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REVIEW ARTICLE

Palliative Care in the Intensive Care Unit: Not Just End-of-life Care

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Abstract
Initially, palliative care in the intensive care unit (ICU) was designed to improve hospice care. Today it has emerged as a core component of ICU care. ICU palliative care should follow the ethical principles of autonomy, beneficence, nonmaleficence, justice and fidelity. To integrate primary palliative care and professional palliative care into ICU care management, there are different modes: integrative, consultative, and a combined approach. All ICU patients should receive palliative care which includes symptom management and shared decision-making. Further research is needed to explore how to provide the best palliative care for ICU patients and their families.

Keywords Palliative care · End-of-life care · Intensive care unit

1 Introduction

The term "palliative care" is popular, but is often mistakenly regarded identical to "end-of-life care" without any treatments [1]. As a clinical field that emerged in the 1990s, palliative care is defined by the World Health Organization (WHO) as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification, impeccable assessment, and treatment of pain and other problems: physical, psychological and spiritual" [2]. Up to 75% of patients admitted to the intensive care units (ICUs) experience distressful symptoms [3]. The critical feature of the disease, the invasive treatments and the uncertainty of prognosis make the ICU a "hell" for critically ill patients and their families. The concept, principles and methods of palliative treatment have been gradually introducing into ICU clinical practice. The importance of providing palliative care in the ICU is well recognized by various studies to alleviate physical symptoms, to set patient-centered goals of care, and to provide end-of-life care [3]. Currently, about 10% to 30% of the dead patients in the world die in ICU [4]. ICU health care providers should integrate primary palliative care and professional palliative care into ICU care management and ensure the autonomy and dignity of dying patients.

2 Ethical Considerations at Palliative Care in ICU

Palliative care should be provided to all critically ill patients until the end of their lives [5]. In ICU environment, palliative care should follow the ethical principles of autonomy, beneficence, nonmaleficence, justice and fidelity.

2.1 Autonomy

The principle emphasizes the protection of patients' autonomic rights, even for those who have lost their decision-making ability. Each patient has the right to decide what kind of care he or she should receive and to accept or refuse life-sustaining treatment (LST). Advance instruction is the core part of advance care planning (ACP), which can

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limit expensive, invasive and useless measures which not required by patients, and the priority of decision belongs to patients. The right of patients capable of decision-making to express their treatment preferences autonomously should be adequately respected, but the availability of advanced treatment measures and the prognosis of the disease should also be taken into account [5]. When patients are unable to participate in decision-making, the designated delegates or patients' families have the right to make decisions, which should be based on the patient's previously known or stated values and desires.

2.2 Beneficence

Beneficence refers to actions that are intended to benefit patients by treating illness, promoting health, and/or relieving pain, suffering, and distress [6]. The do-good principle emphasizes effective interventions to alleviate symptoms that affect the patient's quality of life. In any case, ICU personnel have a responsibility to provide the best possible care measures to their patients.

2.3 Nonmaleficence

The principle focuses on avoiding unnecessary harm and minimizing the risk of harm. In ICU, some treatments or operations inevitably cause pain or injury, and the harm is justified if the benefit outweighs the harm and its purpose is not to hurt the patient. Monitoring and treatment of ICU patients should be individualized.

2.4 Justice

The principle should ensure the equitable distribution of medical resources and maintain fairness in the provision of health services. ICU medical staff have the obligation to advocate for fair, equitable, and reasonable treatment for patients with life-threatening illness, while avoiding unnecessary use of limited resources. In extraordinary situations, such as a pandemic or disaster triage, medical resources should be reasonably allocated consisting with standards of medical practice, so as to maximize the chances of success [6].

2.5 Fidelity

The principle of honesty requires that patients and their families should be truthfully informed about the patients' prognosis and the possible consequences of the disease, and be provided with detailed information about the advantages, limitations, and disadvantages of different treatments to allow them to make the best decision. Even if patients have the right to choose their own treatment methods, ICU medical staff should explain the expected outcomes of all approaches.

3 Modes of Palliative Care in ICU

Palliative care is divided into basic palliative care and professional palliative care. Basic palliative care can be provided by any health professional and includes symptom management and discussion around the ACP, including disease status, treatment goals, prognosis. Professional palliative care is provided by a multi-disciplinary team with advanced training. There are different models for integrating basic and professional palliative care into ICU patient management, and the selection of model should be based on the resources and needs of the different ICUs and the institutions in which they are located.

3.1 The Integrative Model

Basic principles of palliative care and interventions are integrated into the daily practice of the ICU treatment team, providing services to all critically ill patients and their families. The main interventions include the following [7]: early family meetings led by the ICU team, routine palliative care assessment, embedding trained staff into the ICU team, increasing education for ICU team members, and improving education and support for family members of ICU patients. Monitoring and Communication Bundle is a standardized clinical pathway for performing basic palliative care practices in ICU [8]. Doctors who are familiar with the principles of palliative treatment can effectively communicate with the families of critically ill patients and can better access professional assistance in palliative care through consultation. ICU nurses play a vital role in palliative care, including communication between the health care team and the patient/family members [9, 10]. All ICU medical staff should have the basic knowledge and essential skills of symptom management, effective communication, and shared decision-making.

3.2 The Consultative Model

This model utilizes a professional palliative care team that focuses on ICU patients with the highest risk of death. Palliative care professionals have regular access to the ICU to screen and identify patients who may benefit, and more often rely on the judgment of the ICU physicians to initiate the professional palliative intervention. The factors that initiate consultation include acute disease status, and patient factors such as age and different stages of disease. Initiating specialty consultation based on predetermined criteria is the most feasible way to achieve the integration of enhanced treatment and palliative care [11].

3.3 The Combined Model

The integrative model places "extra" demands on ICU staff, and the consultative model requires adequate palliative care expertise and resources. The most effective way to integrate intensive care and palliative care is to combine the two models [12]. Basic palliative care is provided by ICU staff, and professional palliative care is sought when needed. To meet the need for palliative care, it is important to improve the ability of ICU medical staff to provide basic palliative care and to expand the professional palliative care team. The mixed model ensures the quality of standard palliative care and continuity of care even the patients leave the ICU.

4 Timing of Palliative Care Initiation in ICU

Since the ICU setting is burdened by high mortality and high suffering, providing palliative care to critically ill patients and their families is a major goal of ICU care [13]. Palliative care aims to maintain and improve the quality of life of all patients and their families at any stage of life-threatening illness [14]. In a while, palliative care and intensive care share the same values and goals. All ICU patients receiving effective (usually invasive) treatments should receive palliative care either concurrently or separately, depending on the needs and preferences of the patient and family. Invasive treatments are necessary to save the lives of ICU patients, and sometimes they might be helpful for symptom relief. Decision-making, alignment of treatment with the patient's goals, emotional support for families, and the basics of symptom management are core elements of palliative care and should be routine aspects of critical care [15]. Studies have shown that integration of palliative care in the ICU improves quality of life, shortens hospital and ICU length of stay, lowers the care-giver burden, and reduces the use of emergency resources [13, 16–19].

In the ICU setting, the prognosis is frequently unclear. Discussions about changing the treatment goals and more appropriate approaches should begin early. The early initiation of palliative care intervention in the ICU is associated with greater transition to do-not-resuscitate (DNR)/do-not-intubate (DNI) and hospice care. The American College of Critical Care Medicine recommends early palliative care as an effective means of reducing the cost of care and ICU length of stay, although this recommendation is based on low-quality evidence [20]. In a recent cluster randomized crossover trial, comprehensive palliative care initiated early in the ICU (within 48 h of ICU admission) led by experienced palliative care professionals helped patients to shift to DNR/DNI and hospice care while reducing the use of medical resources in the ICU and post ICU [21].

5 Symptom Management During Palliative Care

Palliative care is to prevent and relieve suffering through early identification, perfect assessment and treatment of pain and other physical, psychological, social and spiritual issues. ICU patients are prone to present symptoms such as pain, dyspnea, thirst, anorexia, constipation, fatigue, fear, depression, anxiety and delirium that affect the quality of life. These symptoms persist even after the patients being transferred out of the ICU. The symptom palliation domain includes: presence of palliative care team, patient-family relationship, multidisciplinary team approach, policy of approaching patients, symptom screening and management, and presence of ethical review board [1]. The following describes the management of the three most common symptoms.

5.1 Targeted Analgesia

Unrelieved pain is physically and psychologically harmful [22]. In order to control pain, an appropriate tool should be selected for a comprehensive evaluation. The patient's self-representation of pain is the gold standard for assessment. However, the verbal communication or cognitive ability of critically ill patients is weakened, even unconscious, which affects their expression of pain. The Critical Care Pain Observational Tool is an effective method for pain assessment in ICU patients unable to self-report their pain [23]. The choice of analgesic or non-pharmacologic approach should be based on pain assessment, and reflect the needs and desires of the patients. Opioids remain the primary choice for targeted analgesia.

5.2 Terminal Sedation

Terminal sedation reduces the consciousness level of end-stage patients through injecting specific drugs, so as to relieve symptoms of patients who do not respond to other methods. There are four criteria are required for a patient to be considered for terminal sedation[24]: the patient has a terminal illness; severe symptoms are present, the symptoms are not responsive to treatment, and are unbearable to the patient; a "DNR" order is in effect; and death is imminent (hours to days). The purpose of terminal sedation is not to hasten death but to relieve suffering at the end of life, which differ from euthanasia. The commonly used drugs are midazolam and propofol, and sometimes opioids can be added.

5.3 Management of Dyspnea

Dyspnea is one of the most common symptoms during the terminal period and is associated with pain, fatigue, anxiety and increasing of mortality [25]. Opioids and oxygen

are considered to be the cornerstone of the treatment of dyspnea in end-stage patients. However, the quality of evidences for the use of opioids is low, and oxygen is ineffective in dyspnoeic patients without hypoxemia [26]. The use of anxiolytics can help to reduce the anxiety components in dyspnea, and bronchodilators, diuretics and corticosteroids can also be used as adjuncts.

Palliative ventilation refers to any ventilatory support aiming at dyspnea, not the disease itself. In the case of DNI, compared with oxygen, palliative noninvasive ventilation (NIV) can reduce dyspnea and the dosage of morphine in oncology patients [27].Less invasive high flow nasal therapy (HFNT) has also being used in palliative treatment. HFNT can improve oxygenation, reduce breathing work and decrease the use of NIV in DNI patients complicated with acute respiratory failure [28].

6 Clinical Decision-Making During Palliative Care

Patients should not seek treatment that is not in their best interests, and physicians should not go out of their way to save lives. The vast majority of ICU patients who are incapacitated rely on their families or delegates for medical decision-making. There are important differences between palliative care for patients with malignancies and ICU patients. In the final stage of life, the treatment goal may still be uncertain. The evacuation of advanced LST should be based on the patient's willingness to do not proceed with LST, and the shorter survival time and higher risk of transferring out of ICU to develop low cognitive function, with the involvement of family members and multidisciplinary team, ensuring that the decision is in line with the patient's values and goals and that the entire decision-making process is monitored [29].

6.1 Cardiopulmonary Resuscitation

For some end-stage patients, cardiopulmonary resuscitation (CPR) may be an unnecessary intervention. It is necessary for ICU physicians to understand the need for CPR in patients at high risk of death. DNR decision may be considered in the following patients [24]: patients who may not benefit from CPR; patients for whom CPR will cause permanent impairment or loss of consciousness; patients with poor quality of life and unlikely to recover after CPR. Discussions regarding resuscitation of critically ill patients should be performed for all patients with the first 24 to 48 h after admission to the ICU [30].

6.2 Life-Sustaining Treatment

LST maintains cardiac function, respiratory function and renal function with positive inotropic drugs, intra-aortic balloon counterpulsation, left ventricular assist devices, mechanical ventilation, extracorporeal membrane oxygenation and renal replacement therapy. LST also includes antibiotics, blood products, artificial nutrition and fluids. It is difficult to accurately determine the prognosis in patients, especially those elderly patients with co-morbidities and debilitated patients. In chronic, progressive and incurable non-oncologic patients, it is required to stage and evaluate the potential organ failures [31].

The decision to limit LST in ICU is one of the difficult choices that cause moral dilemma. The types of limitation of LST can be divided into four main categories [32]: disregarding the patient admission to an ICU; omitting treatments; keeping therapies; withdrawing therapies. Omitting means that the LST is not initiated or not increased, and withdrawing indicates that the ongoing LST is stopped. Life support measures may be discontinued if they do not bring any benefit to the patient or no longer achieve the desired goal, or if the expected outcome is not optimal, or if the quality of life is unacceptable according to the wishes of the patient or family members. Legal, evidence-based evidence and available resources should be taken into account in keeping and withdrawing LST. The evacuation time of LST shall be chosen by the patient's family members.

Withdrawal of mechanical ventilation is an important part of palliative care measures in the ICU. The most common symptoms associated with withdrawing the ventilator and resumption of natural ventilation are irritability, dyspnea and anxiety [29]. In the ARREVE study, 226 (50%) of 450 patients experienced discomfort after evacuating mechanical ventilation, and these discomforts were mainly related to pulling out endotracheal tube and poor sedation, so opioids and sedatives should be given before evacuating the ventilator with achieving specific analgesic and sedative goals [33]. The general course of extubation takes about 20–60 min. After palliative extubation, the patient may remain natural breathing for hours or days.

6.3 Nutrition and Hydration

Artificial nutrition and hydration (ANH) is not different from other life-sustaining measures. Feeding and hydration are forms of palliative care to meet basic human needs. However, ANH does not improve the prognosis of end-stage patients, and may sometimes increase the risks of gastrointestinal discomfort, diarrhea and aspiration pneumonia. Decisions regarding ANH should be based on relevant evidence, best practices, clinical experience and judgment, ensuring an effective line of communication with patients

and their families, and respecting for patient's autonomy and dignity [29].

6.4 Euthanasia/Physician Assisted Suicide

The ethics and legality of euthanasia/physician assisted suicide (PAS) remain controversial. The death after refusing LST or evacuating from LST is the natural consequence of the underlying diseases, but the death in euthanasia/PAS occurs with active intervention by physician. Euthanasia is divided into active euthanasia and passive euthanasia [24]: active euthanasia is the intentional ending of a patient's life with medications such as sedatives, muscle relaxants and other drugs, usually given by a physician at the explicit request of a mentally competent patient; passive euthanasia occurs when a patient is suffering from an incurable disease and decides not to use life-prolonging treatment, such as ANH. As for PAS, it is the intentional ending of a patient's life with drugs or prescriptions provided by a physician at the explicit request of the patient, when it is clear that the patient intends to use them to end life. In countries where euthanasia/PAS is legal, physicians also have the right to refuse a patient's request. At present, active euthanasia, passive euthanasia, and PAS are legal in 5, 12, and 7 countries respectively, although the laws in these countries vary considerably in practice [24].

7 Palliative Care and Hospice Care

Palliative care means patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering [34]. Palliative care is often confused with end-of-life care. End-of-life care, also known as "hospice care", is to provide palliative care to patients who are expected to die within six months. Palliative care is based on needs, while end-of-life care is based on poor prognosis. Palliative care is for any stage of serious illness and applies to any patient in the ICU, with continuous illness throughout straight overlapping with end-of-life care. End-of-life care is an important part of palliative care. Patients receiving end-of-life care no longer receive treatments for their underlying illness, and the main focus is on symptom control, emotional and spiritual support for the patient and their families, with the goal of making the patient feel comfortable as much as possible and meeting their needs and wishes at the end of life.

In the context of palliative care in ICU, end-of-life decision may be required. One of the greatest difficulties in making end-of-life decisions lies in the uncertainty about what the patient would want [35]. When making decisions, it is very important to protect the rights and dignity of patients, their families and other parties in the society. When patients shift to "comfortable" care, ICU palliative care team should incorporate end-of-life care in their care plan. All ICU staff and end-of-life care personnel should have basic palliative care skills, such as people-centered and family-oriented communication skills, professional collaboration and symptom management. A meta-analysis showed that end-of-life care can improve the quality of life and prolong life expectancy in patients with advanced disease [36].

8 Conclusions

Palliative care is not a substitute for treatment of disease, and it is not only applicable for terminally ill patients. Alleviating physical and emotional symptoms and making patient-centered decisions are the cornerstone of palliative care. Timely and effective communication with patients and their family members on goals of care, ACP and the shift from curative care to comfortable care is needed to integrate treatment with patients' values and preferences [37].

At the present time, the practice of palliative care in ICU is not yet universally accepted, and further research is needed to explore how to provide the best palliative care (including end-of-life care) for patients and their family members in ICU environment, with a focus on the clinical outcomes and the satisfaction of patients and family members.

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