

The Current Status of Medical Decision-Making for Dying Patients in a Medical Intensive Care Unit: A Single-Center Study

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Background: Many terminally ill patients die while receiving life-sustaining treatment. Recently, the discussion of life-sustaining treatment in intensive care units (ICUs) has increased. This study is aimed to evaluate the current status of medical decision-making for dying patients.

Methods: The medical records of patients who had died in the medical ICU from March 2011 to February 2012 were reviewed retrospectively.

Results: Eighty-nine patients were enrolled. Their mean age was 65.8 ± 13.3 years and 73.0% were male. The most common diagnosis was acute respiratory failure, and the most common comorbidity was hemato-oncologic malignancy. Withdrawing or withholding life-sustaining treatment including do-not-resuscitate (DNR) orders was discussed for 64 (71.9%) patients. In almost all cases, the discussion involved a physician and the patient's family. No patient wrote advance directives themselves before ICU admission. Of the patients for whom withdrawing or withholding life-sustaining treatment was discussed, the decisions were recorded in formal consent documents in 36 (56.3%) cases, while 28 (43.7%) cases involved verbal consent. In patients granting verbal consent, death within one day of the consent was more common than in those with formal document consent (85.7% vs. 61.1%, $p < 0.05$). The most common demand was a DNR order. Patients died 2.7 ± 1.0 days after the decision for removal of life-sustaining treatment.

Conclusions: The decision-making for life-sustaining treatment of dying patients in the ICU very often involves conflict. There is a general need to heighten our sensitivity on the objective decision-making based on patient autonomy.

Key Words: advance directives; intensive care units; terminal care.

Introduction

Life-sustaining treatment (LST) refers to medical interventions that have the potential to prolong the patient's life without providing

beneficial effects on the cause of disease or clinical conditions.[1] However, life-sustaining interventions have increased in line with advancing life-saving medical technology, enabling patients suffering from severe disease with no hope of cure, end-stage cancer patients and brain-dead patients to live longer.[2,3] Decision making about LST in terminally ill patients can become ethical issues in the intensive care unit (ICU).[4]

Developed countries have already implemented regulatory requirements to be followed for decision making about LST.[3,5-7] In 2009, South Korea also introduced guidelines for the withdrawal of LST that define the desired role of physicians in decision making about whether to start or stop LST for patients suffering from irreversible disease to ensure their best possible quality of life.[1]

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In Korea, there have been not many studies investigating LST performed in the local ICU context.[8,9] The purpose of this study was to identify contemporary trends in decision making about LST in patients at the end-of-life. The study was conducted with patients in the medical ICU of a tertiary hospital in Busan, Korea.

Materials and Methods

1) Subjects

Medical records of patients who were at the end-of-life or end-stage of disease before dying in the medical ICU from March 2011 to February 2012 were retrospectively analyzed. 'Patients at the end-of-life,' were defined as those who were acutely and severely ill with no hope of improvement, according to medical decisions, despite all the therapeutic approach performed for them in the ICU. 'End-stage disease' was defined as a life-threatening multiple organ failure that had steadily progressed to the point where the patient's conditions could not be cured nor improved any more, calling for a life-sustaining intervention to prolong the life. The condition in which the patient was expected to die despite LST was also included for analysis. The patients who died within 24 hours after admission to the ICU and the patients under the age of 18 were excluded. This study was approved by the Institutional Review Board of the Pusan National University Hospital (E-2012080).

2) Definition of terms

'LST' refers to medical interventions that have the potential to prolong the patient's life without providing beneficial effects on the cause of disease or clinical conditions. General life-sustaining measures included artificial nutrition by tube, oxygen supply, humidity and temperature control, the use of Foley catheter and/or defecation tubes, sedative drugs, primary antibiotics and prevention of pressure ulcers. Special life-sustaining measures included cardiopulmonary resuscitation (CPR), ventilator care, hemodialysis, transfusion, organ transplantation, chemotherapy and high grade antibiotics.[1] Medical decisions about LST in patients at or nearing the end-of-life were categorized as 'withdrawal of LST,' 'advance decisions' and 'Do-Not-Resuscitate (DNR) order.'

Decisions are made to withhold or withdraw LST. Withholding LST means no additional life-saving support is provided, in addition to the current LST, when a patient's condition worsens although the current LST was maintained, whereas withdrawing

LST means withdrawal of more than one form of life support provided.[10,11]

'Advance decisions' refers to cases where a patient completed an advance directive or living will to make his or her decision about medical procedures or LST known, a patient expressed such a decision specifically to physicians in the presence of family member or legal guardian. A legal guardian was assigned to make a such decision on behalf of a patient, and his or her decision was considered legitimate by medical professionals and entered into medical record.[1]

3) Data collection

Subjects' sex, age, religion, principal diagnosis and the underlying disease at admission to the ICU, total hospital stay and ICU length of stay were collected and analyzed. The severity of illness was measured by the Acute Physiology and Chronic Health Evaluation (APACHE) II scores,[12] and accompanying organ failure was measured by Sequential Organ Failure Assessment (SOFA) scores.[13] At the same time, Charlson's Comorbidity Index (CCI) was calculated to quantify the risk of comorbidity.[14] If the underlying disease was either hematologic malignancy or malignant tumor, treatment response was classified into complete remission, partial remission, stable disease and disease progression.

For the cases where decisions about LST were made after discussion, the person who requested the discussion, the reason for such a request and the timing of request were identified, and the presence and absence of documented decisions was also investigated. Lastly, we tracked the changes in treatment after the decision was made about LST and the time of death.

4) Statistical analysis

Statistical analysis was performed using a SPSS 17.0 version (SPSSTM Inc; Chicago, IL, USA). Continuous variables were presented as mean \pm standard deviation and analyzed using an independent samples t-test. Nominal variables were analyzed using a Chi-square test and the Fisher's exact test. To identify variables that affected decisions to withdraw LST, logistic regression analysis was performed. p value of less than 0.05 was considered statistically significant.

Results

1) Clinical characteristics of subjects

A total of 392 patients were admitted to the medical ICU during the study period, and 292 of them were male (74.5%). The

Table 1. Clinical characteristics of enrolled patients

Variables	Subjects (n = 89)
Age, yr	65.8 ± 13.3
Male gender	65 (73.0)
APACHE II score	32.4 ± 10.1
SOFA score	12.7 ± 4.4
Charlson's Comorbidity Index	5.1 ± 3.3
ICU LOS, days	9.4 ± 14.0
Hospital LOS, days	19.9 ± 20.9
Cause of admission	
Respiratory failure caused by pneumonia	51 (57.3)
Septic shock	20 (22.5)
Acute kidney injury	7 (7.9)
Hepatic failure	4 (4.5)
Others*	7 (7.9)
Religion	
Buddhism	42 (47.2)
Christianity	11 (12.4)
Catholicism	6 (6.7)
None	30 (33.7)

All data are expressed as mean ± standard deviation for continuous variables and number (%) for categorical variables. *Others include mentality change (n = 2), hypovolemic shock (n = 1), cardiac arrest (n = 1), cardiac tamponade (n = 1), hemolytic anemia (n = 1) and postoperative care (n = 1). APACHE: Acute Physiology and Chronic Health Evaluation; SOFA: Sequential Organ Failure Assessment; ICU, intensive care unit; LOS: length of stay.

Table 2. Underlying disease in total patients

Underlying disease	Subjects (n = 89)
Hemato-oncologic disease (cancer, hematologic malignancy)	30 (33.7)
Chronic lung disease (COPD, BE, TB destroyed lung, ILD)	21 (23.6)
Gastrointestinal, biliary disease	12 (13.5)
Infectious disease	10 (11.2)
Chronic renal disease	9 (10.1)
Liver cirrhosis	4 (4.5)
Others*	3 (3.4)

Data are expressed as number (%). *Others include complicated diabetes mellitus (n = 1), rheumatoid arthritis (n = 1) and trauma (n = 1). COPD: chronic obstructive pulmonary disease; BE: bronchiectasis; TB: tuberculosis; ILD: interstitial lung disease.

mean age of total subjects was 53.6 ± 10.8 years, and the mean duration of ICU stay was 24.4 ± 14.8 days. Of total subjects, 129 died in spite of intensive care.

Of those, 89 died while undergoing LST at the end-of-life with irreversible disease or at the end-stage of disease. The mean age of these patients was 65.8 ± 13.3 years and male patients were 65 (73.0%). Their mean duration of ICU stay was 9.4 ± 14.0 days. The main reason for ICU admission was acute respiratory failure caused by pneumonia (n = 51, 57.3%), followed by septic shock (n = 20, 22.5%) and acute kidney injury (n = 7, 7.9%) (Table 1).

Table 3. Demand of withdrawing or withholding life-sustaining treatment

Variables	Subjects (n = 64)
Cardiopulmonary resuscitation	64 (100.0)
Hemodialysis	29 (45.3)
Ventilator care	14 (21.9)
Transfusion	13 (20.3)
Endotracheal intubation	13 (20.3)
Vasopressor	8 (12.5)

Data are expressed as number (%).

The most common underlying disease was solid organ and hematologic malignancies (n=30, 33.7%) (Table 2). Of 30 patients, 3 (10.0%) had complete remission, 3 (10.0%) were undergoing conservative management because chemotherapy was not effective at the end-stage of their illness. The remaining 24 patients (80.0%) were receiving chemotherapy, and 18 of them (75.0%) had disease progression.

Of total patients, 89 underwent general LSTs, and 75 of them (84.3%) were subject to special LSTs as well: 71 patients underwent mechanical ventilation (94.7%), 64 patients received high-grade antibiotics (85.3%), 30 patients had transfusion (40.0%) and 11 patients had dialysis (14.7%).

2) Discussion to make a decision about LST

Of 89 patients, 64 (71.9%) had their LST withheld or withdrawn after discussion took place between their families and physicians. ICU physicians initiated all the discussions after a mean duration of ICU stay of 7.4 ± 10.2 days for 63 patients excluding one patient. No patient had completed an advance care planning document for future medical care, including LST, before and during admission. Physicians therefore had discussions with family members of the patients. A discussion to make a decision on LST was mainly suggested by physicians when a patient was expected to die soon due to irreversible respiratory failure and shock.

There were no statistically significant differences in socio and clinical characteristics between the discussion group (n = 64) and the non-discussion group (n = 25).

In the discussion group, a written LST withdrawal request was submitted to the hospital's ethics committee for 36 patients (56.3%). The same request was made verbally for the remaining 28 patients (43.7%). These requests aimed for withholding or withdrawal of CPR (n = 64, 100.0%), which was followed by dialysis (n = 29, 45.3%), mechanical ventilation (n = 14, 21.9%) (Table 3).

The mean duration between decision making on LST and patients' death was 2.7 ± 1.0 days. The largest number of patients (n = 45, 51.7%) died within 24 hours after decision making.

Discussion

In the present study, the number of patients for whom discussion took place to make a decision about LST was 64 (71.9%) at the end-of-life or at end-stage of disease in the medical ICU. Clinical characteristics of these patients were characterized by irreversible respiratory failure or shock, and they were facing imminent death, according to medical records. Physicians initiated all the discussions regarding LST while no patient made an advance decision.

Of 89 patients, 28.1% belonged to the non-discussion group, meaning that withholding or withdrawing LST was not discussed before they died. The main reason for non-discussion was the disagreement among involved physicians with regard to LST in patients at the end-of-life or end-stage of disease.

In the discussion group withholding or withdrawal of LST was verbally requested by family members in 43.7% of patients. The number of patients who died within 24 hours after decision was significantly higher in the group that made a verbal request, compared the group that submitted a written request (85.7% vs. 61.1%, $p < 0.05$). A largest number of patients died within 24 hours after the request was made to withhold or withdraw LST. This indicates that a discussion took place to make a decision about withholding or withdrawing LST when the patient was expected to die soon, and the decision was verbally delivered to have LST withheld or withdrawn in many cases.

Among life-sustaining measures withheld or withdrawn, DNR order was the most frequent. Also the refusal of mechanical ventilation and endotracheal intubation were more frequently requested in this study, compared with the previous studies published in Korea.[8] Thus families appeared to be concerned about that patients would lose their ability to communicate with mechanical ventilation management. However, it was difficult to verify the exact reason why mechanical ventilation and endotracheal intubation were frequently refused in this retrospective setting.

For patients with an irreversible condition, advanced care planning completed by patients themselves are regarded as the best basis for making a decision about LST because it is an autonomous choice of patient.[15,16] However, advanced directives are not widely completed and used for a decision making about LST both domestic and foreign.[7,15] In this study, no patient completed an advanced directive. This finding implies that patients did not realize their medical condition due to the lack of knowledge on their disease or their ability to communicate was already lost with the worsening conditions at admission.

A study reported that 89.9% of patients said they are willing to withdraw LST and die if they have rely on LST due to severe and irreversible conditions.[17] Although the patient's own decision is considered important in LST, patients' families tend to be reluctant to inform the patient of his or her medical conditions and discuss the future care planning because such an attempt is still unusual from the socio-cultural perspectives, making an advance care planning difficult to take place.[15,16,18] On the other hand, physicians themselves may hesitate to discuss the future care planning with patients or their families because patient outcomes are diverse and unpredictable.[19]

When medical paternalism was dominant in health care, physicians played a central role in making a decision about what is the best care for patients based on ethical principles. The paternalistic model assumes that patients and physicians share similar values, enabling physicians to select the best treatments for patients without consultation with them. However, this assumption is not valid in today's society. And the paternalistic model is replaced by shared decision making in favor of patient autonomy. In a shared decision making approach, physicians work together with patients and their families to evaluate patient's conditions and choose treatment based on preferences of the patient. At the same time, physicians provide clinical information and recommend treatment that fits the values of patients.

ICU patients require aggressive and invasive management and monitoring to sustain their lives, and conflicts and ethical issues can arise during the course of treatment. And conflicts and ethical issues become more complicated when the patient's conditions are progressive and irreversible in the end-stage of illness despite aggressive treatment.

To make a rational life-end decision about LST, patients need to choose the course of action based on enough information on their conditions and management options. It is also important to help patients make an advance decision in cooperation with their families. If no advance decision exists, a conflict is more likely to arise between families and physicians when deciding a management option for worsened conditions.[20] It is therefore important to include patients and their families in decision making about treatment provided before and after ICU admission.

This study contains several limitations, including limited control over data collection and analysis, which is inherent to the retrospective study design. Although we defined the subjects as patients who died during LST at the end-of-life or final stage of illness, moribund patients were also included. With collected data, we could not identify and analyze a wide range of factors that affect decision making about LST. It was also difficult to identify

specific reasons and facts used to make a decision about LST due to the lack of information. The cause of conflict between patient's families and physicians was not available.

This study aimed to identify contemporary trends in decision making about LST in patients at the end-of-life in the medical ICU of a tertiary hospital. No patient had an advance directive, and a decision on LST was made after discussion between family members and physicians. The decision was then entered into medical record. DNR order was the most frequent among the decisions identified in this study. Given that 51.7% of patients died within 24 hours after a decision was made, decisions were usually made when the death of patient was imminent. This finding signifies the need for advancing care planning process before severe progression occurs.

To promote active participation in advancing care planning for future care or LST, greater attention on the quality of death and patient's autonomy is necessary in the society. Also, physicians should be encouraged to play an efficient advisory role in decision making process through education. Regulatory guidelines to support for patient-centered decision making about LST is also required for patients to avoid any medical measures that are unnecessary or not desired by patients. More importantly, medical professionals should protect dignity of patients at the end-of-life by including patients' families in the decision making process and making sure that rational decisions are made in accordance with the patient's values.

References

- 1) Koh Y, Heo DS, Yun YH, Moon JL, Park HW, Chung JT, et al: Characteristics and issues of guideline to withdrawal of a life-sustaining therapy. *J Korean Med Assoc* 2011; 54: 747-57.
- 2) Stevens MB: Withholding resuscitation. *Am Fam Physician* 1986; 33: 207-12.
- 3) Moon JY, Lee HY, Lim CM, Koh Y: Medical residents' perception and emotional stress on withdrawing life-sustaining therapy. *Korean J Crit Care Med* 2012; 27: 16-23.
- 4) Prendergast TJ, Claessens MT, Luce JM: A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med* 1998; 158: 1163-7.
- 5) Angus DC, Barnato AE, Linde-Zwirble WT, Weissfeld LA, Watson RS, Rickert T, et al; Robert Wood Johnson Foundation ICU End-Of-Life Peer Group: Use of intensive care at the end of life in the United States: an epidemiologic study. *Crit Care Med* 2004; 32: 638-43.
- 6) Pochard F, Darmon M, Fassier T, Bollaert PE, Cheval C, Coloigner M, et al; FAMIREA study group: Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multi-center study. *J Crit Care* 2005; 20: 90-6.
- 7) Lo B, Steinbrook R: Resuscitating advance directives. *Arch Intern Med* 2004; 164: 1501-6.
- 8) Lee K, Jang HJ, Hong SB, Lim CM, Koh Y: Do-not-resuscitate order in patients, who were deceased in a medical intensive care unit of an university hospital in Korea. *Korean J Crit Care Med* 2008; 23: 84-9.
- 9) Bae JM, Gong JY, Lee JR, Heo DS, Koh Y: A survey of patients who were admitted for life-sustaining therapy in nationwide medical institutions. *Korean J Crit Care Med* 2010; 25: 16-20.
- 10) Ruark JE, Raffin TA: Initiating and withdrawing life support. Principles and practice in adult medicine. *N Engl J Med* 1988; 318: 25-30.
- 11) Luce JM, Raffin TA: Withholding and withdrawal of life support from critically ill patients. *Chest* 1988; 94: 621-6.
- 12) Knaus WA, Draper EA, Wagner DP, Zimmerman JE: APACHE II: a severity of disease classification system. *Crit Care Med* 1985; 13: 818-29.
- 13) Vincent JL, Moreno R, Takala J, Willatts S, De Mendonça A, Bruining H, et al: The SOFA (Sepsis-related Organ Failure Assessment) score to describe organ dysfunction/failure. On behalf of the Working Group on Sepsis-Related Problems of the European Society of Intensive Care Medicine. *Intensive Care Med* 1996; 22: 707-10.
- 14) Charlson ME, Pompei P, Ales KL, MacKenzie CR: A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987; 40: 373-83.
- 15) Heo DS: Patient autonomy and advance directives in Korea. *J Korean Med Assoc* 2009; 52: 865-70.
- 16) Yun YH, Lee MK, Chang YJ, You CH, Kim S, Choi JS, et al: The life-sustaining treatments among cancer patients at end of life and the caregiver's experience and perspectives. *Support Care Cancer* 2010; 18: 189-96.
- 17) Kwon I, Koh Y, Yun YH, Heo DS, Seo SY, Kim H, et al: A study of the attitudes of patients, family members, and physicians toward the withdrawal of medical treatment for terminal patients in Korea. *Korean J Med Ethics* 2010; 13: 1-16.
- 18) Yun YH, Rhee YS, Nam SY, Chae YM, Heo DS, Lee SW, et al: Public attitudes toward dying with dignity and hospice-palliative care. *Korean J Hosp Palliat Care* 2004; 7:

17-28.

- 19) van Asselt D: Advance directives: prerequisites and usefulness.
Z Gerontol Geriatr 2006; 39: 371-5.

- 20) Fassier T, Lautrette A, Ciroldi M, Azoulay E: Care at the end of life in critically ill patients: the European perspective.
Curr Opin Crit Care 2005; 11: 616-23.