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Changes in End-of-Life Discussion for Patients with Advanced Cancer after the Life-Sustaining Treatment Decisions-Making Act in Korea

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Abstract

Background: Cancer is a leading cause of death in Korea. To protect the autonomy and dignity of terminally ill patients, the Life-Sustaining Treatment Decision-Making Act (LST-Act) came into full effect in Korea in February 2018. However, it is unclear whether the LST-Act influences end-of-life (EOL) discussion and decision-making processes for terminally ill cancer patients.

Methods: This was a retrospective study conducted with a medical record review of cancer patients who died at Ulsan University Hospital between July 2015 and May 2020. Patients were divided into two groups: those who died in the period before the implementation of the LST-Act (from July 2015 to October 2017, Group 1) and after the implementation of the LST-Act (from February 2018 to May 2020, Group 2). We measured the self-determination rate and the timing of documentation of Do-Not-Resuscitate (DNR) or Physician Orders for Life-Sustaining Treatment (POLST) in both groups.

Results: A total of 1,834 patients were included in the analysis (Group 1, n=943; Group 2, n=891). Documentation of DNR or POLST was completed by patients themselves in 1.5% and 63.5% of patients in Groups 1 and 2, respectively ($p<0.001$). The mean number of days between documentation of POLST or DNR and death was higher in Group 2 than in Group 1 (21.2 days vs. 14.4 days, $p=0.001$). The rate of late discussion, defined as documentation of DNR or POLST within seven days prior to death, decreased significantly in Group 2 (46.6% vs. 41.4%, $p=0.027$). In the multivariable analysis, hospice palliative care referral (OR [odds ratio] 0.25, $p<0.001$) and patients’ years of education (OR 0.68, $p=0.027$) were positively related to self-determination. However, physicians with clinical experience of less than three years had a higher rate of surrogate decision-making (OR 5.1, $p=0.029$) and late discussion (OR 2.53, $p=0.019$).

Conclusions: After the implementation of the LST-Act, the rate of self-determination increased and EOL discussion occurred earlier than in the era before the implementation of the LST-Act.

Keywords: end-of-life process, life-sustaining treatment, cancer, Physician orders for life-sustaining treatment
Background

Despite recent advances in cancer treatment, cancer has become a leading cause of death worldwide. In Korea, it has been the most common cause of death since 1990 and accounted for 27.5% of all deaths in 2019 [1].

For cancer patients, especially those in the terminal stage, it is important that their personal values and wishes for end-of-life (EOL) care are respected. EOL discussion may reduce aggressive medical care, increase patient and family satisfaction with care, and improve quality of life and survival [2–4]. Advance care planning (ACP) refers to an ongoing process of discussion and review to help patients and families reflect on their goals and values, and to document their preferences for care towards EOL.

In Western countries, it is accepted that patients should be involved in the process of making decisions regarding EOL care [5], and patients can discuss the Physician Orders for Life-Sustaining Treatment (POLST) and Advance Directives (AD) approaches to protect autonomy and dignity.

However, there are many taboos in Korea and other Asian countries regarding discussions on death [6]. In Korea, EOL discussions were avoided or postponed, resulting in very late discussions taking place only when the patient’s death was imminent [7, 8]. Therefore, EOL discussions predominantly occurred between physicians and family members as surrogate decision-makers, excluding patients [9–11]. To advocate for the patients’ wishes and to allow for self-determination in EOL care, the “Life-Sustaining-Treatment Decision-Making Act (LST-Act)” for terminally ill patients came into effect in February 2018 in Korea [12]. Since the implementation of the Act, patients have been able to decide whether they want to apply or suspend life-sustaining treatment (LST) during the EOL process by documenting POLST during the period when death is imminent with no possibility of recovery, and there is a rapid worsening of symptoms despite treatment. Patients can address preferences for LST by documenting POLST at the terminal stage or during the EOL process, and by documenting AD regardless of their illness.

Before the implementation of the LST-Act, decisions for LST care were documented in the do-not-resuscitate (DNR) order, which was not legally effective and may not have entirely reflected the patients’ decisions. Since the implementation of the LST-Act, it has become necessary to document POLST for
all patients who died in hospital. However, it is unclear whether the LST-Act influences EOL discussion in terms of the rate of self-determination and timing of documentation of DNR or POLST.

Therefore, we conducted this study to investigate the changes in EOL discussion in advanced cancer patients during the EOL process after the implementation of the LST-Act.

Methods

Patients, study design, and data collection
This was a single-center, retrospective study of cancer patients who died at the Ulsan University Hospital between July 2015 and May 2020. We assessed patients who had died during two separate periods: the period before the implementation of the LST-Act (from July 2015 to October 2017, “Group 1”) and after the implementation of the LST-Act (from February 2018 to May 2020, “Group 2”). The same inclusion and exclusion criteria were applied to both groups. Cases were limited to patients with cancer at the primary site of head and neck, esophagus, lung, breast, stomach, colorectal, hepatobiliary, and pancreas. We excluded patients with hematologic malignancy, who were younger than 19 years old, or who passed away within two weeks of their first visit to Ulsan University Hospital.

We obtained the two groups’ data from the following sources: the clinical data warehouse platform in conjunction with the electronic medical records, Ulsan University Hospital Information of Clinical Ecosystem, the patient characteristics, the type of document for LST (DNR or POLST), decision-makers, date of documentation of DNR or POLST, date of hospice palliative care (HPC) referral, and period between HPC referral and death.

Definition and outcome measurements
The ‘EOL process’ is when death is imminent with no possibility of recovery, and there is a rapid deterioration of symptoms despite treatment. ‘Terminally ill patients’ are defined as those diagnosed with cancer or other diseases who are expected to die within a few months, and have no possibility of recovery from the underlying disease even with active treatment. ‘LST’ is defined by the LST-Act as
CPR, mechanical ventilation, renal replacement therapy, chemotherapy, and other medical procedures that only extend the duration of the EOL process without any therapeutic effect.

Before the implementation of the LST-Act, the decisions for LST were documented with DNR, and since the implementation of the LST-Act, LST has been decided on using POLST. According to the LST-Act, three steps are required to withhold or withdraw LST in cancer patients during the EOL process. First, two physicians should judge whether the patient is in the EOL process. Second, the patient or patient’s family members should express the patient’s intentions regarding LST by documentation of POLST. If the patient has the ability to make decisions, he/she should express his or her own intentions by in-person documentation of POLST. When the patient is unable to make their own decisions, family members express their intentions for LST on behalf of the patient based on statements made by two or more family members. If it is impossible to verify the patient’s intentions, POLST can be documented through consensus with all adult members of the patient’s family. The final step is clarification of the execution form, describing which LST to withhold or withdraw, as documented by a physician.

To investigate the changes in EOL discussion in advanced cancer patients during the EOL process, we measured the changes between the two separate periods as follows: (1) the rates of patients’ self-determination in documentation of DNR or POLST; (2) the number of days since the date of documentation of DNR or POLST; and (3) the rate of documentation of DNR or POLST within seven days prior to death, reflecting late EOL discussion.

**Statistical analysis**

We examined between-group associations of demographic and clinical variables using Fisher’s exact test for categorical variables and an independent t-test for continuous variables. The factors affecting surrogate decision-making and late EOL discussion (documentation of DNR or POLST within seven days prior to death) were analyzed using logistic regression analysis. Statistical analysis was performed using the Statistical Package for the Social Sciences (IBM, Armonk, NY, USA) version 22.0. We considered a p-value of less than 0.05 to be statistically significant.
Results

Patients’ characteristics

A total of 1,834 patients were included in this analysis: 943 from Group 1 and 891 from Group 2. The rate of national health insurance cover was higher in Group 2 (95.7% vs. 93.3%, \( p = 0.018 \)), and there was no significant difference between the two groups in terms of sex, mean age, primary tumor site, years of education, and rates of receiving chemotherapy. The demographic and clinical characteristics of the patients are summarized in Table 1.

Documentation of DNR or POLST and decision-makers

Table 2 presents the pattern of documentation of DNR or POLST in Groups 1 and 2. During the study period, 713 (75.6%) patients in Group 1 documented DNR. In Group 2, 771 (86.5%) and 4 (0.01%) patients documented POLST and DNR, respectively. The rate of self-determination increased significantly in Group 2 (1.5% vs. 63.5%, \( p < 0.001 \)). The timing of documentation of POLST or DNR prior to death was prolonged in Group 2 (mean, 14.4 days vs. 21.2 days, \( p = 0.001 \)). The rate of late discussion, defined as documentation of DNR or POLST within seven days of death, decreased significantly in Group 2 (46.6% vs. 41.4%, \( p = 0.027 \)).

Referral to hospice palliative care

The rate of referral to hospice palliative care (HPC) was 42.2% and 68.1% in Groups 1 and 2, respectively (\( p < 0.001 \)). Among the referred patients, 35.4% and 54.7% provided consent for referral to HPC in Groups 1 and 2, respectively (\( p < 0.001 \)). The mean duration between HPC referral and death was 36.5 days and 46 days in Groups 1 and 2, respectively (\( p = 0.035 \)) (Table 3).

The factors associated with late discussion and surrogate decision-making
The factors that were associated with inappropriate decision-making, late EOL discussion (documentation of DNR or POLST within seven days prior to death), and surrogate decision-making are presented in Table 4.

Female patients (odds ratio [OR] 0.80, 95% confidence interval [CI] 0.65-0.97, \( p = 0.024 \)) and patients with 12 years of education or more (OR 0.71, 95% CI 0.53-0.84, \( p = 0.022 \)) were significantly less likely to engage in late EOL discussion. When the physician in charge at the time of the patient’s death had less than three years of professional experience, the rate of late discussion significantly increased (OR 2.53, 95% CI 1.18-5.45, \( p = 0.019 \)).

Physicians with clinical experience of less than three years had a higher rate of making decisions with the surrogate decision-makers than with the patients themselves (OR 5.1, 95% CI 1.18-22.1, \( p = 0.029 \)).

The self-determination rate was higher in patients who had 12 years of education or more (OR 0.68, 95% CI 0.419-0.96, \( p = 0.027 \)) and those who were referred to HPC (OR 0.25, 95% CI 0.20-0.33, \( p < 0.001 \)).

**Discussion**

We found positive changes in EOL discussion in advanced cancer patients, such as increased self-determination and earlier EOL discussion after the enforcement of the LST-Act.

In Korea, it is still difficult for physicians to talk about death with patients directly because of the reluctance of family members and the family-centered culture in which families make important decisions about a patient’s care [13]. Physicians also have difficulty in delivering bad news directly to patients and experience emotional discomfort when discussing EOL care [14]. Therefore, EOL discussions are frequently delayed, and communication about a patient’s condition occurs between physicians and surrogate decision-makers when it deteriorates [8, 15]. In previous reports in Korea, DNR directives were documented by surrogate decision-makers in almost all cases [9, 11]. However, contrary to the expectations of physicians and family members, patients wanted to hear about their condition directly from the physician [7]. With the aim of increasing patients’ autonomy regarding the right to make their own decisions about LST during the EOL process, the LST-Act came into full
effect in February 2018 in Korea. Since the LST-Act’s implementation, the rate of self-determination improved to reach 63.5% of our study population, which is a significant increase compared to 1.5% before the implementation of the LST-Act. The self-determination rate in our study is comparable with the rates of previous studies carried out in Western countries, ranging from 23% to 60% [16–18].

Our findings suggest that the LST-Act might promote patients’ participation in EOL discussion. The timing of decision-making regarding LST occurred earlier than before the LST-Act. The mean time between documentation of DNR or POLST and death increased from 14.4 days to 21.2 days after the implementation of the LST-Act. In a recent retrospective study from Korea, decision-making occurred earlier than before the LST-Act’s implementation, ranging from 17 to 33 days prior to the patient’s death [19]. In Korea, DNR directives were usually documented within a week prior to death, which was too late to reflect patients’ wishes for EOL care [8, 9]. Our results imply that the LST-Act has had a positive effect on earlier EOL discussion.

In our study, the rate of HPC referral increased from 42.2% to 68.1% over the study period, and the mean time between HPC referral and death increased from 36.5 days to 46.0 days. Findings from previous studies showed that HPC referral was associated with a reduced frequency of aggressive EOL treatment near death and earlier EOL discussion [19–22]. In multivariable analysis between inappropriate EOL decision-making (late discussion or surrogate decision-making) and patient characteristics, there was a significant decrease in surrogate decision-making in patients who were referred to the HPC team (OR 0.25, \( p < 0.001 \)). HPC consultation could promote earlier EOL discussion, helping patients and family members to understand disease status and HPC options. HPC referrals also help physicians feel less of an emotional burden when discussing EOL treatment. Additionally, the rate of self-determination was high at 63.5% in our study population, compared to the rate of 30% from other Korean analyses conducted at a similar time [19, 23]. This high rate of self-determination could be interpreted as having been activated by the HPC referral system of Ulsan University Hospital which offers inpatient HPC units and home hospice services. Increased HPC referral might have had positive effects on promoting earlier EOL discussion and patient self-determination in our study population.
Multivariable analysis between inappropriate EOL decision-making (late EOL discussion or surrogate decision-making) and patient characteristics showed that female patients and patients with more than 12 years of education were less likely to experience late EOL discussion, and HPC referral was related to less surrogate decision-making. However, physicians with less than three years of professional career experience were related to a higher rate of late EOL discussion and surrogate decision-making. Physicians often receive insufficient training and lack confidence in EOL communication with patients and family members [24]. In a previous study from Korea, medical oncologists and residents stated that knowledge of the medical, legal, and ethical aspects and communicational preparation were needed in broaching EOL discussion [25]. Previous studies have shown that appropriate education and training improve EOL communication skills and ACP [26]. The LST-Act has increased the documentation of POLST, but physicians are still struggling with EOL discussion. Therefore, physicians need to be trained and supported to discuss EOL care, and programs to integrate EOL conversations and ACP documentation are needed for implementation in routine medical care.

Our study has several limitations. First, it is a study from a single institution, and the pattern of EOL discussion and documentation of DNR or POLST might be different from those at other medical institutions. Therefore, caution is needed to not generalize the study findings. Second, it was a retrospective study, with information sources limited to medical records. Interpretation of data needs to be cautious in causal relationships. Despite these limitations, to our knowledge, this is the first study to compare the decision-making patterns before and after the LST-Act.

Conclusions

Our study showed that since the implementation of the LST-Act, the self-determination rate rose in clinical practice and EOL discussion occurred earlier than in the era before the LST-Act. To encourage EOL discussion between physicians and patients, more active interventions, including medical education and training for EOL discussion and HPC referral, are needed to ensure that patients’ goals and values are better reflected in the EOL process.
List of abbreviations

EOL: End-of-life
ACP: Advance Care Planning
DNR: Do-not-resuscitate
POLST: Physician Orders for Life-Sustaining Treatment
AD: Advance Directives
LST: Life-sustaining treatment
LST-Act: Life-Sustaining Treatment Decision-Making Act
HPC: hospice palliative care

Declarations

Ethics approval and consent to participate
The Institutional Review Board of Ulsan University Hospital approved the study protocol (2020-01-018) and waived the need for informed consent for this study given the non-requirement of consent in retrospective analyses covered by regulations in Korea. This study was performed in accordance with the ethical standards of the institutional research and the Declaration of Helsinki.

Consent for publication
Not applicable.

Availability of data and materials
The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Competing interests
The authors declare that they have no competing interests.
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**Authors’ contributions**
- Study concepts: HK, JC, SK
- Study design: HK, JC, SK
- Data acquisition: All authors
- Data analysis and interpretation: JC, HK, DK, CK
- Statistical analysis: JC, DK, CK
- Manuscript preparation: HK, JC, SK
- Manuscript editing: HK, JC, SK
- Manuscript review and approval: All authors

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