

Perceived Nurses' Ethical Challenges in End-of-life Care for Patients with COVID-19

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ABSTRACT

COVID-19 pandemic has caused many ethical challenges in the health system and since one of the most challenging aspects of nursing is end-of-life care for patients, ethical challenges in caring for the dying during the COVID-19 pandemic is unknown. This study aimed to understand the ethical challenges perceived by nurses in end-of-life care for patients with COVID-19. In this qualitative study, in-depth semi-structured interviews were conducted for data collection and conventional content analysis method was used for data analysis. 18 nurses who wished to participate in the study were selected by purposeful sampling and shared their experiences in the field of ethical challenges of end-of-life care for patients with COVID-19. This study was conducted in two training hospitals of COVID-19 Center in Lorestan, Iran and collected and analyzed data since December 2020 to June 2021. This study has five main themes and 19 categories. The main themes extracted included disregarding the human dimension of care, immature organizational process, unfair end-of-life care, increased uncertainty in treatment-care processes, accelerated job burnout, and disregarding solutions. This study provided a clear picture of the ethical challenges experienced by nurses providing end-of-life care for patients with COVID-19 and can improve managers' understanding of nurses' Ethical challenges in this field, supportive and educational planning and adopting appropriate leadership styles. It is suggested to use the interventions reducing the nurses' ethical challenges in future studies as a new approach.

Keywords: Nurses; Ethics; Terminal Care; COVID-19; Qualitative Research

Introduction:

One of the most challenging fields of nursing care is end-of-life care, which is considered stressful and painful process [1]. Observing patients' daily suffering, their family reactions and internal conflicts to select the best treatment and care strategy are among the ethical challenges in this field [2].

Providing high-quality palliative and end-of-life care is one of the most important dimensions of health organization responses, both nationally and globally, in response to epidemics [3]. The crisis of COVID-19 pandemic has put considerable pressure on the healthcare system in Iran [4]. Nurses have always played an important role in the prevention and control of infection, isolation,

and public health, and they are even risking their lives by serving at the frontline of the fight against COVID-19[5]. A study on nurses' work stress found that nurses endured a lot of workloads that is directly related to their stress and anxiety, and can finally lead to job burnout and decline in nursing services in that sensitive situation [6]. The presence in an unfamiliar workplace, exposure to diseases, lack of personal protective equipment, growing fear of infection, and lack of caring experience for patients have all made the COVID-19 pandemic a challenging ethical condition for nurses [7].

The ethical challenges that nurse experience in COVID-19 wards included negligence

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regarding patients' rights, lack of emotional support for patients, inappropriate response to emergencies due to fear of infection, and lack of necessary knowledge and skills [8]. In intensive care units (ICUs), lack of evidence-based practice, high burden of responsibility, social isolation, lack of personal protective equipment and fear of infection, changing protocol, and restricted family visits especially in end-of-life care, made ethical challenges the dominant feature and determinative phenomenon of the COVID-19 pandemic in all aspects of nurses' lives [9, 10]. These ethical challenges have destructive consequences, including feelings of fear, anxiety, insomnia, irritability, and damage to nurses' mental health. On the other hand, growing uncertainty in decision-making as the engine of ethical challenges is an inseparable part of the the COVID-19 pandemic [11].

The first step in planning and improving service delivery in the health system is to recognize the challenges and problems caused by the COVID-19 pandemic. The severity of ethical challenges in end-of-life care varies in different societies, and the diversity in this field is mostly influenced by the cultural, social, and religious differences in the studied society [12, 13]. Considering the different perceived ethical challenges in the care of patients with COVID-19 mentioned above, the newness of this disease, and the ethical challenges in the end-of-life care of these patients have not been identified. Although end-of-life care is a challenging issue for nurses, the outbreak of this emerging disease has caused new and more complex challenges. Therefore, to better understand this issue, it is necessary to conduct a qualitative study to explain the dimensions of ethical challenges in end-of-life care of patients with COVID-19. Nurses have a unique position in providing health services [14]. Therefore, explaining the ethical challenges arising from the human nature of this profession is necessary.

Objective: This study aimed to understand the ethical challenges perceived by nurses in end-of-life care for patients with COVID-19.

Materials and Methods

This study, used a qualitative approach and conventional content analysis.

The study inclusion criteria were providing end-of-life care to patients in COVID-19 wards; tendency to express experiences, and informed consent to participate in the study. The exclusion criteria included an unwillingness to continue to participate in the study.

First, semi-structured interviews with open-ended questions were used for general recognition, in which participants were encouraged to share their experiences with the ethical challenges of end-of-life care. They were first asked to explain one day of end-of-life care to the patient. Then the interview continued with questions, for example, "What are your perception of ethical challenges?" and "Please describe your experience of the ethical challenges in the end-of-life care for the patients." The questions then focused on the perceived challenges in caring for patients with COVID-19. In this study, the Elo and Kyngäs content analysis method [15] and Lincoln and Guba's criteria, as quoted by Shenton [16] (see Table 1), were used for data analysis and rigor, respectively.

According to Elo and Kyngäs, the steps of qualitative content analysis include open coding, code indexing, grouping, categorization, and abstraction. All interviews were considered coding analysis units and words, sentences and paragraphs from the interview texts were considered semantic units. The related semantic units were then placed next to each other in terms of the main content and labeled as codes. The whole text was revised after coding, and the codes were compared in terms of similarities and differences and categorized into categories and sub-categories with a more abstract label. After careful and deep reflection on the categories and comparing them with each other, the latent content of the categories appeared as study themes.

□

Table 1: Lincoln and Guba's criteria to ensure the rigor

Credibility	The following provisions were made by the authors to promote credibility: prolonged engagement between the researcher and participants, frequent report sessions between members of the research team, peer debriefing of the research project, and member checks.
Confirmability	To increase confirmability, the methodology of this study is described in detail.
Dependability	For this purpose, the present study provided a detailed report with full information of the process and methodology so that the external evaluators (two expert faculty members in the field of nursing ethics and qualitative studies as internal research referee and two expert faculty members from other universities in the field of qualitative studies as external research referees) could audit the research
Transferability	The details of the research process have described properly. For this purpose, the report was intended to be information-rich and accurately describe of the context of the study. In addition, the sampling involved maximum variability (based on gender, location, age, etc.) To achieve a broad range of perspectives and experiences and make a sound judgment about transferability for the participants

Results

In this study, after interviewing the 15th nurse, data saturation was reached; however, another three interviews were conducted, in which no new data appeared. All 18 nurses participating in the study were female with mean age of the 32.25 ± 8.2 years, %66.7 married, and 62.5% of them had a master's

degree. The working experience of these nurses varied from 3 to 15 years, except for one person; the rest worked rotating shifts. Half of the nurses in this study were in ICU-COVID-19 wards and the other half in other wards provided end-of-life care for patients with COVID-19. A total of 256 codes were obtained from the data analysis, which finally appeared in 22 categories in the form of six themes (Table 2), which are explained below.

Table 2: Summary of Themes and categories

Disregarding the human dimension of care	Ageism Oppression Lack of unconditional care
Immature organizational processes	Vertical violence and unfair division of labor Poor teamwork Feelings of being ineffective
Unfair end-of-life care	Reducing the quality of care Inability to provide timely services Futility of care Increased missed nursing care Disruption of the family-centered care Reluctance to give bad news
Increased uncertainty in treatment-care processes	Complexity and ambiguity of the treatment process Decision to discontinue or continue treatment Changes in care standards Discontinuation of treatment due to lack of supply or shortage of drugs
Acceleration of job burnout	Anxiety caused by the death of the patient due to lack of facilities Rumination Frequent exposure to the concept of death

Disregarding the Human Dimension of Care

Nurses witness behaviors on a daily basis, including object-oriented perceptions of patients, presumption of end-of-life patients as dead, and frustration with treatment. In addition to all these cases, the heavy burden on the treatment system due to the COVID-19 pandemic leads nurses to believe that the human dignity of patients, which is a large part of the concept of human care, is not preserved.

Ageism

Discrimination in the treatment and care processes based on age is one of the types of inhumane behaviors in the health care system.

"Sometimes we are faced with the challenge of whether we should separate our end-of-life patient from the ventilator and connect a younger patient to the ventilator, who is more likely to survive." (P3)

Oppression

Infectious diseases, hospitalization in wards where family visits are generally prohibited, and end-of-life patients' lack of treatment choices are special conditions that lead to a reduction in patients' authority.

"As a nurse, I'm really upset when I see that the patient's rights are being violated, both legally and in terms of care. I'm really upset when I see unprotected end-of-life patients because of the disease and unconsciousness." (P5)

Lack of unconditional care

With the knowledge of the ways of transmission of this emerging disease, speculations about the guilt and/or innocence of patients have intensified. Since the past, different causes of the disease have been related to the patients, although new conditions such as irreparable damage, death, psychological damage, increasing the costs of the health system, and finally harm to all members of society due to non-compliance with health protocols exacerbate the social stigma of the disease. The fact that individuals' judgments affect patients' treatment processes is one of the ethical challenges nurses faces.

"I don't think some nurses treat patients with COVID-19 well. The patient needs care now, he needs support, how he got it, where he was or whatever, does not help me or my patient. We have no right to humiliate the patient like this" (P2).

Immature Organizational Processes

Vertical violence and unfair division of labor

This challenge is mainly faced by novice nurses. In addition to the care role they play, nurses coordinate the implementation of treatment programs as well as ward management. This exposes the nurses to many activities. Meanwhile, unfair division of labor, leads to increased workload and a sense of inefficiency and no sense of belonging to the medical team for novice nurses, most of whom have entered the healthcare system during the COVID-19 pandemic and its challenges.

"In ICUs, especially when there are many end-of-life patients, the work gets really heavy because I am a novice is no reason for me to take care of most of the patients in the ward... I provide better care instead of just running until the shift is over if the distribution of patients is fair." (P1).

Poor teamwork

In the event of a crisis in the healthcare system, nurses are pressured as frontline healthcare providers.

"Sometimes, when there are too many patients, none of my colleagues help me. I understand that they are also doing their job, but I think if this help is between the colleagues, the atmosphere will be better, our relations will be more friendly and sometimes when you need help, you feel calm and you know there is someone who can help you." (P11).

Feelings of being ineffective

This crisis has led to the highlighting of its shortcomings. The extensive care needs of end-of-life patients, followed by an increase in the workload of nurses, which despite shortcomings of nurses' care and organization, caused a lack of power and motivation to make fundamental changes.

"I'm alone with all end-of-life patients. I cannot do anything to improve my system. I think I like to provide good care. My care is effective, but I feel it's no use. Because one cannot be effective with this volume of end-of-life patients." (P13).

Unfair End-of-Life Care

Reducing the quality of care

During the COVID-19 pandemic it is evident that nurses were not satisfied when assessing the quality of care internally and reported a reduction in the quality of their care, which has no consequence other than the emergence of various mental concerns.

"It is right to spend time for the patient, to care for him and to take care of him. However, no matter how much we adhere to ethical principles, there is so much work that it cannot be done. Sometimes I am not satisfied with the quality of my care, but there is no way out" (P14).

In some cases, patients with end-of-life care should be admitted to general wards, where the number of patients is high, the number of nurses to patients is low, and there are no facilities for intensive care. Meanwhile, nurses face many care needs, along with a shortage of nurses. Obviously, it is impossible to fully meet these requirements under the above conditions.

Inability to provide timely services

From the beginning to the end of a shift, end-of-life patients face many care needs and life-threatening conditions; however, the rate of therapeutic responses reduces, and the routine or specific treatment needs of each patient are not fully addressed.

"When the staff number is low and the workload is high, it becomes difficult to provide good and proper care. Sometimes patients are so ill together that even in critical situations it takes a few minutes to reach them." (P17).

Futility of care

When the end result of treatment and care only leads to keeping patients alive without maintaining their quality of life, nurses' perception of care as a dynamic process change

to futile practice without the desired effectiveness.

"In my opinion, a number of procedures that are performed for the end stage patient are not really necessary and only torment the patient. For example, the patient that we know will not return, why do we test him repeatedly or inject plasma? This hurts both financially and humanely. I had a patient who died, and after death his test results were available. This situation upsets his family. Why did we do something to hurt him until the last moment?" (P15).

Increased missed nursing care

Unfortunately, owing to the collective incidence of individuals in each wave of disease prevalence, nurses are required to prioritize the care needs of patients. This causes some care to be either ignored or not performed continuously. In this situation, nurses' minds turn to the question of whether neglecting care is an ethical function. Is it possible to think about completing the care process of all patients in situations where their lives are in danger?

"The important end-of-life care for a patient is emotional and spiritual care, both for himself and his family. I think my care in this field is inadequate for the patient and those around him. Honestly, sometimes I get confused in this case" (P18).

Disruption of the family-centered care process

COVID-19 nature has caused the medical personnel to prevent the presence of the family on the patients' beds to maintain the health of society, which has led to ethical conflicts and bottlenecks for nurses. On the one hand, patients' families are eager to participate in care, and on the other hand, the provision of this care coincides with a threat to the health of society.

"The fact that you have to face the families of patients every day that you know patients may not be alive, but you cannot let them in to see it really hurts. The contagious nature of this disease has made patients deprived of visits." (P7).

Reluctance to give bad news

Nurses have an inner desire to conceal facts, hide part of the truth, or create false hope when giving the patient's history to their family by observing the pain and suffering of hearing bad news. Although most nurses suppress this inner desire and feel compelled to tell the truth, they may not function well in establishing a proper therapeutic relationship solely to report bad news. In fact, there was a combination of do's and don'ts in dealing with patients' families before the current pandemic. In addition, the special conditions resulting from this pandemic and the lack of training of nurses to deal with the current situation led them to think about whether they have had a useful performance in this field. Has the nurse been able to convey the truth without further exacerbating the patients' suffering or have they themselves exacerbated the emotional pressures of the patients' families?

"There are times when the family wants to hear a hopeful word from a nurse. We also like to make their families happy, but we can't. Sometimes, when I want to tell the news of the patient's death or anything bad, I like to escape from that situation. Sometimes I think I cannot speak well or my behavior may hurt them more." (P10).

Increased Uncertainty in Treatment-Care Processes

Complexity and ambiguity of the treatment process

As an emerging disease, COVID-19 had a vague treatment process. However, with the onset of the disease and the end-of-life stage, treatment cannot be stopped until the effectiveness and side effects of drugs are determined. Therefore, nurses are faced with uncertainty in treatment plans and see that patients' treatment processes are frequently changing. Due to the rapid spread of the disease and the lack of medical personnel in the current crisis, in addition to adhering to health protocols, they recommend reducing the time spent at the patient's bedside; therefore, some care standards have changed.

"One of the problems is that because it is not yet clear exactly which drug has a better effect, the number of drugs used for patients is increasing. For example, two or three months ago, patients were taking a number of drugs, but now they are taking vitamins, painkillers, and a number of new drugs. You do not know much about the effects of these drugs and you do not know whether the treatment of the disease will change again later or not, and the complex treatment program of patients with end-of-life care makes you not very sure of your work." (P8).

Decision to discontinue or continue treatment

When patients enter the end-of-life stage and therapists determine that further treatment is no longer necessary, the treatment is discontinued. Nurses, as those who have the most contact with patients among medical personnel, suffer from emotional and ethical problems. On the one hand, the person is deprived of the care and treatment that he has the right to receive, but on the other hand, continuing the treatment is finally useless for the patient and only leads to more harm and suffering.

"Sometimes when there is no hope for the patient to recover, the physician orders no code. It's so scary for me that I cannot see that the patient is dying and I do not do anything for him. On the other hand, I know it will bother me if I continue my treatment. It's very painful and a kind of uncertainty." (P7).

Discontinuation of treatment due to lack of supply or shortage of drugs

With the outbreak of COVID-19, the increasing need for some drugs and medical equipment and lack of access to drugs in some cases have affected treatment. Nurses who are required to prescribe medication face an unsolvable problem that causes severe psychological pressure. This can lead to patient death, especially under unstable conditions.

"Certain drugs used for patients are expensive. Some cannot afford to buy them. When we cannot give drugs to the patient or complete the course of treatment, given that the patient needs end-of-life care, it is very difficult for us, because the treatment is half over and at any moment the patient's condition may worsen and even die." (P3).

Acceleration of Job Burnout

Anxiety caused by the death of the patient due to lack of facilities

The large number of patients referred to hospitals with each pandemic wave causes no empty beds to receive patients, even patients with end-of-life care in the ICU. These deprivations put heavy ethical and psychological pressure on nurses.

"Sometimes we do not have an empty bed; and we have to keep the patient in the emergency room until the bed is empty. The reduction in oxygen pressure is also an issue that really makes the ward really tense" (P14).

Rumination

Nurses become idealistic due to their sense of conscientiousness and blame themselves for possible shortcomings. These blames and negative thoughts continue outside the workplace and cause psychological problems for nurses.

"When a patient has severe respiratory distress, and everything we do does not get better, even intubation, there is the thought that it is our fault. Always we think that we miss something" (P7).

Frequent exposure to the concept of death

Despite the constant efforts of nurses, the daily death of patients has a devastating effect on the nurses' morale. The feelings of despair and escape from the treatment environment due to daily exposure to the death of the patient and the reactions of families are well visible in nurses. The lack of knowledge about the end of the pandemic, observation of patients' deaths to whom nurses have become accustomed due to long-term hospitalization, and feelings of guilt over the death of patients are among the factors that reduce nurses' motivation and increase their willingness to leave the profession.

"I have had a feeling for a long time why I have to see so much death. When I entered the hospital, I encountered the screams and moans of the patients. When I see these things, until the end of the day, I think about how long the deaths of so many people will continue. I am so tired." (P5).

Discussion

This study describes the ethical challenges that nurses face in providing end-of-life care to patients.

One of the main challenges nurses face is disregarding the human dimension of end-of-life care for patients. In a study [11], a range of inhumane behaviors were identified in dealing with patients admitted to ICUs, which included not introducing the treatment team to patients, lack of knowledge of the treatment process, disregarding the patient as a human being, not involving the patient as a decision maker in the treatment process, blaming the patients, and disregarding the patient's privacy. Another found that questioning human dignity and disrespect for patients and their families is frequent in ICUs. [17]. What can be deduced from the present study is that in addition to the inhumane behaviors mentioned in the studies, stigma caused by COVID-19, the contagiousness of the disease, the massive need of the ICU, and ageism increasingly threatened the human dignity of the patients and disregarding the human dimension of care.

The results of the present study showed that organizational barriers are among the most challenging sources in the health system. Saberi et al. acknowledged that the factors predicting the occurrence of ethical conflicts in nurses included organizational culture, managerial leadership style, reward system, organizational structure and rules [18]. In one study, it was found that non-civil behaviors by supervisors, patients and their families had a negative impact on ICU nurses' performance, although task-oriented and teamwork culture positively improved the performance of personnel [19]. The similarity of the challenges mentioned in the studies with the present study indicates the importance of selecting appropriate management strategies to support nurses and improve their performance, although the challenges faced by health systems during the COVID-19 crisis doubled the need to review management strategies.

Unfair end-of-life care was another important issue addressed in this study.

Another study also mentioned the risk of reduced quality of care, poor spiritual care, and lack of family-centered care in caring for patients with COVID-19 [20]. In addition, the feeling of inadequacy in managing patients' conditions and interpersonal relationships is a significant challenge for medical personnel [21]. Nurses' communication experience in ICUs is recognized as a key element in nurses' care. One of the most challenging aspects of communication is facing unpredictable communication difficulties, which include the inability to describe the situation in a way that is understandable to the patient and his family, the inability to establish non-verbal communication along with verbal communication, the patient connected to a ventilator, and inappropriate handling of the family of the patient with the nurses and blame them (the nurses) [22]. In the present study, nurses also considered communication barriers as barriers to providing person-centered and family centered care. Although nurses believe that these barriers have long existed for patients with end-of-life care, factors such as social distancing and the contagiousness of the disease exacerbate them.

The results showed that one of the challenging concepts in caring for these patients is futility care. In one study, a strong significant relationship was found between the ethical distress of nurses working in ICUs and providing futile care, especially in the legal and organizational dimensions [23]. It seems that end-of-life care of patients with COVID-19 has intensified the communication gaps and care shortcomings that existed before the pandemic and caused deeper ethical dilemmas.

What is evident in this study is that the treatment process was affected by this pandemic, something that no disease has been less able to cause in recent years. It was found that the lack of treatment facilities, especially ICU beds during this pandemic, led to several ethical dilemmas. Here, the author considers the observance of the ethical principle of utilitarianism in the sense that the degree of a patient's treatability is the basis for admission, continuation of treatment and allocation of medical teams and services in the ICU. Non-

admission of end-of-life patients, allocation of ICU beds to younger patients, and isolation of patients from the ventilator if the treatment process does not progress are among the ethical dilemmas [24]. However, it should be noted that the ethical principle of utilitarianism, although aimed at preserving the lives of more patients, is not applicable in all countries because of differences in the laws and culture of societies. The main solution that the researchers are considering is to increase the number of ICU beds and facilities in the wards [24, 25]. However, it should be noted that owing to the heavy costs imposed, this approach to the healthcare system of developing countries is slow. In the present study, one of the main and well-known causes of ethical challenges was the lack of facilities, which increased the uncertainty of treatment and care processes.

The changes in care standards that have no effect other than reducing the time spent at the patient's bedside are also one of the important ethical challenges of the present study and always provides the nurse's view that the care provide is ineffective. One study found that the dilemma between nursing care and disease among nurses has led to a change in their perception of care and the patient care process [4, 26].

Another important theme was the acceleration of job burnout. Concepts related to death and its consequences for nurses have been mentioned in several studies [27]. In a study investigating stressful conditions for nurses during the COVID-19 pandemic, it was found that by observing the death of patients with end-of-life care and inability to save their lives, nurses felt helpless and inadequate [28]. In the present study, nurses also mentioned that they were less satisfied with the effectiveness of their care, sense of inadequacy, and rumination in this field, even outside the workplace. Other sources of stress for nurses during the pandemic include workplace problems. Workplace atmosphere, especially relationships between colleagues, management errors, and lack of necessary training, are among these stressors. In fact, lack of support by colleagues and supervisors has been among

the factors causing dissatisfaction among nurses [28]. In the present study, nurses considered the existence of supportive colleagues as a defense strategy against problems, and considered the cohesion of the nursing team as a source of support. It can be inferred that nurses are always more affected by the treatment environment because of the extensive communication they establish with patients and other members of the medical team, and the COVID-19 pandemic place heavier responsibility on nurses and accelerates their job burnout even more.

Limitation

Limitations of this study include the small sample size that was collected in only two hospitals and explored only Lorestan nurses' experiences. The nature of the qualitative study limited the generalizability of the findings; however, it is recommended that this study be conducted in other contexts to validate the generalizability of the data. The timing of data collection could have impacted our findings because of the long distance between December 2020 and May 2021.

Conclusion

The variety and complexity of ethical challenges in the present study indicate that the COVID-19 pandemic not only as a crucible of humanity but also as a great ordinal for health organizations to impress nurses' lives. Some challenges such as immature organizational processes, lack of attention to solutions and job burnout have been seen rapidly in the past decades in health organizations however COVID-19 pandemic create an opportunity to unequivocally understand weaknesses in health organizations.

In fact, creating supportive environments for nurses by using strategy like supportive services for improving mental health and reducing the negative effect of ethical challenges, emphasizing nurses' safety as priority, using appropriate leadership styles, and creating an ethical climate can improve our preparation for future crises as well as flourish the nursing profession.

Conflict of Interests

Authors declare that they do not have any conflict interests.

Abbreviations

This manuscript is extracted form data of research project (the number 1595) approved by Lorestan University of Medical Sciences, Khorramabad, Iran. We wish to thank the Deputy-in-Research of the University, and the nurses who helped us greatly in filling and returning the questionnaires.

Ethical Consideration

Maintaining anonymity, permission to record interviews, voluntary participation in the study, and the ability to withdraw at any stage of the investigation were ethical considerations used in this study. Also, this study was approved by the Research Department of Lorestan University of Medical Sciences with the ethics code IR.LUMS.1400.032.

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