

Maximum variation sampling was adopted to ensure the selection of a wide variety of participants in terms of age, gender, education, and job. In this study, data saturation was achieved after interviewing 12 participants, and the primary categories were thus drawn; however, to further ensure data saturation, two other interviews were conducted, but no data were drawn from them that could lead to the development or formation of new categories.

The data collection strategy used in-depth interviews, open-ended questions, and follow-up questions to encourage participants to provide in-depth experiences. The duration of the interviews varied between 60 to 90 minutes. The participants themselves determined the time and place of the interviews. The interview questions were open-ended, beginning with a general question: "Tell us about your experience after the death of your loved one." Follow-up questions were used to explore the phenomenon in depth, such as "Can you explain more about this?"

Data analysis

Since the purpose of the study was to describe CG in the family of COVID-19 victims, Colaizzi's descriptive

phenomenology was used. For data analysis, the recorded data were first transcribed word for word. It took 6-10 hours to transcribe each participant's interview. Subsequently, the researcher listened to the recordings to improve the accuracy and reliability of the data. Data were analyzed using the method described by Colaizzi (10). In the first stage of analysis, the researcher read the transcribed data several times and selected important phrases, focusing on the context of the data and the participant's responses. Then, similar expressions were grouped and organized among the extracted expressions and reconstructed more abstractly. After that, a theme was extracted by grouping similar content into meaningful phrases, and similar themes were grouped and categorized into themes with high abstraction. Data collection and analysis were performed simultaneously. The interviews were conducted until theoretical saturation was reached so that no new content appeared in the interviews and similar concepts and themes emerged in the data analysis.

Trustworthiness

In order to assess the trustworthiness of phenomenological research, we examined various criteria, including internal validity, external validity, reliability, and objectivity (11). The findings of this study were assessed using the following criteria: credibility, transferability, dependability, and confirmability (11). Credibility was confirmed by having the participants review the interview descriptions to ensure the transcripts conveyed their intention. Transferability was established via thorough descriptions that described the context extensively and carefully until saturation of concepts occurred. Dependability and confirmability were supported by documenting the logic of the research process so that two reviewers could track the data and its source and understand the interpretations. Two professors with experience in phenomenological studies were required to ensure that the data analysis procedures were reviewed, that the analyses were logical, and that the resulting descriptions were comprehensible. In addition, results were verified by 3 participants to ensure validity and reliability in qualitative research.

Results

In the present study, 14 family members of COVID-19 victims of CG, including four men and ten women, were interviewed in-depth and semi-structured, and the researcher achieved data saturation by conducting 12 interviews. It should be noted that the recorded information from the initial interviews of 14 participants at the time of sampling was also recorded and added to the data of the main interviews. The study data comprised 28 interviews (14 initial interviews and 14 main interviews). The participants in the present study were between 16 and 64 years old. Their education ranged from high school to graduate school. The majority had housewives. Other specifications are provided in Table 1.

Based on the first of Colaizzi's phenomenological

Table 1. Participants characteristics

Participant	Gender	Age	Education	Job	The deceased's Relative with the participant
No. 1	Male	56	Bachelor	retired	Spouse
No. 2	Female	64	Primary school	housewife	Son (31-year- old)
No. 3	Female	23	Bachelor	University student	Mother
No. 4	Male	59	Bachelor	retired	Mother
No. 5	Female	17	High school	student	Father
No. 6	Female	54	Diploma	housewife	Spouse
No. 7	Female	22	Bachelor	Employee	Father
No. 8	Male	16	High school	student	Father
No. 9	Female	41	Diploma	housewife	Daughter (21-year-old)
No. 10	Male	40	Master	Employee	Spouse
No. 11	Female	16	High school	student	Mother
No. 12	Female	29	Diploma	housewife	Mother
No. 13	Female	43	Diploma	housewife	Mother
No. 14	Female	54	Bachelor	retired	Son (28-year- old)

analysis steps, "important statements" related to the phenomenon of CG were extracted from each interview, of which 260 important statements were obtained from 14 interviews. Then, the underlying meaning of each of the important statements was extracted and written under the title of formulated meaning. Conceptual similarities were then categorized, and 53 initial concepts were obtained. Similar basic concepts were organized into broader concepts, and 15 subcategories were obtained. Finally, in order to achieve a more accurate meaning of the concept of CG, five main categories were extracted (Table 2).

Incompatibility

The main theme, "Incompatibility," was obtained from the sub-theme "physical problems" (Physical pain, insomnia, nightmares), "psychological problems" (Boredom, hallucinations, depression, feelings of loneliness), "social problems" (Social isolation, anger and conflict), and "Spiritual problems" (Anger with God, failure to perform religious rites, a sense of disbelief).

"Since this happened, I have had severe digestive problems for months, and I went to the doctor several times. I am still involved. One day, I have severe headaches, and by the way, these did not happen before, and I think these headaches and digestive problems started from the time this happened" (p 1).

"After the death of my daughter, I became very nervous with this damn disease. I am very ill; I have no patience. The family tries to avoid me and do things that make me happy, but I am not happy. I cannot reach myself at all. I wake up regularly at night, always feeling like someone is coming through the door or the curtain is moving" (p 9).

"We are not in a good mood. My wife, she was not very

ill. It is very difficult for me to accept that she died with a few coughs and left the children alone. Everywhere they look in the house, they miss their mother. They do not eat well. They are constantly fighting with each other. I am very tired. The children are also very tired and lonely. Corona destroyed our lives in the blink of an eye" (p 10).

"I did everything I could for my wife. We recite Quran verses every day for her health. We prayed a lot for her health. We slaughtered sheep. After her death, I lost my faith. I always tell myself, we prayed so much, we made so many vows, we appealed so much" (p 1).

Helplessness

Helplessness falls under the subcategories of mentalemotional helplessness with content: deep loneliness, destruction of the person, destruction of life, intense anger towards the disease and constant blame of oneself and others, breaking the foundation of the family after the death of the parent, a feeling of extreme helplessness; and physical helplessness with constant use of sedatives and extreme fatigue were formed.

"My dad was very calm, very kind and patient. He is gone now, and his absence bothers us all. Somehow, we grieve together now. I understand that we are not all well, but I cannot do anything. I think we are all depressed. We became like a rosary that no longer has a thread as if we had sprinkled it" (p7).

"It seems that our happy days are over after my mother's death. It's very hard for us. My brother and I can no longer stand it. I always remember that day when we put a shrouded corpse in the grave and said this is your mother. I still do not believe she is gone; I always think she will come back. When I sleep every night, I want to dream of her. I miss my previous days very much (crying). I understand that my brother is also not in a good mood. God help us; our lives have become very black. It is crushing us all like a crushing wheel" (p 3). "Corona was really like an avalanche. Suddenly, everything destroyed us! It feels so bad!" (p 1).

Untimely death

Untimely death was formed from the subcategories of unbelievable death with the content of rapid death, being shocked by death news, unexpected death, and failure to say goodbye at the moment of death with the content of the ban on visiting the patient during hospitalized in the intensive care unit, and more importantly, a short distance between hospitalization and death. An experience that almost all participants in the study shared and had suffered a lot from.

"When we arrived at the hospital emergency room, my mother was unconscious (Cries). She was taken to the cardiopulmonary resuscitation room. I could see my mother's pale face (long cry) because they could not do anything for her. Saying that she had a brain hemorrhage because of Covid. They came and took

Table 2. Categories and subcategories with the interview coding process and data classification

Theme	The main theme's theme	Subthemes	Content (basic concepts)	
Prolonged grief disorder (CG)	Incompatibility	Physical problems	Physical pain, insomnia, nightmares	
		Psychological problems	Boredom, hallucinations, depression, feelings of loneliness	
		social problems	Social isolation, anger, and conflict	
		Spiritual problems	Anger with God, failure to perform religious rites, a sense of disbelief	
	Helplessness	Emotional	Deep loneliness, destruction of the person, destruction of life, intense anger towards disease and constant blame of oneself and those around, rupture of the family foundation after the death of a parent, feeling of helplessness.	
		Physical	Continued use of sedatives, severe fatigue	
	Untimely death	Unbelievable death	Quick death, to be shocked by death news, unexpected death	
		Failure to say goodbye at the moment of death	Prohibition of visiting the patient at the time of admission to the intensive care unit, short distance between hospitalization and death	
	Inconsolable grief	Failure to hold a grief ceremony	Unconventional grief ceremonies, absence of friends and relatives at the funeral, lack of support and consolation of close family and relatives, lack of consolation, requiring relatives participating in the funeral to observe 15 days of home quarantine	
		Absence from the moment of burial	Not allowing the presence of children and adolescents at the time of burial, not attending the moment of burial due to a family member suffering from underlying diseases, and the possibility of transmission of the disease from the deceased.	
		Desolate death	Few participants in the funeral ceremony due to the contagiousness of the disease	
	Neuroticism	Physical	Severe physical fatigue and decreased physical activity tolerance, disruption of daily life	
		Psychological	Compassion for the deceased, constant crying, non-acceptance of death, reliance on summoning the soul of the deceased to console the loss, and grief	
		Social	Isolation, avoidance of family gatherings, severe academic failure	
		Spiritual	Spiritual conflict (The contradiction between being angry with God and at the same time praying for the deceased), achieving emptiness	

it quickly, not allowing me to kiss her face for the last time, saying that she had Corona. They told us to come back tomorrow to receive the body. I could not come home from the hospital; I stayed in the hospital for a few hours. I always ask what this disease was, where it came from, and how quickly it took my mother from us. (Cries) (P4)." "My mother was in ICU for nine days, and we had no chance to meet her. We requested a visit, but they didn't answer much. They said that relatives of patients admitted to the ICU for COVID-19 are not allowed to visit. When my mother was in the hospital, we went through a difficult time. Nurses worked hard. Doctors bothered, but none of them understood us. On the ninth day, at 5 pm, they called my brother to say that my mother had died. I cried so much that night. My mind was full of thoughts about why my mother died alone with this strange disease. She supported us (her children) all the years of her life and was by our side, and now we were not by her side in the most difficult moments of illness and death. They didn't even let my brother see her face for the last time and say goodbye; they said she had COVID-19" (p 13).

Inconsolable grief

The main theme obtained was inconsolable grief, including the lack of grief ceremonies with the content of unconventional grief ceremonies, lack of friends and relatives at the funeral, lack of meeting and consolation

of family and relatives, Requiring funeral participants to undergo 15 days of home quarantine and absence at the moment of burial with the content of absence of children and teenagers at the moment of burial, absence at the moment of burial due to having family members with underlying diseases, the possibility of the disease spreading from the deceased, and finally desolate burials with the presence of very few people due to the infectious disease, and all study participants described it as a painful experience.

"No matter how much I cried, they did not let me kiss my dear child for the last time. My only son! (cries). After a year, the sadness of losing him is still fresh for me. My whole being burns in sadness. I walk like a walking dead. I always say that my son died very alone (cries severely)" (p. 14).

"The day they called me that your wife died, I was devastated. The next day, we took the body to the cemetery. I did not take my daughters to the funeral because of laws limiting the number of people attending funerals and the fear of contracting the disease. My wife died very unjustly. For my wife's funeral, I asked the funeral officials for permission to cooperate, and they accepted and said that I should observe my social distance from others for 15 days. When my daughters were informed of their mother's death, they cried profusely and I was not even allowed to hug them. It was very painful and terrible. My heart still hurts" (p 10).

Neuroticism

Neuroticism was one of the most important categories of experience including the subcategories of physical domain with severe physical fatigue content and reduced physical activity, impaired daily life, mental-psychological domain with compassion content for the deceased, constant crying, rejection of death, trying to summon the deceased spirit to comfort and grief, and in social domain with isolation content, avoiding family attendance, the severe academic failure and spiritual domain with the content of spiritual conflict (The contradiction between being angry with God and at the same time praying for the deceased) and reaching absurdity.

"I was a believer. From the day Fatima died, I have not read the Quran anymore; I have not prayed for a long time. I believe in nothing. I had begged God for years to have a child, and He had given me Fatima. In the blink of an eye, he took her from me; why? Why my Fatima? Now only when I go to the tomb I read Quran for the peace of her soul" (p. 9).

"I was very scared at first. I could not believe it at all. Now I really can't believe my dad is dead. I couldn't cry in the cemetery that day. From that day, I felt that my life was meaningless. My father's death destroyed us. I'm totally devistated. I have no motivation to study. I spend more time in my room. When I'm so upset, I cry steadily. My heart is heavy. I need to be close with someone right now, but I can't talk to my mom, my sister or my friend! I used to succeed in studying before, but now I'm a failure in education. I still think about my father every hour that passes. Why should he die? Why should we die? I'm afraid of dying. I always say, why do people have to die? If I have to die, then why should I live now? Why should I study? I am constantly sad" (p. 8).

Discussion

This study examined the CG experiences in the family of COVID-19 victims in Isfahan, Iran. Based on the experiences of our participants, incompatibility, helplessness, untimely death, inconsolable grief, and neuroticism were extracted as main categories, which, in general, formed the CG experiences of the COVID-19 victims.

In this regard, one of the main categories experienced by the families of victims of the Covid -19 was incompatibility. "Adaptation disorder" in DSM-III (The Diagnostic and Statistical Manual of Mental Disorders, 3rd edition) is defined as incompatibility to one or more stressful psychosocial factors. The disorder manifests with sleep problems, restlessness, irritability, nervousness, fatigue, anxiety, loss of concentration and isolation, severe nervousness, concern, and inability to attend work, school, or be with others (12,13). What is involved in the event of these incompatible experiences today is that the COVID-19 pandemic has had a widespread and severe impact on human life without a specified end date, offering

a complex combination of stressors and restricted access to protective and supportive sources. During this stressful and potentially traumatic time, many people are forced to adapt to new facts (14). The findings of the qualitative study of Araghian Mojarad et al also showed that most of the participants (families of the COVID-19 victims) were in shock and disbelief, loneliness, despair, and loss (15).

Helplessness is another main theme that was experienced by participants following a CG. Helplessness is one of the emotions that humans sometimes experience in their lives, and it happens when one surrenders to events and allows outside conditions to dominate their lives. In other words, it is a psychological discomfort that interferes with one's activities in daily life (16). Psychological helplessness can be based on negative views of their own, others environmental conditions. Sadness, anxiety, distraction, and symptoms of mental illness such as reduced concentration, willingness to loneliness, and isolation are psychological manifestations of helplessness (17).

The results of qualitative interviews with Hoseininezhad and Rezaeian Faraji in the study of COVID-19 victims revealed that the families of the deceased experienced feelings of futility and woefulness and thought more about death after the death of their loved one, as well as a high degree of helplessness and despair (18).

Another theme in the lived experience of COVID-19 victims' families with CG was untimely death. An unexpected and unbelievable death that was accompanied by the impossibility of being with loved ones for the last moments of life. Numerous studies acknowledge that even though grief poses a risk to mental health (19), there is a strong connection between the unexpected death of a loved one and the occurrence of several mental disorders (20). In this regard, deaths directly caused by COVID-19 appear to have a greater impact on mental health than normal deaths (21). These individuals are expected to be at greater risk of developing mental disorders or increased symptoms of separation distress, dysfunctional grief, and post-traumatic stress disorder (PTSD) (22).

Dying alone in the intensive care unit and the impossibility of visit, not being able to say goodbye to the body of the deceased due to the epidemic of the disease formed a painful and bitter experience for the participants. In a qualitative study, Hannah et al. examined the end-of-life experiences of bereaved relatives during the COVID-19 pandemic. They reported that when patients are admitted to the intensive care unit, they should have the opportunity to communicate with their loved ones in the last weeks and days of life and make a final farewell call before they die. It was a challenging issue that could not be addressed directly by healthcare providers due to the Pandemic, and maintaining the health of family members was a bitter experience for them (23).

In the CG, the inconsolable grief was another lived experience of the COVID-19 victim's family. To illustrate

this point, Stroebe and Schut, in a review study, examined the theoretical framework of grief in the COVID-19 and pointed out that during the epidemic, unprecedented actions were taken to protect community health, reduce the risk of infection, and promote safe care. These actions have had an effect not only in the normal routine of people's daily lives but also in the field of mortality, burial, and grief. Isolated care during illness, protective clothing and communication through a mask or veil and wearing a cape, often viewed from a distance, the rapid occurrence of death (often sudden and unexpected) and the last hours of life without the presence of loved ones, Burial ceremony in a limited manner and with social distancing, little chance for the bereaved to say goodbye in the usual way or to perform cultural and religious ceremonies. On the other hand, Protection from the spread of the disease has deprived the bereaved people of physical, mental, spiritual, and social support from friends and relatives. It has brought them the experience of grief in solitude and severe isolation (24). In the present study, these issues also played an important role in the difficult passage of the grief process. They led to the experience of inconsolable grief in the families of the COVID-19 victims.

Another experience of family members who lost a member as a result of COVID-19 was neuroticism, which was experienced in various physical, mental, spiritual, and social ways in a prolonged grief disorder (CG). Recent studies show an overall increase in psychiatric symptoms in the general population during pandemics (25,26). Tian et al observed an increase in obsessive-compulsive disorder, interpersonal sensitivity, anxiety, and psychosis in a Chinese sample of older people at the beginning of the COVID-19 pandemic (27). Liu et al found in a report of 898 Americans that depression 6-fold and stress disorder and PTSD 4-6-fold increased following the arrival of the COVID-19 epidemic (28). Ran et al reported an increase in the prevalence of depressive symptoms (47.1%), anxiety (31.9%), and physical symptoms (45.9%) in a sample of 1770 Chinese population following the outbreak of COVID-19 (26)

In the present study, Spiritual neuroticism was characterized by a state of constant grief in which the bereaved person was faced with deep separation, disturbing psychological feelings and disturbing thoughts about the deceased, and feelings of emptiness and meaninglessness of life. Research also shows that for a group of bereaved people who have a spiritual desire, grief can form a crisis of faith, especially at a time when their spiritual ways of experiencing, understanding, and expressing their ancient religious life and beliefs are in question. In the context of bereavement, long-term and debilitating spiritual distress, which involves the collapse or loss of a deep sense of connection to God or their community of faith, is called complicated spiritual grief (CSG) and shows an empirical relationship consistent with CG (29).

In light of the COVID-19 pandemic, images have been published of patients dying in the intensive care unit without their family members or spiritual care providers (30). This issue and other factors, such as untimely death and lack of emotional and social support in the Pandemic, can be considered as an effective factor in the experience of spiritual hurt and CG in the families of the victims of COVID-19.

Study limitations

The study's limitations were obtaining the participants' consent to participate in the research and controlling the interview conditions to sympathize with the participants.

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.

Conclusion

This study helped identify the CG experiences of the families of the victims of the COVID-19 pandemic in the form of main categories such as incompatibility, helplessness, untimely death, inconsolable grief, and neuroticism.

Therefore, the results of the present study, identifying the specific physical, mental, spiritual, and social experiences of the COVID-19 victims' families during CG, may help plan treatment interventions and accelerate their transition from debilitating and long-term stages of grief. Also, these findings can be effective in increasing our understanding of the psychological needs and anticipating potential problems of the families of victims of COVID-19 disease.

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Authors' Contribution

Conceptualization: Narges Kheirollahi, Nasrollah Alimohammadi. Data curation: Narges Kheirollahi, Nasrollah Alimohammadi, Mohammad Sadegh Abotalebi.

Formal analysis: Narges Kheirollahi. Nasrollah Alimohammadi, Hassan Babamohamadi.

Funding acquisition: Narges Kheirollahi.

Investigation: Narges Kheirollahi, Nasrollah Alimohammadi, Mohammad Sadegh Abotalebi

Methodology: Nasrollah Alimohammadi.

Project administration: Nasrollah Alimohammadi.

Supervision: Nasrollah Alimohammadi, Hassan Babamohamadi. **Validation:** Narges Kheirollahi, Nasrollah Alimohammadi,

Mohammad Sadegh Abotalebi, Hassan Babamohamadi.

Abotalebi.

Writing-review & editing: Narges Kheirollahi, Nasrollah

Writing-original draft: Narges Kheirollahi, Mohammad Sadegh

Alimohammadi, Mohammad Sadegh Abotalebi, Hassan Babamohamadi.

Competing Interests

The authors declare no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

Ethical Approval

Approval for this study was issued by the Ethics Committee of Isfahan University of Medical Sciences (ethics code: IR.MUI.RESEARCH. REC.1399.298). The participants were briefed about the voluntary nature of participation in the study and the confidentiality of the data and identity of the interviewees, and they were also assured that they could withdraw from the study whenever they wished. Then, they provided written informed consent to participate in the study.

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