Received: 7 June 2021 | Revised: 9 November 2021 | Accepted: 23 December 2021

DOI: 10.1111/jocn.16206

Journal of Clinical Nursing WILEY

ORIGINAL ARTICLE

Life-Sustaining Treatment Decision in Palliative Care Based on Electronic Health Records Analysis

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Funding information
National Research Foundation of Korea, Grant/Award Number: 2020R1I1A2069183

Abstract

Aims and objectives: This study sought to explore the present status of life-sustaining treatment decisions in a tertiary hospital to improve the life-sustaining treatment decision-making process.

Background: Life-sustaining treatment decisions are crucial for palliative care because they encompass decisions to withdraw treatments when patients cannot articulate their values and preferences. However, surrogate decisions have settled many life-sustaining treatment cases in South Korea, and this trend is prevalent.

Design: We conducted a retrospective, descriptive study employing a review of electronic health records.

Methods: We extracted and analysed electronic health records of a tertiary hospital. Our inclusion criteria included adult patients who completed life-sustaining treatment forms in 2019. A total of 2,721 patients were included in the analysis. We analysed the decision-maker, the timing of the decision, and patients' health status a week before the decision. We followed the STROBE checklist.

Results: Among 1,429 deceased patients, those whose families had made life-sustaining treatment decisions totalled 1,028 (70.6%). The median interval between life-sustaining treatment documentation completion to death was three days, more specifically, two days in the family decision group and 5.5 days in the patient decision group. As the decision day neared, there were marked changes in patients' vital signs and laboratory test results, and the need for nursing care increased.

Conclusions: Life-sustaining treatment decisions were made when death was imminent, suggesting that the time required to discuss end-of-life care was generally insufficient among patients, family, and healthcare professionals in Korea.

Relevance to clinical practice: Monitoring changes in laboratory test results and symptoms could help screen the patients who need the life-sustaining treatment discussion. As improving the quality of death is imperative in palliative care, institutional

Abbreviations: ADs, advance directives; EOL, end-of-life; LST, life-sustaining treatment; POLST, physician orders for life-sustaining treatment.

efforts, such as clinical ethics support services, are necessary to improve the life-sustaining treatment decision-making process for patients, families, and healthcare providers.

KEYWORDS
decision-making, electronic health records, life-sustaining treatment, palliative care, terminal care

1 | INTRODUCTION

Despite advanced technology, death tends to be inevitable in the terminally ill phase. Palliative care has been developed based on global interest in pursuing quality of life and relieving symptoms of patients with advanced chronic diseases (Gómez-Batiste et al., 2019). With the passage of time, palliative care will become more imperative owing to increases in deaths from chronic diseases among older patients (Etkind et al., 2017). Correspondingly, the National Institute of Nursing Research (NINR) has consistently funded end-of-life (EOL) and palliative care research to improve planning for EOL decisions for individuals, families and healthcare professionals (National Institute of Nursing Research, n.d.).

The decision to withdraw life-sustaining treatment (LST) is considered imperative in palliative care because it involves decisions to withhold and withdraw treatments when the patient cannot express his or her values, beliefs and preferences (Singer et al., 1999). The purpose of the LST decision is to allow patients to decide whether or not to receive LST when they are in the terminal or EOL phase. In Korea, the 'Act on Hospice and Palliative Care and Decisions on LST for Patients at the EOL' has been enforced since 2018 (Ministry of Government Legislation, 2016). This act ensures that the patient's right to self-determination is respected and that their best interests are guaranteed through the legal protection of their decisions (Ministry of Government Legislation, 2016). For this reason, advance directives (ADs) and physician orders for life-sustaining treatment (POLST) forms have been prepared to realise the patient's autonomy (Choi, 2016; Ministry of Government Legislation, 2016).

Traditionally, Eastern culture places more importance on the family as one's guardians than the West does; hence, EOL decisions tend to be made by family proxy (Ko, 2019; Tanaka et al., 2020). After the act's enforcement, the number of people who register their own LST decisions has consistently increased in Korea (National Agency for Management of Life-Sustaining Treatment, n.d.). In terms of implementation, however, the proportion of family surrogate decisions has still prevailed over the patient's own decision regarding LST. As of December 2020 in Korea, 64.1% of the decisions to withhold or withdraw LST were made by the family of the patient. This rate is higher in tertiary hospitals, at 66.1% (National Agency for Management of Life-Sustaining Treatment, n.d.).

If the patient's condition deteriorates and the patient fails to express a preference regarding LST, the family members' proxy decision is required to infer the patient's intention (Ministry of Government Legislation, 2016). However, as this proxy decision does not always represent that of the patient, the adequate 'timing' of LST decision-making is crucial to reflect their opinions. In critical circumstances, the LST decision-making process might be more complicated due to unplanned admissions or emergent situations in which the patient's condition is often too deteriorated to participate in the decision-making process. However, there is little research to describe the characteristics of the patients who make LST decisions at tertiary hospitals and their health status at that point. Therefore, it is necessary to understand the LST registration status, the decision-making process, and the health conditions of patients who complete the LST form in tertiary hospitals.

This study aimed to explore the current status of LST decisions in a tertiary hospital, the patients' characteristics according to decision-makers, and patients' health status within a week before the decision. Specifically, our research questions comprised the following: 1) Are there any differences in general and clinical characteristics between the two groups with LST decisions made by patients and by families? 2) Does the priority of nursing care change as the LST decision date approaches? 3) Are there any differences in laboratory data and vital signs within seven days as the LST decision date approaches? and 4) Are there any differences in laboratory data and vital signs within seven days before the LST decision between the patients' and the family's decision groups?

What does this paper contribute to the wider global clinical community?

1. Changes in vital signs, symptoms and nursing care needs tended to occur within a week prior to the life-sustaining treatment (LST) decision.
2. The most frequent nursing issues on the LST decision day were 'routine check-up', 'vital sign change' and 'ineffective breathing pattern'.
3. Institutional efforts are necessary, such as clinical ethics support services, to improve the LST decision-making process.

2 | METHOD

2.1 | Study design and participants

This study employed a retrospective descriptive design. We extracted the electronic health records of patients who completed LST decision documents in the Severance Hospital, Yonsei University Healthcare System. Following approval (IRB No. Y-2020–0166) by the institutional review board (IRB) of Yonsei University Healthcare System, on 26 October 2020, we gathered electronic health record data via the Severance Clinical Research Analysis Portal (SCRAP) system, excluding any private personal information. The need for written informed consent was waived due to the nature of our retrospective secondary data analysis. Subsequently, we included patients aged over 20 years. We excluded patients with missing discharge dates or LST forms submitted in a foreign language. In total, we included 2,721 patients' records in the final analysis, which we retrospectively reviewed (Figure 1). We followed the Strengthening the reporting of observational studies in epidemiology (STROBE) checklist for cross-sectional studies (Supplementary Material File 1)

2.2 | Data collection

We based this study on electronic health data written by physicians, nurses and administration staff. Variables were selected based on the four topics approach to clinical ethics case analysis (Jonsen et al., 2015): medical indications, patient preferences, contextual features and quality of life. First, we selected admission and discharge data and comorbidities as medical indications. Particularly, we used diagnoses reported according to the International Classification of Diseases (ICD-10) code to calculate the patients' Charlson comorbidity index (CCI; Charlson et al., 1987). Second, orientation at the time of admission and the type of LST decision reflected patient preferences. Third, contextual features were represented by marital status and the primary caregiver. Lastly, activities of daily living, discharge type, and the period from LST decision to discharge reflected the quality of remaining life.

Furthermore, we collected the participants' nursing records written during the admission period in which the LST decision was made to understand patients' care needs and healthcare providers' clinical burden at the time of the decision. The hospital's electronic nursing record system consists of standard terminologies in three hierarchical groups: nursing diagnosis/protocol, nursing intervention and nursing activities (Kim et al., 2015). Nursing diagnoses are based on the definition and classification of nursing diagnoses of the North American Nursing Diagnosis Association-International (NANDA-I; Herdman & Kamitsuru, 2017). Protocols are defined as nursing issues requiring various nursing interventions and activities, such as catheter care or medication administration (Baik et al., 2019). Nursing diagnosis and protocols have clinical significance given that they are the initial process for nursing intervention and activity decided through a clinical judgment. Nurses' decision for nursing problems is written in the standardised form of a nursing diagnosis/protocol.

We also included vital signs data and the results of laboratory tests performed the nearest day before the LST decision date. The laboratory test results included data relating to participants' albumin, blood urea nitrogen (BUN), creatinine, C-reactive protein (CRP), haemoglobin, lymphocyte, white blood cells (WBC), potassium and sodium. We selected these variables based on their prognostic importance for dying patients, as reported in previous studies (Hwang et al., 2017; Reid et al., 2017). A systematic literature review shows that serum CRP, WBC, lymphocyte count, albumin, BUN and sodium have high-quality evidence as death biomarkers in cancer patients (Reid et al., 2017). In addition, serum haemoglobin, creatinine and potassium are considered biomarkers of mortality in chronic haemodialysis patients (Liu et al., 2021).

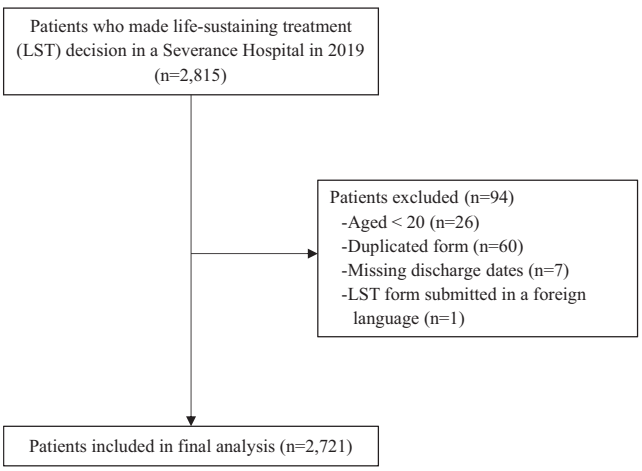

FIGURE 1 Flowchart for selecting the study population

2.3 | Data analysis

We performed data analysis using the software R v4.0.2 and obtained descriptive and inferential statistics to describe and compare the characteristics of the patients who made the LST decisions (version 4.0.2 for Windows; The R Foundation; Vienna, Austria). There are four types of forms related to LST. Form 1 comprises POLST. Using this form, terminal or EOL patients can make the LST plan with their intention to withhold or withdraw LST. Form 10 comprises ADs, representing patients' decisions concerning EOL care ahead of time. If there is neither POLST nor ADs, and patients cannot express their intention concerning LST, two or more of the patients' family members must jointly state the decision regarding the patients' LST intention (Form 11). If none of the above is possible, the entire patient's family should reach a consensus on LST decisions on behalf of the patient (Form 12). We considered Forms 11 and 12 as family decisions while Forms 1 and 10 as patient decisions. From this result, we divided the participants into two groups according to LST decision-makers. We explored the differences between the two groups using the independent t test, Mann–Whitney test or

chi-square test. We would consider a two-sided p-value of less than 0.05 as statistically significant.

We used nursing records to identify frequent nursing issues. First, we extracted nursing diagnosis or protocol written seven days prior to, three days prior to, and on the day the LST decision was made. Even if the same nursing diagnosis or protocol was recorded in multiple lines, it was treated as one case if recorded simultaneously. After this process, the number of nursing diagnosis/protocol logs could reflect the actual number of nursing activities. Hence, we sorted the top 15 nursing diagnoses or protocols of each day in order of frequency to identify patients' care needs. We then calculated the total number of nursing records written on that day and the number of nursing records per patient to estimate nurses' burden.

We sorted vital signs data and laboratory test results conducted within seven days before the LST decision from raw data and divided them into two groups according to the LST decision-makers. We also classified laboratory data and vital signs based on the date when they were conducted or measured. One was from 4 to 7 days before the LST decision, and the other was from 1 to 3 days before the LST decision. Then, we made a comparison between the two groups using an independent t test, excluding missing data.

2.4 | Findings

2.4.1 | Patients' Characteristics

Table 1 shows the patients' general and clinical characteristics. The mean age of patients who made the LST decision was 67.6 ± 13.5 years, and male patients numbered about 60%. More than half of the patients had the LST decision made by their family (53.9%), while only 1.4% of patients used ADs, and 44.7% of patients used POLST. Nearly 60% of the patients died at the hospital, and 25.2% were discharged to go home. There was a median of three days from the LST decision date to discharge or death. The patient's descendant was the most common primary caregiver, followed by a spouse. A total of 87.1% of the patients had an intact orientation regarding time, place and person, while 48.7% of them were independent in their daily living at admission. The mean CCI was 3.4 ± 1.7, and 66.6% of the patients had more than three comorbidities.

Comparison between the two groups according to decision-makers are also shown in Table 1. The patient decision group was younger than the family decision group ($p < .001$), and the proportion of patients who died in the hospital was significantly higher in the family decision group ($p < .001$). The patient decision group exhibited a longer median period from the LST decision to death ($p < .001$). In the patient decision group, most patients had intact orientation (97.4%), and more than half of the patients were independent at activities of daily living (58.4%). However, in the family decision group, 79.2% of the patients had intact orientation ($p < .001$), and only 41.2% of the patients were independent in daily living ($p < .001$). Cancer patients numbered 93.2% of the patient decision group and 69.1% in the family decision group ($p < .001$). Most of the patients suffered from cancer (80%), of which, 52.7% had metastatic solid tumours, followed by those suffering from diabetes without complication and chronic obstructive pulmonary disease (Figure 2).

2.5 | The frequent nursing diagnosis or protocol within a week before the LST decision

Table 2 shows the nursing diagnoses or protocols that were frequently used within a week before the LST decision. At seven days before making the LST decision, there were reported 77,894 nursing diagnoses or protocols. On average, there were 28.6 nursing diagnoses made per patient. The most frequently written diagnosis or protocol was 'Routine check-up' (n = 9,691, 12.4%) followed by 'Acute pain' (n = 6,249, 8.0%) and 'Ineffective breathing pattern' (n = 6,169, 7.9%). Three days before the LST decision, there were 102,593 nursing diagnoses or protocols reported. The number of nursing records per patient was 37.7, which was higher than that of the previous seven days. Similar to the record of the previous seven days, 'Routine check-up' was the most frequently used (n = 12,967, 12.6%), followed by 'Ineffective breathing pattern' (n=8,641, 8.4%) and 'Acute pain' (n = 8,282, 8.1%). On the day of the LST decision, the total number of nursing records and the number of nursing records per patient increased nearly 2.5 times from the previous week (n = 184,303, 67.7, respectively). 'Routine check-up' was still the most frequent nursing protocol (n = 21,581, 11.7%), with the emergence of 'Vital sign change' (n = 19,368, 10.5%). The rank of 'Blood products administration' increased (n = 10,680, 5.8), while the rank of 'Acute pain' decreased (n = 10,329, 5.6%) on the day of the LST decision.

2.6 | Patients' health status within a week before the LST decision

Table 3 represents the patients' health status within a week prior to the LST decision. Especially, we compared clinical data from patients whose laboratory tests and vital signs were conducted 1 to 3 days before the LST decision and those whose were conducted 4 to 7 days before it. Albumin, haemoglobin and lymphocyte in those tested 4 to 7 days prior were higher than in those tested 1 to 3 days prior while BUN, creatinine, CRP, WBC count and sodium were lower in those tested in the preceding 4 to 7 days. In terms of vital signs, patients who were measured 4 to 7 days prior to the LST decision date had higher systolic and diastolic blood pressure and lower heart rate and respiratory rate. There was no significant difference in body temperature between the two groups.

We also compared these results between the two groups according to the LST decision-maker. The family decision group showed

TABLE 1 General and clinical characteristics of participants according to the life-sustaining treatment decision

				(N = 2,721)
	Total (N = 2721)	Family decision (N = 1465)	Patient decision (N = 1256)	
Variables	Mean ± SD, Median [Q1, Q3] or n (%)			p
Age	67.6 ± 13.5	69.6 ± 13.7	65.2 ± 12.9	<.001
20–29	22 (0.8)	17 (1.2)	5 (0.4)	<.001
30–39	49 (1.8)	22 (1.5)	27 (2.1)	
40–49	200 (7.4)	82 (5.6)	118 (9.4)	
50–59	437 (16.1)	185 (12.6)	252 (20.1)	
60–69	709 (26.1)	354 (24.2)	355 (28.3)	
70–79	775 (28.5)	438 (29.9)	337 (26.8)	
≥80	529 (19.4)	367 (25.1)	162 (12.9)	
Sex				
Female	1099 (40.4)	600 (41.0)	499 (39.7)	.541
Male	1622 (59.6)	865 (59.0)	757 (60.3)	
Life-sustaining treatment decision				
1 (POLST)	1217 (44.7)	-	1217 (96.9)	-
10 (ADs)	39 (1.4)	-	39 (3.1)	
11 (≥ 2 family members)	875 (32.2)	875 (59.7)	-	
12 (All family members)	590 (21.7)	590 (40.3)	-	
Admission department				
ER	248 (9.1)	183 (12.5)	65 (5.2)	<.001
ICU	241 (8.9)	202 (13.8)	39 (3.1)	
Ward	1638 (60.2)	913 (62.3)	725 (57.7)	
Others	343 (12.6)	158 (10.8)	185 (14.7)	
Outpatient	251 (9.2)	9 (0.6)	242 (19.3)	
Discharge department (n=2470)				
ER	248 (10.0)	183 (12.6)	65 (6.4)	<.001
ICU	343 (13.9)	325 (22.3)	18 (1.8)	
Ward	1873 (75.8)	947 (65.0)	926 (91.3)	
Others	6 (0.2)	1 (0.1)	5 (0.5)	
Discharge type (n=2470)				
Death	1429 (57.9)	1028 (70.6)	401 (39.5)	<.001
Normal discharge	623 (25.2)	218 (15.0)	405 (39.9)	
Transfer to another hospital	326 (13.2)	168 (11.5)	158 (15.6)	
Hopeless discharge	71 (2.9)	35 (2.4)	36 (3.6)	
Discharge against advice	20 (0.8)	6 (0.4)	14 (1.4)	
Death on arrival	1 (0.0)	1 (0.1)	0 (0.0)	
Days from decision to discharge	7.6 ± 13.9 3 [1,10]	8.4 ± 16.6 3 [1,10]	6.7 ± 9.6 4 [0,10]	<.001 .644†
Days from decision to death (n = 1429)	7.0 ± 14.0 3 [1,8]	6.4 ± 15.1 2 [0,7]	8.4 ± 10.8 5.5 [2,11]	.005 <.001†

(Continues)

TABLE 1 (Continued)

Variables	Total (N = 2721)	Family decision (N = 1465)	Patient decision (N = 1256)	p (N = 2,721)
	Mean ± SD, Median [Q1, Q3] or n (%)			
Marital status (n = 2199)				
Married	1763 (80.2)	987 (79.5)	776 (81.1)	.024
Never married	115 (5.2)	58 (4.7)	57 (6.0)	
Divorced or separated	75 (3.4)	36 (2.9)	39 (4.1)	
Bereavement	243 (11.1)	160 (12.9)	83 (8.7)	
Missing	3 (0.1)	1 (0.1)	2 (0.2)	
Primary caregiver (n = 2217)				
Descendant	1219 (55.0)	756 (60.1)	463 (48.2)	<.001
Spouse	772 (34.8)	385 (30.6)	387 (40.3)	
Sibling	114 (5.1)	53 (4.2)	61 (6.4)	
Parents	62 (2.8)	39 (3.1)	23 (2.4)	
Others	23 (1.0)	8 (0.6)	15 (1.6)	
None	27 (1.2)	16 (1.3)	11 (1.1)	
Orientation at admission (n = 2224)				
Intact	1936 (87.1)	999 (79.2)	937 (97.4)	<.001
Not intact	288 (12.9)	263 (20.8)	25 (2.6)	
ADL at admission (n = 2237)				
Independent	1082 (48.7)	520 (41.2)	562 (58.4)	<.001
Partially dependent	733 (33.0)	403 (31.9)	330 (34.3)	
Totally dependent	409 (18.4)	339 (26.9)	70 (7.3)	
Cancer				
Yes	2182 (80.2)	1012 (69.1)	1170 (93.2)	<.001
No	539 (19.8)	453 (30.9)	86 (6.8)	
Diabetes‡	190 (35.3)	154 (34.0)	36 (41.9)	.202
COPD‡	188 (34.9)	153 (33.8)	35 (40.7)	.266
Renal diseases‡	183 (34.0)	154 (34.0)	29 (33.7)	1
Congestive heart failure‡	180 (33.4)	143 (31.6)	37 (43.0)	.052
Cerebrovascular disease‡	175 (32.5)	159 (35.1)	16 (18.6)	.004
Charlson comorbidity index	3.4 ± 1.7	3.5 ± 1.9	3.3 ± 1.5	.002
0	52 (1.9)	49 (3.3)	3 (0.2)	<.001
1–2	857 (31.5)	428 (29.2)	429 (34.2)	
3–4	1190 (43.7)	611 (41.7)	579 (46.1)	
>=5	245 (19.5)	377 (25.7)	245 (19.5)	

Note: The independent t test was used for continuous variables, and the chi-square test was used for categorical variables.

POLST: physician orders for life-sustaining treatment, ADs: advance directives, ER: emergency room, ICU: intensive care unit, ADL: activities of daily living, Diabetes: diabetes without complication, COPD: chronic obstructive pulmonary diseases, SD: standard deviation.

†Mann–Whitney–Wilcoxon Test, ‡Multiple responses.

higher sodium, BUN, creatinine, CRP, and WBC count than the patient decision group. Systolic and diastolic blood pressure and body temperature of the family decision group were lower than those of the patient decision group. Heart rate and respiratory rate were higher in the family decision group (Table 4).

3 | DISCUSSION

This study showed that among the 1,429 deceased patients in 2019 at a tertiary hospital, patients made their own LST decisions at a rate of 28.1%, while 71.9% were made by their families. There was

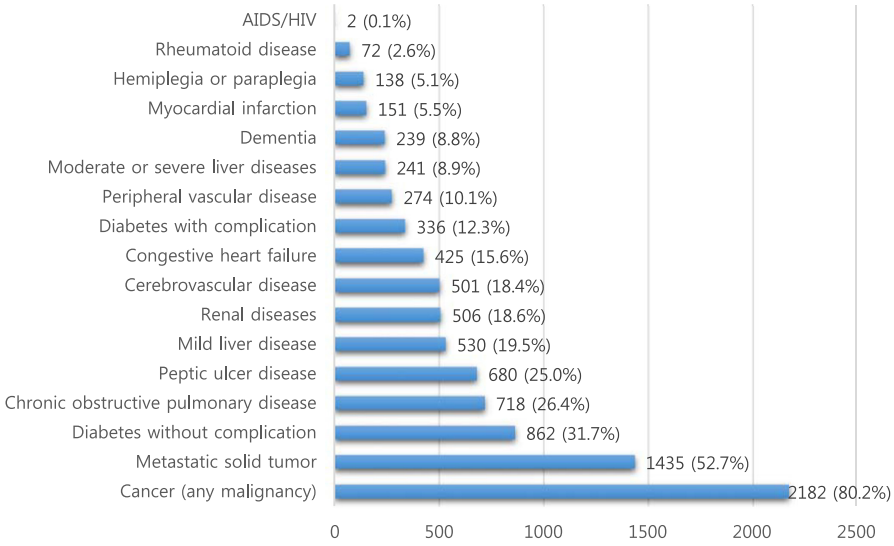

FIGURE 2 Comorbidities of participants (N = 2,721) [Colour figure can be viewed at wileyonlinelibrary.com]

TABLE 2 Trend of frequent nursing issues before making life-sustaining treatment decisions

				(N = 2,721)	
Seven days before the LST decision	**n (%)**	**Three days before the LST decision**	**n (%)**	**The day of the LST decision**	**n (%)**
Total number of nursing records	77,894	Total number of nursing records	102,593	Total number of nursing records	184,303
The number of nursing records/patient	28.6	The number of nursing records/patient	37.7	The number of nursing records/patient	67.7
1. Routine check-up	9,691 (12.4)	1. Routine check-up	12,967 (12.6)	1. Routine check-up	21,581 (11.7)
2. Acute pain	6,249 (8.0)	2. Ineffective breathing pattern	8,641 (8.4)	2. Vital sign change	19,368 (10.5)
3. Ineffective breathing pattern	6,169 (7.9)	3. Acute pain	8,282 (8.1)	3. Ineffective breathing pattern	17,414 (9.4)
4. Medication administration	5,920 (7.6)	4. Medication administration	8,163 (8.0)	4. Medication administration	16,381 (8.9)
5. Catheter care	4,554 (5.8)	5. Catheter care	5,953 (5.8)	5. Blood products administration	10,680 (5.8)
6. Vital sign change	4,085 (5.2)	6. Vital sign change	5,799 (5.7)	6. Acute pain	10,329 (5.6)
7. Risk for falls	3,532 (4.5)	7. Blood products administration	5,014 (4.9)	7. Catheter care	9,943 (5.4)
8. Blood products administration	3,374 (4.3)	8. Risk for falls	4,673 (4.6)	8. Tube care: Urinary	9,024 (4.9)
9. Tube care: Urinary	3,109 (4.0)	9. Tube care: Urinary	4,345 (4.2)	9. Risk for falls	6,107 (3.3)
10. Risk for injury	2,663 (3.4)	10. Risk for injury	2,925 (2.9)	10. Risk for injury	4,110 (2.2)
11. Tube care: Drainage	1,956 (2.5)	11. Tube care: Drainage	2,598 (2.5)	11. Tube care: Gastrointestinal	3,839 (2.1)
12. Neurologic monitoring	1,831 (2.4)	12. Tube care: Gastrointestinal	2,342 (2.3)	12. Tube care: Drainage	3,344 (1.8)
13. Hyperthermia	1,740 (2.2)	13. Hyperthermia	2,286 (2.2)	13. Hyperthermia	3,218 (1.7)
14. Tube care: Gastrointestinal	1,737 (2.2)	14. Neurologic monitoring	2,157 (2.1)	14. Neurologic monitoring	3,078 (1.7)
15. Risk for impaired skin integrity	1,655 (2.1)	15. Risk for impaired skin integrity	1,989 (1.9)	15. Deficient knowledge	2,900 (1.6)

Abbreviations: LST: Life-sustaining treatment.

TABLE 3 Comparison of clinical data according to days before making a life-sustaining treatment decision

					(N = 2,271)
Variables	**4~7 days ago**	**n**	**1~3 days ago**	**n**	**p**
Albumin (g/dL)	3.09 ± 0.61	227	2.87 ± 0.57	2026	<0.001
BUN (mg/dL)	22.51 ± 17.02	164	33.10 ± 24.52	2088	<0.001
Creatinine (mg/dL)	0.90 ± 0.76	164	1.24 ± 1.16	2078	<0.001
CRP (mg/L)	82.80 ± 85.54	246	105.46 ± 90.65	1812	<0.001
Haemoglobin (g/dL)	10.49 ± 2.25	150	9.69 ± 1.92	2116	<0.001
Lymphocyte (%)	14.67 ± 12.11	200	10.58 ± 11.28	1977	<0.001
WBC count (10^3/μL)	9.64 ± 5.61	151	12.18 ± 10.79	2115	<0.001
Potassium (mmol/L)	4.26 ± 0.58	138	4.20 ± 0.74	2086	0.301
Sodium (mmol/L)	135.28 ± 5.71	138	136.42 ± 6.60	2087	0.026
SBP (mmHg)	125.34 ± 18.55	59	119.47 ± 21.04	2039	0.034
DBP (mmHg)	77.36 ± 12.22	59	72.66 ± 14.89	2039	0.017
HR (beat/min)	86.66 ± 14.95	59	98.50 ± 20.56	2039	<0.001
BT (°C)	36.98 ± 0.50	291	36.92 ± 0.76	1129	0.093
RR (breath/min)	18.88 ± 2.03	57	20.58 ± 4.30	2035	<0.001

Note: The independent t test was used BUN: blood urea nitrogen, CRP: C-reactive protein, WBC: white blood cell, SBP: systolic blood pressure, DBP: diastolic blood pressure, HR: heart rate, BT: body temperature, RR: respiration rate.

TABLE 4 Comparison of clinical data within seven days according to decision-maker for life-sustaining treatment

					(N = 2,271)
Variables	**Family decision**	**n**	**Patient decision**	**n**	**p**
Albumin (g/dL)	2.86 ± 0.59	1257	2.94 ± 0.56	996	0.001
BUN (mg/dL)	36.79 ± 26.30	1251	26.75 ± 19.96	1001	<0.001
Creatinine (mg/dL)	1.34 ± 1.24	1243	1.06 ± 0.97	999	<0.001
CRP (mg/L)	109.23 ± 96.49	1177	94.10 ± 80.64	881	<0.001
Haemoglobin (g/dL)	9.68 ± 2.03	1258	9.82 ± 1.85	1008	0.083
Lymphocyte (%)	10.95 ± 12.85	1205	10.97 ± 9.35	972	0.958
WBC count (10^3/μL)	12.51 ± 10.85	1258	11.38 ± 10.12	1008	0.011
Potassium (mmol/L)	4.20 ± 0.75	1242	4.22 ± 0.72	982	0.443
Sodium (mmol/L)	137.53 ± 7.08	1243	134.86 ± 5.46	982	<0.001
SBP (mmHg)	118.86 ± 22.35	1195	120.66 ± 19.01	903	0.047
DBP (mmHg)	70.55 ± 15.71	1195	75.76 ± 13.04	903	<0.001
HR (beat/min)	100.57 ± 21.46	1195	94.98 ± 18.73	903	<0.001
BT (°C)	36.89 ± 0.83	845	36.99 ± 0.49	575	0.004
RR (breath/min)	20.87 ± 4.89	1193	20.09 ± 3.19	899	<0.001

Note: The independent t test was used. BUN: blood urea nitrogen, CRP: C-reactive protein, WBC: white blood cell, SBP: systolic blood pressure, DBP: diastolic blood pressure, HR: heart rate, BT: body temperature, RR: respiration rate.

a median gap of three days between decision-making and death across both groups, which meant that they still made LST decisions at the end of their life.

From Korean national data in the same period, patients made their own LST decision at a rate of 34.4%, and this gradually increased until December 2020, with 35.9% (National Agency for Management of Life-Sustaining Treatment, n.d.). This trend shows that more respect may be given to patients' autonomy than in the past. Similarly, in the United States, approximately 45% to 70% of older people who needed EOL decisions in one study could not make those decisions due to their deteriorated condition (Institute of Medicine, 2015). These facts show that there is room for improvement to prevent continued futile LST, which causes family members' financial and emotional distress and decreases patients' quality of death (Carr & Luth, 2017).

In terms of timing, there was a median interval of 5.5 days between the ADs or POLST decision to death. In a study using the Oregon POLST registry, POLST decisions were completed

several weeks before death (median 6.4 weeks; Zive et al., 2015). In another study, most ADs were completed more than a year in advance (median 41 months; Enguidanos & Ailshire, 2017). This means that these patients started discussing EOL and palliative care earlier and had more time to prepare for their deaths than Korean patients did. Conversely, this study showed that families made these decisions at a median of two days before death. Of the patients whose families made the surrogate decision, 23.9% were admitted through the Intensive Care Unit (ICU) or Emergency Department (ED), and 20.8% did not have intact orientation at admission. Therefore, they would have been less likely to make their LST decision during hospitalisation due to their health status. However, the patients who had intact orientation at admission (80%) also failed to make LST decisions independently. This implies that they had missed the opportunity to make a timely decision for reasons such as an acute deterioration before discussing EOL care. This resulted in their family or surrogates making LST decisions shortly before their demise. Usually, delayed LST decisions lead to aggressive care (Kehl & Kowalkowski, 2012). Therefore, we need to find an appropriate time and ways, according to their respective conditions, to help patients articulate their preferences concerning LST while they are still cognitively intact.

We need to focus on changes in vital signs, laboratory test results, and symptoms for early LST discussions. Our study results show that laboratory test results had already shown some changes three days before the LST decision, becoming more obvious as the day approached. Additionally, the nursing protocol of 'vital sign change' and 'blood product administration' increased during this period in the nursing record. These results imply that the LST decision was made after patients' health status worsened. According to a systematic review, serum CRP, albumin, WBC, and lymphocyte count can be used as biomarkers of imminent demise in cancer patients for prognosis (Reid et al., 2017). Terminal patients experience dyspnoea, pain, and confusion most frequently in the last two weeks of their lives (Kehl & Kowalkowski, 2012). This means that patients who need an imminent LST discussion could be screened using these laboratory test results and their symptoms at least two weeks before death. Without a doubt, a regular neurological assessment for detecting changes in consciousness is crucial to ensuring a more appropriate time for the LST decision.

Although there are many predictive tools that can be employed to better navigate the EOL, sometimes it would be less accurate to predict death than physicians' or nurses' clinical predictions of survival (Stone et al., 2021). For example, the Palliative Performance Scale could predict one's remaining life (Lau et al., 2009), but it is likely to be subjective and have relatively low face validity (Kalpakidou et al., 2018). The palliative prognostic index based on several signs and symptoms in addition to the performance scale can also be useful, but it has high accuracy to estimate imminent dying (Stone et al., 2008). More objective measures using biomarkers have also been developed, such as the modified Glasgow prognostic score using albumin and CRP and Prognosis in Palliative care Study predictor models (Baba et al., 2015; Gwilliam et al., 2011; Proctor et al., 2011). However, studies usually examine these in the context of advanced cancer patients, while disease trajectory can significantly differ between advanced cancer and other advanced chronic diseases (Teno et al., 2001).

We suggest it would be valuable to combine relevant data, including the changed pattern of nursing records, signs, and symptoms, in the prognostic model for dying patients' personalised care. According to the findings of this study, nurses' primary duty was monitoring vital signs and symptoms, given that the most frequent nursing protocol was 'routine check-up.' It encompasses monitoring patients' pain, neurologic status, quality of sleep, and even defecation status. Therefore, in addition to prognostic judgment based on laboratory data, nurses' insights that integrate various data play a crucial role in grasping sudden condition changes among EOL patients.

The nursing diagnosis 'knowledge deficit' tended to exhibit on the decision day, which means the health care professionals (HCPs) assessed knowledge and provided information regarding the LST when patients' demise was imminent. Decision-making, including patient autonomy and surrogate decision-making, is the most frequent ethical issue in the terminal stage (Wasson et al., 2016). Therefore, we should ensure that there is a system to support communication between patients, family and HCPs in advance rather than recommend or negotiate LST withdrawal shortly before the patients' demise (Piscitello et al., 2019). Family readiness towards patients' death is also essential. According to a systematic review regarding advance care planning (ACP), conversation about ACP was only valuable when patients were ready for the discussion (Zwakman et al., 2018). When there is discordance between families and HCPs, they tend to continue the patients' treatment regime (Carr & Luth, 2017). Thus, HCPs should support them in coming to a consensus for LST decision-making earlier in the disease trajectory (Wiegand, 2008). As an institutional effort, including clinical ethics support services, such as ethics education, consultation, or ethics committees for HCPs, patients and family members, would help improve the decision-making process for patients receiving palliative care.

This study has several limitations. First, we were not able to identify each patient's level of withdrawal from LST. We only found whether or not they completed the LST form and the type of form they used. Therefore, various analyses according to the withdrawal level of LST were limited. Second, as we could not extract longitudinal laboratory data, only a simple comparison between test results conducted in different periods was possible rather than a paired comparison of the same patient. Third, since we decided that the variables were insufficient to find relative factors affecting LST decisions or predict decisions with good validity, we only conducted a bivariate analysis to identify the difference between the two groups. Therefore, a prospective study is needed to validate the predictors' effects. Lastly, the generalisability of this study is limited because it was conducted at a single medical centre.

Despite these limitations, our study is valuable in that we tried to grasp the trend of LST decisions in a tertiary hospital. We

comprehensively analysed patients' health conditions and their needs for nursing care around the time of the LST decision. To improve patients' quality of death and reduce families' and HCPs' burden regarding the LST decisions, we suggest that further studies should introduce clinical ethics support services and examine their effect on patients' comfort and the quality of EOL care.

4 | CONCLUSION

This retrospective study, based on patients' electronic health records, showed that families' decisions regarding LST withdrawal were still more prevalent than patients' own decisions. In Korea, the LST decisions were made a few days before the patients' demise. As the lack of sufficient time to discuss LST causes a decreased quality of death for patients, a timely discussion about patients' intentions and preferences about EOL care is necessary before their conditions deteriorate.

5 | RELEVANCE TO CLINICAL PRACTICE

Monitoring changes in laboratory test results and symptoms could help screen the patients who need the life-sustaining treatment discussion. As improving the quality of death is imperative in palliative care, institutional efforts, such as clinical ethics support services, are necessary to improve the life-sustaining treatment decision-making process for patients, families, and healthcare providers.

ACKNOWLEDGEMENTS

None.

CONFLICT OF INTEREST

The author(s) declare no potential conflicts of interest concerning the research, authorship and/or publication of this article.

AUTHOR CONTRIBUTION

Sanghee Kim involved in conceptualisation, methodology, formal analysis, resources, writing – review and editing draft, final approval, supervision, project administration, funding acquisition. **Arum Lim** involved in data curation, formal analysis, writing – original draft, review and editing draft, final approval. **Hyoeun Jang & Misun Jeon** involved in formal analysis, writing – review and editing draft, final approval.

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SUPPORTING INFORMATION

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How to cite this article: Kim, S., Lim, A., Jang, H., & Jeon, M. (2023). Life-Sustaining Treatment Decision in Palliative Care Based on Electronic Health Records Analysis. *Journal of Clinical Nursing*, 32, 163–173. https://doi.org/10.1111/jocn.16206