ATTAINING GOOD END-OF-LIFE CARE IN INTENSIVE CARE UNITS IN TAIWAN—THE DILEMMA AND THE STRATEGY

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SUMMARY

One of the major challenges for intensivists is resolving the conflicting interests in end-of-life care. We reviewed patients’ characteristics in an intensive care unit to determine the major barriers of practicing good end-of-life care and the medical ethics involved for the care team to resolve these conflicts. [International Journal of Gerontology 2009; 3(1): 26–30]

Key Words: double effect, medical ethics, medical futility, uncertainty

Introduction

Every member in the care team has the same fiduciary obligation that is to protect and promote patients’ health-related interests and implement patients’ preferences in pursuit of this goal. However, the conflicting interests of end-of-life (EOL) care result in stress for intensivists in clinical practice. The urgent need for treatment and complexity of the diseases being cared for in an intensive care unit (ICU) make the situation even more complicated. The purpose of this article is to clarify the situation the intensive care team meets on a daily basis, and to equip them to deal with the ethical issues associated with these dilemmas.

Good EOL Care—Where We Are in Taiwan

There is a growing number of issues concerning the quality of EOL in modern medicine1–3. Physicians in Taiwan are engaged in applying palliative care concepts to care for the patients in the terminal stages of their cancer in hospice units4. They are well practiced in the concerns to alleviate the suffering in dying patients and the grief of family caregivers4.

ICUs are environments where patients have illnesses of high morbidity and mortality5. There is a high frequency of intensivists and oncologists dealing with the EOL care for patients in ICU. Attaining good EOL care is as important as prescribing life-sustaining management in ICUs6,7. Several activities have been held to promote palliative care principles and service in intensive care4.

Patient Characteristics in the ICU—What Situations Do We Encounter

The ICU is a specialized medical environment where critically ill patients are cared for. Patients in ICU have
their own unique characteristics. Their mortality rates are high, varying from 10% to 20% in different ICUs\(^5\). Half of them will die within 3 days after admission to the ICU\(^6\). One-third of the patients spend more than 10 days in the ICU during their final hospitalization\(^8\). Most patients at the onset of critical illness are ill-prepared to accept death. Their deaths almost always occur earlier than expected.

Avoidance of futile care is an essential task in ICU, since the ward is supposed to resuscitate dying patients\(^9\). These conflicts come from not only the dilemma of human dignity between the right of life and death, but also the dilemma of differing attitudes toward EOL care between the medical staff and family members\(^10\).

The Major Barrier of Practicing Good EOL Care in the ICU

Patients in ICU need care that focuses not only on life sustainment but also on comfort\(^9\). However, every patient’s background is different. Personal attitudes towards life are so heterogeneous that we can hardly expect to know their wishes for EOL care without communication\(^11\). The factors influencing EOL care decisions include age, diagnosis of the disease, severity of the disease(s), length of hospital stay, cost of medical care, and different beliefs based on geography and religion\(^12-14\). In Taiwan, although there is no available data regarding diverse decisions of EOL care between patients and their clinicians in the ICU, this fact has been shown in cancer groups\(^10\).

Holistic care includes not only curative care but also palliative care. Patients in the ICU do change their wishes with regards to their health conditions\(^6\). As the patients’ conditions in ICU changes minute by minute\(^9\), and because futile therapy should be avoided\(^15\), frequent communication to clarify patients’ demand for the goal of management at different points in the disease process is essential in attaining good EOL care\(^16\).

Difficulty assessing the appropriate use of advanced technology in an incapable patient is another common problem in ICU. Several features in the ICU such as an ill patient incapable of making decisions autonomously, a new care team\(^17\), difficulty in organizing meetings\(^11\), overbearing family members\(^11\) and discordant views on appropriate care among care givers\(^10,11,18-22\) have made this problem more complicated.

What Concepts Should We Be Aware of to Overcome the Dilemma of Attaining a Good EOL Care in the ICU?

In view of the patients’ backgrounds and the influencing factors for good EOL care in ICU, only a qualified intensivist can guarantee individualized EOL care during the different stages of the disease for each patient\(^11\). The concepts that are essential to attain a patient-centered good EOL care in ICU are outlined below.

A good death or good EOL care

There are five components to good EOL care that meets a dying patient’s needs: comfort, absence of pain, dignity and respect, closeness to significant family members and other caring persons, and peace. These are most frequently considered part of a good death\(^23\).

Autonomy

Rather than paternalism, a patient’s autonomy is a sovereignty of medical ethics during medical decision making. Three elements in “real” autonomy should be considered: the patients’ competence, understanding, and willingness\(^24\).

There are four questions that a clinician needs to ask in order to assess whether patients have the capacity to make decisions autonomously: Do they understand the nature of the procedure? Do they realize the purpose and the effects of the proposed therapy? Do they have the ability to comprehend and retain relevant information? Can they weigh up the benefits and disadvantages of various interventions?

However, it is difficult for the patient to imagine completely what will occur as a result of their decisions. A gap exists between a patient’s understanding and reality. This is not only because patients are not familiar with the language of medicine, but also because most of them cannot really remember what has been mentioned by the clinicians. In addition, the inherently uncertain nature of medicine sometimes also leads to misunderstandings between caregivers and the patients.

Consent is also a primary element of patient’s autonomy. Physicians should give more weight to the patients’ interests rather than their own. Clinicians should avoid manipulating the medical information or coercing their patients during communication.
Medical futility
The strict definition of futile care is still being debated by health care professionals, bioethicists, investigators, and other experts. The definition of a futile treatment should not only be based on a success rate of less than 1 in 100 treatments\textsuperscript{25}, but also focused on other factors, such as quality of life, the emotional and financial costs of treatment, the likelihood of treatment success and the expected effect on longevity\textsuperscript{26}. The perceptions of patients regarding medical futility should be explored and should be considered in the decision\textsuperscript{26}. Any reasonable doubt or uncertainty about the irreversibility of a patient's medical condition is appropriate to initiate intensive care. Frequent queries, reappraisals of the effect of management, and realistic, honest medical advice in combination with patient and family input on EOL choices are the best way to determine if the treatment is futile\textsuperscript{6,15}.

Palliative care
The distress of patients in the ICU is varied\textsuperscript{27}. Interventions in the ICU can increase patient discomfor\textsuperscript{27}. Patients may have a reduced quality of life\textsuperscript{29}. Palliative care in the ICU is an approach that assists the patients and their families to face the discomfort associated with life-threatening illness\textsuperscript{1,29}. Physical, psychologic and spiritual distress can be prevented and relieved by early identification and excellent treatment. Given that dying is a normal process of life, physicians who care for patients should neither hasten nor postpone their death. An explicit patient-centered decision making process for EOL care, including discomfort assessment and control, decisions about life-sustaining therapy, minimizing the symptoms during withdraw therapy and maximizing support for the bereavement of the family, are the body of palliative care in the ICU\textsuperscript{13,19,30,31}.

Ethical differences among withdrawing treatment, physician-assisted dying and killing
Although withdrawal of treatment may or may not hasten death\textsuperscript{36}, it differs from active euthanasia in that sole intent of hastening death obstructs provision of treatment. Physician-assisted dying and killing is unacceptable in most countries in the world, including Taiwan. On the other hand, the concept that patient autonomy can be an overriding force in decision making at the EOL has been approved in some areas, including Oregon and the Netherlands.

Double effect
Clinicians prescribe management because these interventions are good for the patient, but inherent unintended “bad” effects may exist at the same time. A common example is cardiorespiratory depression in opioid agents for terminal sedation and analgesia\textsuperscript{6}. There is no clear distinction between the dose of opiates and benzodiazepines for withdrawal therapy and for active life-shortening, further proving this phenomenon\textsuperscript{12,34}. This phenomenon has been called the “double effect”. There is a consensus, “the doctrine of double effect in practice”, having been set to protect patients’ benefit and to confirm the intensivists’ morality\textsuperscript{24}. We are using morphine as an example to show its utility:
1. The act itself must be morally permissible.
   - Morphine for pain is morally permissible.
2. The negative effect, while possible to predict, must be unintended.
• Morphine for pain rather than for respiration depression.
3. The negative effect must not be disproportionate to the good effect.
• Morphine for pain outweighs loss of life in a dying patient.
4. The negative effect is not the means by which the good effect is achieved.
• Pain is relieved by the administration of morphine and not by the death of the patient.

To increase the transparency at EOL care, proper documentation, including record keeping on timing and doses of drug and the physician’s intention at each step, is recommend

Justice

It is difficult for a human to clarify one therapy as a futile management or a life-sustaining high technology. Since resources are undeniably limited, we may deprive one patient the chance of surviving, while we rescue another one in every way. We suggest the formation of a national institute to oversee just the medical resource allocation.

Uncertainty

Why do we try to avoid discussing death in conversation? Can we predict when or how we will die? The sense of losing control makes us feel the anxiety and fear, as we face the issues of death. These emotions are common and normal. Medical uncertainties in dealing with EOL care, such as the prognosis of diseases, illness progression, death, modest dosing of pain medication and the death process, also make caregivers uncomfortable. However, recognizing the situation that we are involved in is the best way to overcome this challenge.

Conclusion

Autonomy, beneficence, non-malefeasance and justice continue to be the basis of medical bioethics. Recognition of the double effect of management as relieving patients’ suffering, performing withholding and withdrawing life-sustaining therapy according to the “Hospice Palliative Medical Act” and overcoming the stress from uncertainty of the clinical medicine are especially useful for the intensivists handling the palliative and intensive care morally in the ICU. Furthermore, accounting for cultural influence factors, such as the legal constraints, religious beliefs and sociocultural circumstances, and physician’s experience with similar cases will resolve the conflicting interests in EOL care in a correct way, and achieve patient-centered medical care based on sound ethical reflection and judgment.

References