

**Enclosed in the synergistic rings of suffering: The experience of conscious patients under mechanical ventilation in the intensive care unit of the causes of suffering**Fatemeh Hajiabadi<sup>1</sup>, Abbas Heydari<sup>2</sup>, Zahra Sadat Manzari<sup>3</sup>

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**Type of article:** Original**Abstract**

**Background:** Patients undergoing mechanical ventilation in intensive care units are in a special position of suffering, and discovering their experiences in the painful situations of the intensive care unit can contribute greatly to improve the quality of nursing care for them.

**Objective:** The present study was performed aiming to explain the experience of conscious patients receiving mechanical ventilation in the intensive care units of the causes of suffering.

**Methods:** This is a qualitative content analysis study conducted in Iran in 2017. Participants of this study included 15 conscious mechanically ventilated patients in the intensive care unit. Semi-structured interviews and observations were used to collect data. For sampling, first, the purposeful and then theoretical methods (guided by the created categories) were used and the procedure continued until saturation of the data. The text of the handwritten notes of recorded interviews were analyzed using conventional qualitative content analysis.

**Results:** Four subclasses of "unpleasant consequences of disease", "bitter elixir of therapy", "an inconvenient environment" and "understanding the threat to family safety and comfort" all under the general category "enclosed in the synergistic rings of suffering" were extracted from the profound descriptions of contributors.

**Conclusion:** Mechanically ventilated patients in the intensive care unit are enclosed in the rings of suffering, so that each of these rings imposes a great deal of pain and suffering on the patient and have a synergic and intensifying effect on each other. Therefore, design and application of strategies and nursing care is essential to reduce the severity of the suffering and discomfort of these patients.

**Keywords:** Intensive care unit, Mechanically ventilated patient, suffering

**1. Introduction**

Suffering as a mental experience of humans is a common phenomenon that occurs repeatedly in everyday life of every person and has a profound effect on the individual and their relatives (1). In this way, human life is full of conditions where there is a risk of suffering (2) and illnesses are the most common of these conditions. Obviously, various kinds of diseases have a degree of suffering depending on the type of disease, its severity and deterioration, and the individual's condition (3). However, mechanically ventilated patients admitted to intensive care units are in a particular position of suffering due to special and often life-threatening conditions, and due to reasons such as being in a closed and confined environment, having a trachea, medical equipment dependency, often painful procedures, etc. (4). In addition, due to having an endotracheal tube, these patients are not able to explain their suffering

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verbally. The results of the studies on these patients regarding their experiences in the intensive care unit indicate the high prevalence of distressing symptoms and experiences such as fatigue, restlessness, anxiety, sadness, hunger, fear and confusion in mechanically ventilated patients (5). For example, in a study by Almeida et al in Brazil in 2016 aiming to determine the factors leading to agitation in critically ill patients, in addition to pain and delirium, the presence of mechanical ventilation was an important factor in agitation of the patient (6). In the study by Marasinghe et al., in 2014 in Sri Lanka, aimed at explaining the experiences of patients in mechanical ventilation, internal feelings of suffering such as pain, dependence, fear, anxiety, thirst, noise, coldness and nightmares were identified as the main experiences of patients in mechanical ventilation (7). The results of study by Karlsson et al. (9) in Sweden also indicate that, in addition to shortness of breath, inability to speak was the worst experience in conscious mechanically ventilated patients in the intensive care unit (8). The desire to study the suffering of patients in mechanical ventilation is due to researcher's experiences as well as work in the intensive care unit as a nurse and instructor. During this time, the researcher saw that these patients experience a lot of mental and physical painful conditions, and the conditions of these wards are such that the potential for creating painful conditions is very high. On the other hand, most of these patients are in life-threatening conditions and require advanced therapeutic measures and specific therapeutic equipment such as mechanical ventilation. In these patients, the comfort of the patient is sacrificed for their treatment. In this regard, much distress and tension of various sources are introduced to them, so that the focus of all therapeutic teams is on improving the physical condition of the patient while paying no attention to the patient's suffering, emotions and what happens within them as a human being affected by all these pressures and tensions, and care for the suffering of the patient as the essence of nursing has been forgotten. Obviously, in order to provide complete and comprehensive nursing care for these patients, first it is necessary to identify the nature of the causes of suffering in these patients and this is achieved only by in-depth study of the experiences of these patients. In this context, qualitative research is not efficient enough and cannot examine all the obvious and hidden dimensions of the suffering of patients. This is the same assessment on the study by Kalfon et al. (9) as well as Kareshki et al. (10). In these studies, although the researchers have tried to identify the causes of discomfort in patients admitted to the intensive care unit by providing comprehensive questionnaires, taking into account the experiences of themselves, the nurses and even patients, in practice, these questionnaires are not able to determine the true causes of the patient's discomfort, and the discovery of these factors cannot be done except through in-depth interviews with patients. Qualitative research conducted in this area does not provide a comprehensive and complete categorization of all the causes of suffering, but each of which highlights a small part of the factors that make these patients uncomfortable. For example, Karin and Samuelson (11) studied understanding the patients in intensive care regarding the discomfort caused by the tracheal tube. Tembo et al. (12) also described the experiences of patients in the intensive care unit regarding communicating. Among the studies that specifically examined the suffering of these patients is the study of Zeilani (13), which examined the suffering of Muslim women hospitalized in the intensive care unit in Jordan, which a particular group (Muslim women) were studied. Therefore, due to the lack of comprehensive qualitative research in the field of suffering and its causes in the intensive care unit, the present study was designed and implemented aiming to explain the experience of conscious mechanically ventilated patients in ICU as the suffering condition.

## **2. Material and Methods**

The present study was conducted in 2017 in Iran, aiming to explain the experiences of mechanically ventilated patients in the ICU. To obtain rich and in-depth information, the qualitative content analysis method with the conventional approach was used (14, 15). The participants of this study were patients in mechanical ventilation in the intensive care unit who remembered the experience and were able to explain it. Having a minimum age of 18 and a maximum of 60 years, lack of mental illness or dementia, minimum mechanical ventilation time of 24 hours, full knowledge of Persian language, physical and mental ability, and consent to be interviewed were among the features that were considered to select participants. Semi-structured in-depth interviews were used to collect data. To this end, at the beginning of each interview, the researcher, after introducing himself and explaining the purpose of the research and requesting the contributor to explain their current health status and asking about the reason for admission to the ICU, sought to establish a friendly relationship with them and make a warm-up phase before the interview. Then, the official interview started with the question "Please tell me your memories and experiences of the time you were admitted to the ICU", and a specific question "Define your experiences of situations that caused you anger and suffering". As the study progressed, questions were given according to the main classes. For example, according to other participants' statements and mentioning some factors as the cause of suffering, the rest of the participants were asked about the same experience. In this study, 19 interviews were performed with 15 contributors, 4 of which were supplementary interviews. The duration of interviews varied from 25 minutes to 2 hours and 36 minutes in primary and secondary interviews. The location of the interviews was selected by the participants, which

included the ICU and post-ICU wards of Mashhad state hospitals, Mashhad Nursing and Midwifery Faculty, and patients' homes. In order to further validate the data, the researcher also used the observation technique to observe conscious patients in mechanical ventilation during admission to the ICU. In this way, the researcher, in coordination with the ICU authorities, attended the ward where the patient underwent conscious mechanical ventilation, and was located somewhere in the ward where the patient would be fully observed, and then began to observe and record the patient's states and reactions. The duration of these observations varied from 2 to 5 hours for each patient. The sampling was done purposefully until the data saturation progressed, so that sampling was completed when there were no new codes in the last 3 interviews as well as in the observations. To analyze the data, conventional content analysis method was used consisting of seven successive steps (16). Accordingly, and based on the steps of this method, all recorded interviews were initially handwritten. Then the text of the interviews were read several times as the analysis unit. To immerse in the data, the researcher repeatedly listened to interviews and reviewed the manuscripts several times. In the next step, designing was performed to develop codes and classes. Using the continuous comparison method greatly helped to discover the differentiation between classes. In the next step, coding was done based on the sample text. After converting a sample from text to code, the coding stability was checked. This procedure was to increase the validity of the data. In the next step, the entire text was encoded, which led to the creation of classes and the discovery of connections between them and revealing inner themes. Then, with respect to the whole data, these internal themes were reviewed (17). Several methods were used to validate the data. Using member check was one of these methods (14, 17), so that some interviews were returned to the participants after coding, and their views on the given code were collected to ensure the correctness of codes and interpretations, and the codes that did not reflect their views were corrected. Another approach was to use "External Check" as well as peer debriefing (14, 18, 19). Thus, codes and classes were provided to some of the professors of the Faculty of Nursing and Midwifery of Mashhad and their views were considered. In the present study, to maintain and observe the ethics of research, sampling and initiating the research project was performed after obtaining the approval of the project and the approval of the Ethics Committee from the relevant authorities of Mashhad University of Medical Sciences (code 922379 dated 27/4/2014). Following the selection of participants on the basis of the initial criteria, a detailed and comprehensive explanation was given to them about the goals and method of the study and their informed consent to participate in the study was obtained. They were informed about the need for recording the interviews and their consent was obtained. The participants were assured that their recordings would be kept private and no one would access the audio files, and that they would be deleted in the presence of the participant if they requested it.

### 3. Results

In the analysis process, 985 initial codes were first reduced to 67 classes by classification process, then to 23, and finally to 4 (Table 1), all below a general class called "enclosed in the synergistic rings of suffering". The four main subcategories of the study were: the unpleasant consequences of disease, bitter elixir of therapy, an inconvenient environment, and understanding the threat to family safety and comfort. These four subcategories, each form one of the rings of the suffering enclosure.

**Table 1.** Categories and subcategories extracted from the raw data

Categories	Subcategories
The unpleasant consequences of disease	Feeling helpless and sorrowful, Breathing in a difficult and unpleasant way, Communication difficulty, Insomnia Suffering, The limbo of suspension between consciousness and anesthesia, Confusion and contradiction after consciousness, Endless thirst, Lack of control over defecation, Cause of shame
Bitter elixir of therapy	Mechanical ventilation, the cause of suffering, Suffering and torment during tracheal suctioning, Distressful replacing of the sheets, Annoying diagnostic procedures, Sedative drug prescription; Continued feeling of confusion, The suffering of tied hands and feet, Exhausting exercises, The suffering of bed bath
An inconvenient environment	Noise as the cause of discomfort, Unfavorable temperature in the ICU, The ICU bed, the cause of uncomfortable feeling, The annoying atmosphere of the ICU
Understanding the threat to family safety and comfort	Feeling of shame because of concern from a family member, Unable to fulfill their duties in the family

### **3.1. Theme 1: The unpleasant consequences of illness**

Illness, critical health, and being in unstable conditions are integral parts of a patient's condition requiring mechanical ventilation in the intensive care unit, and this is what makes the patient experience the horrendous moments of life. This class represents the suffering and complications of the disease, which was expressed by the vast majority of participants in the current study that consists of eight sub-categories:

#### **3.1.1. Feeling helpless and sorrowful:**

Participants in this study introduced pain as the continuous suffering companion. A pain without relief, which its severity causes severe weakness, snatches away the relief and sleep of the patient, and redemption from it is all that the patient needs and wishes. Contributor No. 3, a 22-year-old man with a history of 20 days under mechanical ventilation says: "There, I always thought of my pain. I was awake most of the time, at night until three or four o'clock, I could not sleep because of much pain. I asked for painkillers again and again and when I received them, I had so much pain that it was not effective anymore." P3

#### **3.1.2. Breathing in a difficult and unpleasant way:**

Among the causes of suffering that the participants described as the terrible ICU experience was breathing in a hard and unpleasant way to the extent that they wished for death in order to escape the torment. A 35-year-old female participant with a history of 35 days under mechanical ventilation said: "when I felt very bad and I was breathing so hard, ... I was breathing like this, ... I remember it very well. Then by the second breath I was suffering so much that I wished for death. It was so much painful."

#### **3.1.3. Communication difficulty:**

Connection to mechanical ventilation, weakness, lethargy, dizziness and drowsiness are among the main reasons for the patient's difficulty to use verbal communication in mechanical ventilation to express their needs, to offer the correct information to their doctor and talk to others so that many participants introduced the disability as their main problem in the ICU. Along with the inability to speak, severe weakness of the hands that impeded the use of writing techniques or hand gestures for the expression of needs, as well as lack of familiarity with lip-reading technique between the patient and many personnel, blocked all channels of expressing the needs that led to failure to understand the patient's gestures or misinterpret them. This situation made the patient agitated and distressed, causing such feelings as stress, insensitivity, helplessness, inefficiency, worry and anxiety, and created extremely difficult conditions for the patient. "When they tied my legs, for example, I wanted to tell them not to do it. I tried to talk, but no voice came out. I was so tormented that I could not say it to them. Why can I not make them understand? Or, for example, that my legs hurt. Then they changed the position after two hours based on routine" (a 35-year-old female participant with a history of 35 days under mechanical ventilation).

#### **3.1.4. Insomnia Suffering:**

Too much noise in the ICU, severe pain without relief, distressing thoughts and severe discomfort were among the factors that made the condition of the intensive care unit unfavorable for a comfortable sleep that caused nervous pressure, weakness, confusion, energy depletion and lethargy during the improvement process. "In the twenty days when I was in the ICU, I did not sleep at all. That is, except for just two or three hours a day, and under much fatigue. I could not sleep in the ICU, because in normal days I'm sensitive to sound and light. I had pain too. The condition of my body was severe. There I could not sleep well and it was suffering. I mean when I was in the ICU" (a 28 year old woman with a history of 19 days under mechanical ventilation).

#### **3.1.5. The limbo of suspension between consciousness and anesthesia:**

One of the difficult and painful conditions that patients undergo in mechanical ventilation for several reasons including the treatment process, frequent prescription of sedative sleep drugs, as well as possible conditions such as hypoxia, hemodynamic, acid and base disorders, are the fluctuations between consciousness and anesthesia. Contributors cited experiences like painful dreams in which death and dying nightmares, feelings of falling into a heavy, terrible and inexhaustible sleep add to the suffering of a sick person: "It was a state that I knew I was in hospital, but I thought I was captured by some people. I wanted to run away from there. All that while I was anesthetized it was as if I was fighting all the time, so that I could try to escape somehow. I was planning in my mind. I thought I had to escape. I thought the place was somewhere out of town and far away from it". (a 35-year-old woman with a history of 35 days under mechanical ventilation).

#### **3.1.6. Confusion and contradiction after consciousness:**

Usually, many patients requiring mechanical ventilation are not conscious at the time of attachment to the device, so they are confused and sometimes anxious after they come to their senses and see themselves under mechanical ventilation and having different tubes and catheters. They are unaware of the events that have happened to them during the anesthesia and cannot understand the behavior and speeches of the people around them and their reactions to their condition and become confused and contradictory: "Suddenly I saw my mom come up in a very good mood. She said: My dearest girl, I love you. She kept laughing. She said: Do not be upset because you are in a very good

condition. But I thought: God! Now I am feeling so bad, I cannot talk at all, I cannot move, like a piece of meat. Why is my mom behaving like this?" (35-year-old female with a history of 35 days under mechanical ventilation).

**3.1.7. *Endless thirst:***

An extreme thirst and a ban on drinking water through the mouth due to having an endotracheal tube has caused the suffering of such thirst to be a bitter and unforgettable memory of the time of admission to the intensive care unit for patients. "I was thirsty. I asked for a little water. They would not give me the water. Just a little distilled water, for example, that which is used for injection. They opened it and gave me two drops and no more. They gave me two drops just to wet my tongue and that was all. It was like showing water to a thirsty person and then keeping the water out of reach. It felt like that. Each time I told them to give me a little water, they said it was not good for me" (a 33-year-old male participant with a history of mechanical ventilation for 32 days).

**3.1.8. *Lack of control over defecation, cause of shame:***

Motionlessness, attachment to a mechanical ventilation device, weaknesses, and so on, are the reasons why patients in mechanical ventilation cannot handle their bowel movements. Participants in this study stated that although in many cases they were able to detect the need for defecation because of alertness, for reasons such as the inability to interact by verbal communication as mentioned above, they were unable to express it to the personnel and ask them for help and for reasons such as weakness and inability to lip-read, etc., they were unable to make the personnel understand their need. Sometimes, when the personnel became aware of their need, it was too late and the bed sheets were soiled. Though this was beyond the control of the patient, the obscenity in the mind of the patients imposed a great deal of shame and embarrassment on them to the extent that caused them to cry and grieve. This feeling of shame and discomfort was so much that some contributors remembered it a long time after discharge and felt embarrassed to recall it. "I even remember once when I was anesthetized. I remember it well that even in the moment of unconsciousness I wanted to control myself to prevent it, but I remember that it happened. Then I was very upset. It was so awful. 'Why should it happen?' I thought. After that, I wanted to cry all the time because I was so sad. ... I could not say anything. I was very upset. I was really embarrassed." (a 35-year-old woman with a history of 35 days in mechanical ventilation).

**3.2. *Theme 2: Bitter elixir of treatment***

Another of the patient's enclosing rings of suffering is a series of therapies in the mechanical ventilation that, although it is unavoidable to use them due to the patient's illness, most of them are invasive therapies and impose much suffering and distress on the patient along with their vital nature. Connection to the mechanical ventilation device, suction, gastric catheter, bed bath, changing bed sheets, frequent prescription of sleeping drugs, hand and foot closures, exercises and most importantly, repeated and numerous diagnostic procedures are cases that patients undergo in mechanical ventilation. They recall them as bitter treatments that attack the patient's ease and comfort, and each will be discussed in the following.

**3.2.1. *Mechanical ventilation, the cause of suffering:***

Participants described the suffering and difficulty of being in mechanical ventilation with terms such as sleeping disability, inability to speak, throat irritation, extreme thirst, dryness of the lips and mouth, and breathing difficulty. In addition, complications associated with having a trachea tube including tiredness of the tubes, stretching of the tubes, throat irritation, inability to swallow water, having high discharge and fear of permanent disability in speaking also form the unpleasant experiences mentioned by the patients. Moreover, the idea of being mechanically ventilated as a sign of being close to death also sparked fears. "It's really hard. It's so painful. You cannot swallow your saliva. You cannot... well, a foreign object is in the lung. It's too painful to be in your mouth. Because I had seen other patients and I did not expect to have it myself, for the first four or five days, believe me, there was not a moment when I did not cry, because I did not expect it." (a 22-year-old female with a history of 17 days in mechanical ventilation).

**3.2.2. *Suffering and torment during tracheal suctioning:***

Tracheal suctioning is an experience shared by all participants in this study, which is one of the most painful experiences in the ICU. A feeling of nausea, feeling of death, inability to breathe, choking feeling, severe pain, wounds in the mouth and throat and the feeling of lungs being drawn out of the body, were the emotions mentioned by the participants followed by tracheal suctioning. "Especially this suction... They did it when I was... very sick in the first day, they started to suction when I felt very bad. I was so annoyed with the suction. The pain was too much. May God prevent it from happening to anyone else! I felt I was going to die. I felt myself very close to death and I felt I was dying. At one moment, I felt like my soul was leaving my body" (a 35-year-old female participant with a history of 9 days under mechanical ventilation).

**3.2.3. *The suffering of the prohibition of eating:***

Restrictions on food intake and the necessity for gavage created hardships for the patient, and participants in this study mentioned sufferings such as inadequacy of gavage in satisfying the severe desire for food, difficulty and suffering created by the gavage, pain and discomfort caused by catheter and regret and craving to eat through the mouth. "I really disliked feeding through the tube. Sometimes I felt nauseous. I did not vomit, but I felt I was going to vomit. It was hard to eat something through the nose. Gavage made me feel very bad" (a 22-year-old woman with a history of 15 days under mechanical ventilation).

**3.2.4. *Distressful replacing of the sheets:***

In the patients under mechanical ventilation, due to inability to leave the bed, the bed is prepared while occupied by the patient. Since the patient is attached to a mechanical ventilation device, tubes, connectors and catheters, their chances of being drawn and causing pain and the discomfort of the connected devices being stretched during the process of replacing the sheets are very high. Furthermore, since weakness, hard breathing and anxiety prevail over the patient, they do not have the power of the slightest movement, and while being moved during replacement of the sheets, it is difficult to tolerate it so much so, that some contributors describe this difficulty as being breathless like swimming upstream. "Because there were a lot of things connected to me, and on this side I was connected to a chest tube, and serum and many things were connected to me.... when they came to change the sheets, it was very hard for me. I remember once my chest tube was pulled out and it was very painful. When they wanted to change the sheets, it was very difficult for me. I became breathless. It was like swimming upstream." (a 35-year-old woman with a history of 35 days under mechanical ventilation).

**3.2.5. *Annoying diagnostic procedures:***

Several different diagnostic procedures used in the intensive care unit, which are mostly invasive and create severe pain and discomfort, caused fear and anxiety about the complications of each of them and increased discomfort. "One day they came and said that I needed to do an LP, but I said I will never agree to it. I wrote that I would not let them do it. They asked why and I said I was afraid of it" (a 47 year old male with a history of 15 days under mechanical ventilation).

**3.2.6. *Sedative prescription; continued feeling of confusion:***

Sedative prescription is one of the measures used in the intensive care unit to manage the anxiety and pain of patients, but confusion and sometimes forgetfulness in the patient make the therapeutic procedure an annoying factor. "It was very hard for me because I just could not stay awake. I could not keep my eyes open because of the effects of the anesthesia... Anesthetic drugs. Then there were a lot of unpleasant feelings like forgetfulness". (a 35-year-old female with a history of 35 days in mechanical ventilation).

**3.2.7. *The suffering through tied hands and feet:***

Tied hands and feet and movement limitation is one of the common measures in patients with mechanical ventilation. This action, however considered by the staff to be absolutely essential, many participants have described it like a torture. "Then they came and tied my hands. I thought to myself that they had forced me into a small place so that I could not move at all, like a single cell where you can only sit. I felt so because my hands were tied. My legs were also completely tied and I had no control over my body" (a 52-year-old male with a history of 13 days in mechanical ventilation).

**3.2.8. *Exhausting exercises:***

Physical recovery in patients in the ICU requires exercise and physiotherapy, which with all its benefits, is demanding for the patient, and the participants complained about the exhaustion of the heavy exercises and breathlessness after them. "The physiotherapist told them to tie some weights on my legs, and then they made them heavier. I lifted my legs up and brought them down. Then I was tired because of them. The exercises for my legs were very exhausting for me. I could not do it at all. I soon became tired. I became breathless and I breathed with difficulty and I could not move my legs" (a 35-year-old female with a history of 35 days in mechanical ventilation).

**3.2.9. *The suffering of bed bath:***

Bed bath is another care measure used in patients of mechanical ventilation in the ICU and the patient is compelled to tolerate it because of inability to leave the bed. Feeling choking during bed bath is especially reported by participants who have been in a semi-conscious state. In addition, the feeling of chill and extreme cold following this procedure was one of the things that the participants referred to as the factors of creating a sense of adversity during bed bath. A contributor described the feeling of choking sensation in the bathroom as follows: "There they washed me. Patients were washed on the bed. Once I felt they had put me into the water. Like a pool or something. I felt like I was choking. Suddenly I came out of the water. I thought I was getting wet. I later realized that they were bathing me." (a 35-year-old woman with a history of 35 days in mechanical ventilation).

### **3.3. Theme 3: Unpleasant environment**

The physical and psychological atmosphere of the ICU creates special conditions and turns it into a different environment than other wards of the hospital. The noise, the inappropriate temperature, the ICU bed, and the mental atmosphere governing the ICU are among the main causes of the unpleasant environment mentioned by the participants in this study, each of which will be described in the following.

#### **3.3.1. Sounds as the cause of discomfort:**

The presence of a large number of personnel in the ICU, the use of devices with multiple alarms such as monitoring and mechanical ventilation devices, infusion pumps, etc., the traffic of the various members of the treatment team including the physician, physiotherapist, and nutritionist, as well as long and noisy visits, create a noisy and uncomfortable environment in the ICU. Feeling angry, cluttered, suffering, psychological stress, feeling sick and an inability to sleep are among feelings that the participants mention in the crowded and noisy environment of the ICU. "They made a lot of noise. My nerves were so weak and I felt so bad that I was not able to tell them to be quiet. I could not tell them that with all the noise they make, I cannot be calm. I could not be calm because of my condition, then your noise makes it worse. Then I became cluttered and asked myself why they make so much noise? Think about what kind of psychological pressure I had, but I could not tell them to be quiet for God's sake" (a 22-year-old female with a history of 30 days in mechanical ventilation).

#### **3.3.2. Unfavorable temperature in the ICU:**

Extremely hot or cold ICU temperature were reported by contributors as a cause of discomfort in the ICU. Contributors mentioned feelings of intense heat like the feeling of being in hell, and the sense of death from the severity of the cold, the exacerbation of pain after shaking from cold, and the fear of extreme cold. "It was very hot there. It was like hell. I told them to turn it off, to make it a little cooler. There was a window in the room, and I told them at least open the window for some fresh air" (a 33-year-old male with a history of 32 days in mechanical ventilation).

#### **3.3.3. The ICU bed, the cause of uncomfortable feeling:**

The ICU bed with its wavy mattress, although is very useful for preventing ulcers, it causes uneasiness and lack of comfort for the patient in mechanical ventilation and cases such as continuous glide on the bed cause the inability to sleep comfortably and deterioration of the comfort of the patients. "They came to pull my body up the bed, because I had slid down the bed. My bed was somehow upright and it slid down. I kept telling them to pull me up." (a 35-year-old woman with a history of 35 days in mechanical ventilation).

#### **3.3.4. The annoying atmosphere of the ICU:**

Separated environment, unfamiliarity and exotic nature of the environment and its equipment along with the presence of critically ill patients and the observation of their death were among the sad and annoying atmosphere of the ICU that created feelings such as sadness, constant discomfort, restlessness, frustration of survival and loneliness in patients. "...and that the ICU was a gloomy place with an unhappy environment. It was grieving. It was annoying. I felt lonely there. It was strange. It felt sad in there. I was sleeping all the time. I was confused. I did not understand what everyone was doing. Everyone was busy with themselves. You did not know what was happening and who the other people were." (a 27-year-old female with a history of 7 days in mechanical ventilation).

### **3.4. Theme 4: Understanding the threat to family comfort and safety**

Patients admitted to the ICU were unable to fulfill their duties in the family, because of their condition whether as the father of the family to pay for living expenses, as the mother to fulfill the mother's role, as a spouse or as a child. In addition, hospitalization also causes concern among the other members of the family and this causes a feeling of shame in the patient. "You know, I was just thinking of my wife and children. I asked myself what they would do if I died. Now that I cannot make money, how are they going to make money? Will they have anything to eat? These were my worries". (a 33-year-old male with a history of 32 days in mechanical ventilation).

## **4. Discussion**

The present study showed that patients in the intensive care unit are enclosed in the synergistic rings of suffering. According to the participants, the most important rings of this fence are the unfavorable consequences of the disease, the uneasy environment, the bitter elixir of treatment, and the perceived threat to the security and comfort of the family, each of which involves a series of factors that cause the suffering. These results are in line with the results of all the studies that have been conducted to investigate the causes of suffering and to discover the experiences of patients admitted to the intensive care unit. In her study, Zeilani (13), examined the experience of the suffering of Muslim women in an intensive care unit in Jordan, the suffering of these patients has been highlighted in terms of physical, social, psychological and suffering from intensive care unit technology. In the study by Zeilani, participants reported often severe, intolerable pain that prevented sleep as the most prominent experience of the

intensive care unit. The researcher said that the lack of familiarity with the intensive care unit, the sudden onset of illness and the uncertainty, caused the patients to be unable to interpret their experiences. In the present study, pain and suffering as one of the components of the ring of the unfavorable consequences of the disease were among the most important experiences of patients. In addition, the unfamiliar environment of the intensive care unit was also a subclass of the main class of the ring of uncomfortable environment. Contrary to Zeilani's study, the factors causing suffering in the present study were classified according to the source of suffering, while in Zeilani's study; the classification was according to existential dimensions of the human being. However, the title "suffering from ICU technology" like the present study, is based on the source of suffering. Classification based on source by highlighting the suffering factor, can be more useful and more effective in designing strategies to reduce patient suffering. One of the main points of the present study is that by carefully studying and conducting interviews with key contributors, a large number of factors causing the suffering of patients in the intensive care unit were identified and classified. Such wide and applied classification was not found in any similar studies.

The results of the study by Karlsson et al. (8), which examined the living experiences of adult patients who were conscious during mechanical ventilation showed that, apart from shortness of breath, inability to speak was considered as the worst experience. The discomfort and pain of the tracheal tube was also remarkable. In the present study, difficulty in breathing has also been mentioned as a bitter experience in the ICU and as well as this, the inability to speak was mentioned as the foremost of the patients' problems. Similarly, the pain and discomfort of the endotracheal tube was cited as one of the main and intolerable causes of suffering. However, Karlsson and Forsberg (20) in a separate study of patients in mechanical ventilation, reported very little noise of alarms and the like, which is inconsistent with the results of the current study. Other studies in this area include the study of Holm and Dreyer (21) in Aarhus, which examined the experiences of conscious mechanically ventilated patients having a tracheal tube. In their study, experiences such as having a tube in the throat, consciousness and confusion were reported in these patients. These experiences are similar to those reported by patients in the current study. The important point is that the study of Holm and Dreyer has highlighted the difficulty of having an endotracheal tube, while in the current study, all problems and causes of suffering and discomfort have been studied. Samuelson (22) has classified the unpleasant experiences of patients as physical, emotional, perceptual, environmental distresses, and care-related stresses, which is roughly the same as the classification of Zeilani for the causes of suffering, which has been in terms of the dimension of the person's character affected by distress. The strength of the above study is that, like the present study, it examined all the causes of discomfort. However, like Zeilani's study, it presented a different classification of the causes of suffering than the present study. Karin and Samuelson (11) investigated the understanding of patients in mechanical ventilation as a cause of endotracheal tube discomfort in a separate study, and indicated that 88 percent of patients reported moderate to severe discomfort. This is one of the studies focusing on only one component of the discomfort in the ICU, which is the discomfort of the endotracheal tube, unlike the present study that comprehensively examined all the causes of suffering. In any case, both studies have cited the suffering and discomfort of the tracheal tube as one of the suffering ICU experiences. Kalfon et al. (9) identified the most important causes of discomfort in the ICU, as sleep deprivation, being restricted by wires and catheters, pain, thirst, anxiety and noise. Although, the factors mentioned by these researchers are similar and in line with the causes of suffering in the present study, the factors obtained in the present study have been achieved through a qualitative study and in-depth interviews with the participants; therefore, they are much more comprehensive and the classification is more extensive and functional.

This study, identified thirst as one of the causes of suffering in mechanically ventilated patients. Kjeldsen et al. (23), also mentioned thirst as one of the most important causes of suffering in mechanically ventilated patients, accompanied by feelings such as different perceptions in the mouth, deprivation of the opportunity to quench thirst, hardship associated with thirst and extreme thirst.

In general, the present study characterizes the suffering and painful situations in which the patient in mechanical ventilation in the ICU experiences. The conditions in which the inevitable causes of suffering are imposed on the soul and the body of the patient and excite each other. On the other hand, the nature of the disease, which is acute and high risk, is the reason for the patient's admission to the ICU and the patient is in a very distressed condition. To maintain the life of such a patient in such a poor condition requires the most invasive therapeutic techniques that despite their vital nature, are the bitter elixir hurting the patient's throat. Such an ill patient, who is being treated with painful and terribly aggressive therapies, is forced to stay in an uneasy and stressful environment where the sound of alarms and people, the high traffic of the personnel and so on, deprive the patient of comfort and peace. The feeling of shame is the worst suffering because of hardships that the family of the patient face after admission.



## 5. Limitations

One of the limitations of the current study was that oblivion in mechanically ventilated patients is a burden on the patients admitted to the intensive care unit. Particularly, patients undergoing mechanical ventilation and most people, especially those who deal with patients believe that mechanically ventilated patients in the intensive care unit are not able to remember the ICU events and forget about almost all the events. Although this is true for a large percentage of these patients, countless patients remember these events well and can recall them in detail. In any case, to further validate the data, the researcher used the observation technique to observe conscious patients in mechanical ventilation during admission to the ICU.

## 6. Conclusions

The results of this study indicate that mechanically ventilated patients in the intensive care unit are enclosed in suffering rings, so that each of these rings impose a great deal of pain and suffering on the patient and have synergistic and exacerbating effects on each other. On the other hand, among the causes of suffering, there are many moderating factors. Therefore, planning for the design and application of some strategies and nursing care can reduce the severity of the suffering and discomfort resulting from these factors, and thus improve the quality of care of the suffering and painful patients of the intensive care unit.

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## Conflict of Interest:

There is no conflict of interest to be declared.

## Authors' contributions:

All authors contributed to this project and article equally. All authors read and approved the final manuscript.

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