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Issues and implications of the life-sustaining treatment decision act: comparing the data from the survey and clinical data of inpatients at the end-of-life process

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Abstract

Background Health professionals had difficulty choosing the right time to discuss life-sustaining treatments (LSTs) since the Korean Act was passed in 2018.

Objective This study aimed to understand how patients decide to undergo LSTs in clinical practice and to compare the perceptions of these decisions among health professionals, patients, and families with suggestions to support the self-directed decisions of patients.

Research design A retrospective observational study with electronic medical records (EMRs) and a descriptive survey was used.

Methods The data obtained from the EMRs included all adult patients who died in end-of-life care at a university hospital in 2021. We also conducted a survey of 214 health professionals and 100 patients and their families (CNUH IRB approval no. 2022-07-006).

Results Based on the EMR data of 916 patients in end-of-life care, 78.4% signed do-not-attempt-resuscitation consents, 5.6% completed the documents for LSTs, and 10.2% completed both forms. LST decisions were mostly made by family members (81.5%). Most survey participants agreed that meaningless LSTs should be suspended, and the decision should be made by patients. Patients and family members (42–56%) and health professionals (56–58%) recommended discussing LST suspension when the patient is still conscious but with predicted deterioration of their condition. The suffering experienced by the patient was considered to be a priority by most patients (58%) and families (54%) during the decision-making process, while health professionals considered “the possibility of the patient’s recovery” to be the highest priority (43–55%).

Conclusions There is still a significant discrepancy in the perceptions of LST decisions among health professionals, patients, and their families despite high awareness of the Act. This situation makes it challenging to implement the

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Act to ensure respect for the rights of patients to self-determination and dignified end-of-life. Further effort is needed to improve the awareness of LSTs and to clarify the ambiguity of document preparation timing.

Keywords End-of-life care, Life-sustaining treatment withhold and withdrawal, Do-not-attempt-resuscitation orders

Introduction

The Korean Act on Hospice Palliative Care and Decisions About Life-Sustaining Treatment for End-of-Life Patients (hereafter referred to as the “the Act”) came into effect in February 2018 in order to ensure that patients are respected and treated with dignity and respect in their end-of-life care [1]. There are many factors that influence patients’ decisions to discontinue life-sustaining treatments (LSTs), including their condition, their family and socio-cultural background, and the laws and regulations of their country. Two major historical events contributed to the enactment of the Act in Korea. In the first event, a doctor was legally punished for removing a life-support machine from a patient at the family’s request, who was uncertain about his recovery, resulting in his death. As for the second care, a family’s request to discontinue life-sustaining treatment for a patient who will never recover was legally accepted, respecting the patient’s dignity and values. These cases played a critical role in shaping public discussion and subsequent legislation on LST withdrawal [2].

There were 289 institutions nationwide as of April 2022 that were accredited to register advance statements on LSTs in South Korea, and patients are increasingly participating in the decision-making process [3]. Despite the increasing use, various conflicts and confusion persist in the application of the Act after 4 years of its being enacted, including procedure complexity and a lack of social awareness and awareness among medical personnel [4, 5]. Prior to the enactment of the law in 2018, clinical settings used consent forms for “Do-not-resuscitate” (DNR) orders from patients or their families when patients had slim chances of recovery, indicating the decision not to perform cardiopulmonary resuscitation in terminally ill patients with no chance of recovery. However, such forms did not provide complete legal protection to healthcare professionals, who were still responsible for discontinuing treatment. There was a strong demand within the medical community for legislation on end-of-life care decisions to ensure legal protection in cases of discontinuing futile life-sustaining treatment. The law was enacted following years of debate between the government, academia, the medical community, and media, reflecting societal consensus and respect for individual autonomy. Although the law was passed after much consideration, there are several areas that need improvement in its application in medical settings [5].

According to the Act, life-sustaining treatment refers to “medical procedures performed on a patient in the

terminal stage, including cardiopulmonary resuscitation, hemodialysis, chemotherapy, mechanical ventilation, transfusion, vasopressors, extracorporeal life support, and other procedures even if they only prolong the dying process without therapeutic effect” [1]. Terminal stage is defined as “a state where there is no possibility of recovery despite treatment, and symptoms rapidly deteriorate to the point of imminent death”. In addition to oral intake, all forms of artificial nutritional support, such as nasogastric feeding, gastrostomy, and parenteral nutritional support, are non-deferrable and non-suspendable. The decision to discontinue life-sustaining treatment is only possible once it has reached the terminal stage [1, 6].

The Act mandates that the decision to terminate LSTs must be made at the end-of-life stage when there is no possibility of recovery [1]. It is challenging to determine the prognosis and potential for recovery of a patient due to inherent medical uncertainty. Life-sustaining treatment can be withheld or withdrawn legally based on a medical judgment about the potential for recovery. It is not permissible to withhold or withdraw life-sustaining treatment in cases of Persistent Vegetative State (PVS) where there is a potential for recovery. However, in irreversible brain injuries such as brain death, withholding or withdrawing life-sustaining treatment is permissible [7]. The meaning of recovery should be interpreted and understood from the perspective of patients and their families since even seemingly insignificant physiological changes may hold significant value for them. It is, therefore, essential for healthcare professionals to adopt an approach that seeks to interpret and understand the meaning of recovery from the perspective of patients and their families [8].

Medical professionals also find it difficult to determine the appropriate time to discuss LSTs due to uncertainty in prognoses [6, 9, 10]. According to Article 17 of the Act, legal representatives, primary physicians, or family members may terminate LSTs on behalf of patients whose prior intent cannot be confirmed and whose medical conditions prevent them from expressing themselves [1]. There is a relationship between “recovery” and “the goal of care”, and differences in perception among healthcare providers, patients, and families regarding the level of recovery and treatment goals complicate decision-making for life-sustaining treatment [8]. Although the family of the patient is given authority and responsibility, a serious concern has been raised about the discrepancy in decisions between patients and their families [6]. Moreover, as the Act only covers spouses and immediate

family members, it would not be applicable to patients living alone or without a legal family member [11, 12].

Hospital ethics committees in the United States determine whether to suspend LSTs when the explicit intention of the patient to live cannot be confirmed. The attending physician of a patient is also often referred to as the decision-making body when life-sustaining medical care is discontinued in many European countries, including France and Germany [13]. Previous studies found that in this case, the primary physician tends to see discontinuing treatment as a failure of their practice [4]. There have also been cases where discontinuing LSTs is regarded as death with dignity or euthanasia, which is not consistent with the original intent to respect the autonomy and dignity of patients.

A primary purpose of the Act is to protect the best interests of the patient in end-of-life care by protecting their right to self-determination. It is essential for health professionals caring for patients to understand the principles of the Act in order to effectively implement and apply it in clinical practice [9]. Nevertheless, surveys on the awareness of the LST determination system that targeted health professionals, patients, and their families have been insufficient since the law was implemented [14].

The purpose of this study was to examine the perceptions of health professionals, patients, and their families on LST decisions, to identify issues related to the decision-making body and the appropriate timing of the LST decision, and to suggest directions for policy improvement to minimize confusion during implementation.

Methods

Study design

The study consisted of two phases. Phase 1 examined the implementation status of the Act through a retrospective observational descriptive study using electronic medical records (EMRs). Phase 2 involved conducting a cross-sectional survey in which patients, their families, and health professionals were surveyed about their perceptions of the decision-making process for LSTs.

Data collection and participants

The first phase of the study comprised a retrospective observational descriptive study on all patients 18 years or older admitted between January 1 and December 31, 2021, who underwent end-of-life care (i.e., legally terminated LSTs) and died in a university hospital. Those admitted to hospice wards or who died after trauma or emergency surgery were excluded. In the EMRs, information on age, sex, admission date, expiration date, and do-not-attempt-resuscitation (DNAR) order and LST-related information (date of signing the consent form, who signed, and clinical status) were collected.

The second phase of the study comprised a descriptive investigation of the awareness of individuals of prior LST decisions. The questionnaire for the study was adapted from the standardized items used for the national survey of public awareness of the system for making decisions to forego LST conducted by the Ministry of Health and Welfare and the National Agency for Management of Life-sustaining Treatment [9, 15]. We selected the sample size based on the recommendation of Johnston et al. [16] that less than 20% of the target subjects fit the descriptive study design. Upon approval of the study protocol by the Institutional Review Board at the university hospital to which the researchers were affiliated, a survey questionnaire was sent to all medical doctors and nurses in August 2022 with the following inclusion criteria: (1) worked directly or indirectly with patients in end-of-life care involving LST decisions and (2) understood the purpose of the study and agreed to participate. The questionnaires were completed by 110 medical doctors and 110 nurses working in medical or hospice units at selected general hospitals. In addition to health professionals, patients and their families who received outpatient or inpatient treatment were also included in the study. Participants had to be 21 years old or older, receiving care in an outpatient or inpatient setting, accompanied by family members, and provided a written consent form. The recruitment process was completed when 110 patients and family members responded to the questionnaires. Following the exclusion of several cases with missing data, a final analysis was conducted on 314 participants.

Data analysis

A descriptive analysis of the demographics and clinical characteristics of patients was performed using descriptive statistics such as mean and standard deviation for the data with normal distribution or median and interquartile range for the data with non-normal distribution, and proportions of patients. ANOVA, Chi-square and t-tests were used to compare the awareness of, participation in, and compliance with LSTs among doctors, nurses, and patients and their families.

Ethical considerations

Institutional review board (IRB) approval was obtained for the protocol of this study from Chungnam National University Hospital, where the researchers were affiliated (IRB no. CNUH-2022-07-006). The study was conducted according to the principles outlined in the Declaration of Helsinki. During the phase 1 retrospective study, after obtaining approval with informed consent waivers, the raw data were extracted from the EMR, and patient identities (names and hospital ID) were de-identified. During the phase 2 survey, a written informed consent form was

obtained from the respondents before interviews were initiated.

Results

Phase 1. Data from EMRs

Timing of the DNAR order and deciding about LST discontinuation

An EMR data set of 916 patients with an average age of 71.4 (median 74) years was analyzed. Early-warning scores predicted that the critical state of patients would increase as the day of death approached, with average scores increasing from 5 (IQR 3–8) at 6 days before death to 11 (IQR 8–11.75) on the day of death. The median periods from ‘time of consent’ to ‘time of death’ were 2 (IQR

1–7) days for DNAR orders and 1 (IQR 0–2) days for LST discontinuation (Table 1).

Implementation status of DNAR orders and LSTs

During end-of-life care, 78.4% signed do-not-attempt-resuscitation consents and 5.6% signed the documents for LSTs, while 10.2% completed both forms. The decisions concerning LSTs were primarily made by the family (81.5%), such as the children, spouses, or parents of the patients. Only 4.1% of patients made a decision about LSTs by themselves. The DNAR and LSTs (withhold/withdraw) consent forms were signed within 1–2 median days before death (Table 1). Additional analysis indicated that those who signed the DNAR orders themselves were significantly younger (64.2 (SD=10.85) vs. 71.7 (SD=14.76) years; $t=3.11, p=.002$), and the period between signing the form and death was longer (17.9 (SD=28.84) vs. 8.4 (SD=25.54) mean days; $t=2.23, p=.02$) than for those who had their forms signed by others.

Table 1 Implementation status of do-not-attempt-resuscitation (DNAR) orders and life-sustaining treatments (LSTs) in electronic medical records

Variable	Median	IQR	
		Q1	Q3
Age (years)	74	64	81
Admission to DNAR (days)	3	0	14
Admission to WHWD (days)	13.5	5	25.25
Admission to consultation (days)	11	4	22
DNAR to death (days)	2	1	7
WHWD to death (days)	1	0	2
EWS on day of death	11	8	11.75
EWS at 1 day before death	8	6	10
EWS at 2 days before death	7	5	9
EWS at 3 days before death	6	4	8
EWS at 4 days before death	6	4	8
EWS at 5 days before death	6	3	8
EWS at 6 days before death	5	3	8
	n	%	
DNAR consent signed	720	78.4	
WHWD consent signed	52	5.6	
Both DNAR and WHWD signed	94	10.2	
Neither signed	52	5.7	
Sex Female	328	35.7	
Male	590	64.3	
Who signed DNAR or WHWD			
Patients	38	4.1	
Spouse	195	21.2	
Children	507	55.2	
Parent	21	2.3	
Sibling	35	3.8	
Others/relatives	15	1.6	
When signed DNAR or WHWD			
Before admission	51	5.6	
After admission	305	33.2	
Critical condition	193	21.0	
Expecting death	264	28.8	

Note. IQR, interquartile range; WHWD, decision to withhold/withdraw LST; EWS, early-warning score

Phase 2. Data from a descriptive survey

The final analysis included 214 health professionals and 100 patients and their families. Figure 1 shows the recruitment process.

Awareness of health professionals about LSTs

Table 2 lists the general characteristics of health professionals and their awareness of the implementation of the Act. Most health professionals (94.6% of nurses and 95.1% of doctors) reported that they were in favor of suspending meaningless LSTs. Regarding the subjects of the decision to discontinue LSTs at hospitals, doctors and nurses both consistently reported the family of the patients as the primary decision-makers (65.5–83.7%), followed by the patients (9.6–23.6%) and their primary physician (6.7–10.9%). These health professionals agreed that the guardian (family) should decide about LSTs if the patient cannot express their wishes. Most doctors (56.7%) and nurses (59.1%) suggested that the appropriate timing to discuss the discontinuation of LSTs should be “when the patients are critical but conscious,” and “recovery possibility” was the most important issue during the decision-making process for LSTs. Both groups suggested “not clear when to start the process” as the main reason why they did not implement the Act in clinical situations, followed by “lack of understanding of the Act,” as reported by 24.5% of nurses and 26% of doctors. The most challenging issues related to implementing the Act were “deciding the right timing” (25.5–39.4%) and “discrepancy in wishes between patients and their families” (25.5–32.7%). When a patient is unable to sign a document and there is no family member or proxy individual,

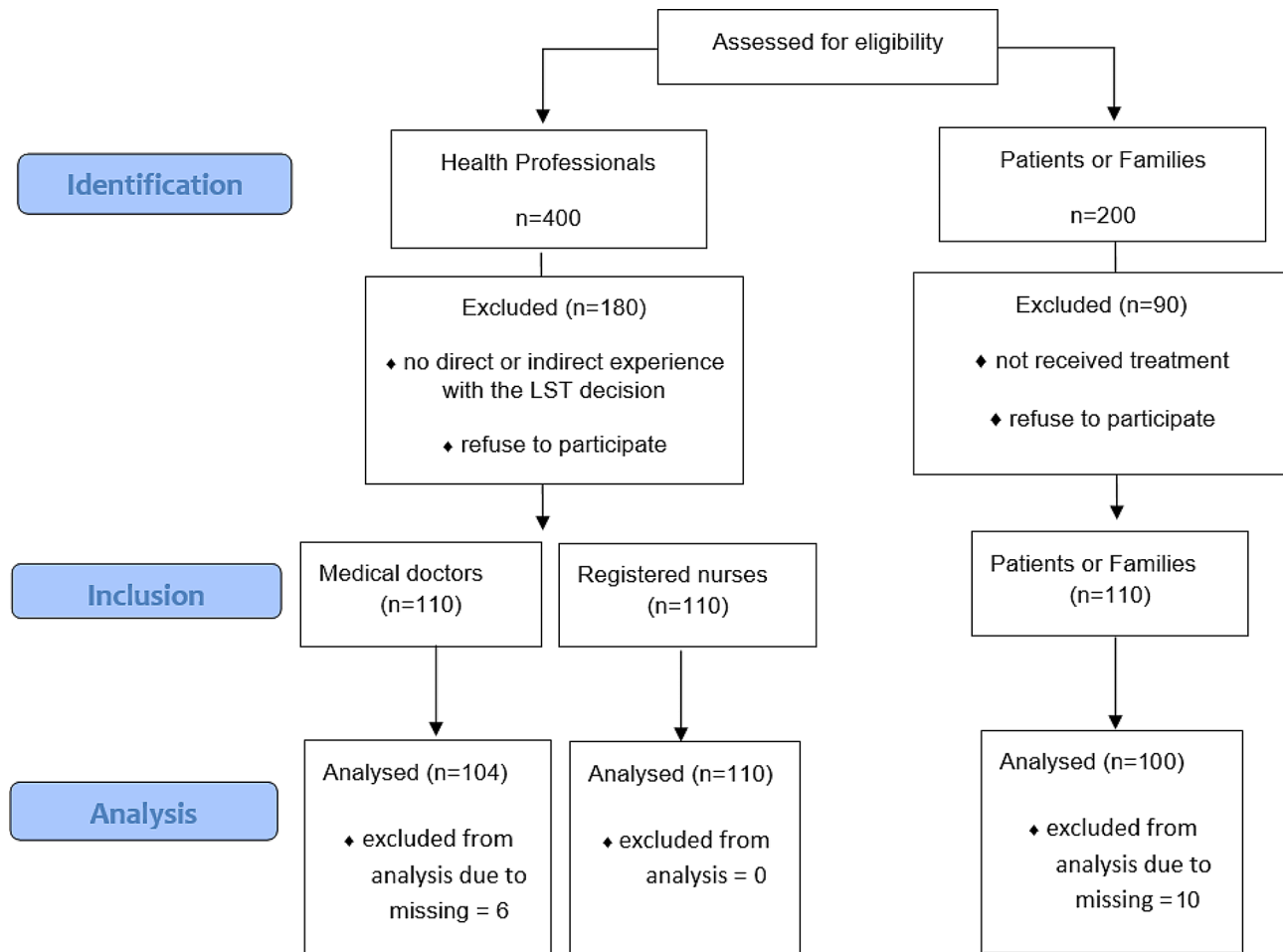


Fig. 1 Flow diagram of the study

both groups agreed that the primary physician should make the decision about LSTs (70.0–86.6%).

Awareness of patients and families about LSTs

Table 3 lists the general characteristics of the patients and their families and their perceptions of implementing the Act. The average ages of the patients and their family members were 57.1 and 53.1 years, respectively. Most patients (58.7%) and family members (72.2%) were married. Most patients (n=33, 71.7%) and family members (n=45, 83.4%) were somewhat or highly aware of the Act. One in five participants signed the LST document, while most patients (84.8%) and their families (87%) supported discontinuing meaningless LSTs. Most family members (77.8%) and patients (73.9%) agreed that patients should make decisions about LSTs. However, most of them would discuss their LST decision with their spouse (30–46%) or children (20–26%). In most cases, patients and their families did not want other people to make decisions about LSTs for them, but 73.9% of patients and 88.9% of their families agreed that other people can make the decision if they are not able to make it for themselves.

Both patients and their families recommended discussing the suspension of LSTs when patients were conscious but severe deterioration was expected (42.5–66%). Patients reported patient suffering (58%) or family suffering (19.6%) as the most important factors for decision-making, whereas families reported patient suffering (54%) or the possibility of recovery (24%). Most patients (80.5%) and family members (94.4%) were willing to sign the DNAR orders at the time of admission. While most patients (69.6%) and families (87%) supported the suspension of LSTs for terminally ill patients, 17.4% agreed that it depended on the situation. The primary doctor or ethics committee is the preferred entity for making LST decisions when the patients have no relatives or immediate family at the end of life.

Discussion

The Act on Life-sustaining Treatment Decisions was enacted in 2018, and the present multiphase study was conducted to determine the clinical implementation status based on EMR data, and the level of awareness among health professionals, patients and their families

Table 2 Awareness of health professionals about the Act

Variable	Nurses (n = 110)		Doctors (n = 104)		t	p
	Mean	SD	Mean	SD		
Age (years)	29.1	6.26	33.81	7.98		
Clinical experience (years)	5.81	6.13	4.71	6.31		
How much explain the Act to patients (0–10)	4.61	2.07	5.73	2.67	−3.38	0.001
How well the Act is implemented in practice (0–10)	5.47	1.66	5.47	2.51	0.005	0.996
Awareness of the Act	n	%	n	%	χ^2	p
Highly aware	13	11.8	27	26	7.33	0.026
Somewhat aware	87	79.1	67	64.4		
Heard of it	10	9.1	10	9.6		
Suspension of meaningless LST						
Definitely agree	34	31	50	48.1	7.42	0.060
Agree	70	63.6	49	47.1		
Disagree	5	4.5	3	2.9		
Definitely disagree	1	0.9	2	1.9		
Who should decide LST suspension						
Patients	26	23.6	10	9.6	14.1	0.003
Family members	72	65.5	87	83.7		
Primary physician	12	10.9	7	6.7		
Time to sign the advance LST statement						
When diagnosed with terminal illness	12	10.9	9	8.7	5.5	0.358
When hospice care is decided	17	15.5	13	12.5		
Critical condition but conscious	65	59.1	59	56.7		
Critical condition and unconscious	15	13.6	20	19.2		
Others	1	0.9	3	2.9		
LST decided by family if patients cannot						
Agree	65	59.1	64	61.5	0.134	0.715
Agree when pre-requested	45	40.9	40	38.5		
Disagree	0	0	0	0		
Important factors for LST-related decisions						
Recovery possibility	47	42.7	57	54.8	4.798	0.441
Patient suffering	28	25.5	20	19.2		
Patient wishes	31	28.2	25	24		
Family wishes and requests	3	2.7	2	1.9		
Economic burden	1	0.9	0	0		
Policy and legal processes	0	0	0	0		
Awareness of LST since the Act						
Improved	72	65.5	75	72.1	2.86	0.239
Somewhat improved	22	20	12	11.5		
No change	16	14.5	17	16.3		
Most challenging issues in implementing the Act						
Filling out the legal form	4	3.6	7	6.7	3.001	0.558
Deciding the right timing	51	46.4	41	39.4		
Family opinion against the patient	28	25.5	34	32.7		
Family overturning the decision	25	22.7	21	20.2		
Inconsistent with personal beliefs	2	1.8	1	1		
Who should make the decision about LST for those without immediate family						
Primary physician	16	14.5	22	21.2	14.2	0.027
Hospital ethics committee	9	8.2	9	8.7		
Doctor and ethics committee	61	55.5	68	65.4		
Appointed social worker	3	2.7	0	0		
Appointed guardian	15	13.6	4	3.8		
Others responsible for the patient	6	5.4	1	1		

Note. Act: Korean Act on Hospice Palliative Care and Decisions About Life-Sustaining Treatment for End-of-Life Patients

Table 3 Awareness of patients and families about LST

Variable	Patients (n = 46)		Families (n = 54)		t	p
	Mean	SD	Mean	SD		
Age (years)	57.1	14.68	53.14	13.57	1.4	0.160
Perceived health (0–10)	4.36	2.31	6.03	2.19	-3.69	<0.001
Sex	n	%	n	%	Chi	p
	28	60.9	41	75.9	2.63	0.105
	18	39.1	13	24.1		
Religion	11	23.9	13	24.1	2.28	0.684
	3	6.5	7	13		
	11	23.9	10	18.5		
	21	45.7	24	44.5		
	7	15.2	11	20.4	6.53	0.088
	27	58.7	39	72.2		
	7	15.2	2	3.7		
	5	10.9	2	3.7		
	6	13	9	16.7	3.62	0.459
	24	52.2	31	57.4		
	14	30.4	9	16.7		
	2	4.3	5	8.4		
Awareness of the Act	14	30.4	17	31.5	2.61	0.455
	19	41.3	28	51.9		
	10	21.7	8	14.8		
	3	6.5	1	1.9		
Advance LST statement signed	9	19.6	13	24.1	0.294	0.587
	37	80.4	41	75.9		
Suspension of meaningless LST	22	47.8	22	40.7	0.89	0.828
	17	37	25	46.3		
	6	13	6	11.1		
	1	2.2	1	1.9		
Who would you discuss suspending LST with	14	30.5	25	46.3	2.652	0.753
	12	26.1	11	20.4		
	7	15.2	6	11.1		
	1	2.2	1	1.9		
	12	26.1	11	20.4		
Experience of participating in LST decisions for family	9	19.6	12	22.2	0.106	0.745

Table 3 (continued)

Variable	Patients (n = 46)		Families (n = 54)		t	p
	Mean	SD	Mean	SD		
No	37	80.4	42	77.8		
Components of meaningless LST you want to discontinue						
Cardiopulmonary resuscitation	19	41.3	20	37	0.19	0.663
Ventilator	17	37	12	22.2	2.61	0.106
Hemodialysis	28	60.9	33	61.1	0.001	0.980
Chemotherapy	32	69.6	30	55.6	2.06	0.150
ECMO	23	50	18	33.3	2.85	0.091
Blood transfusion	31	67.4	36	66.7	0.006	0.939
Vasopressor	35	76.1	34	63	2.01	0.157
Parenteral nutrition	34	73.9	42	77.8	0.203	0.652
Oxygen therapy	26	56.5	37	68.5	1.534	0.216
Fluid therapy	36	78.3	39	72.2	0.483	0.487
Reasons for deciding to discontinue meaningless LST						
Recovery possibility	8	17.4	13	24.1	0.719	0.869
Patient suffering	26	58.5	29	53.7		
Family suffering	9	19.6	9	16.7		
Economic burden	3	6.5	3	5.6		
LST decided by family when the patient cannot						
Agree	34	73.9	48	88.9	3.77	0.052
Disagree	12	26.1	6	11.1		
Advance LST statement signed at admission						
Definitely agree	17	37	27	50	5.36	0.147
Somewhat agree	20	43.5	24	44.4		
Not likely	4	8.7	2	3.7		
Definitely not	5	10.9	1	1.9		
Time to sign the advance LST statement						
When hospitalized for treatment	8	17.4	4	7.4	9.1	0.168
Critical condition but conscious	19	41.3	30	55.6		
When diagnosed with a terminal illness	7	15.2	8	14.8		
When hospice care is decided	8	17.4	6	11.1		
When you are healthy	4	8.6	6	11.1		
Who should decide the suspension of LST						
Patient	34	73.9	42	77.8	0.458	0.795
Family members	10	21.7	9	16.7		
Health professionals	2	4.3	3	5.6		
Who explains LST to the patient at the end-of-life						
Spouse	12	26.1	15	27.8	0.036	0.849
Children	7	15.2	11	20.4	0.447	0.504

Table 3 (continued)

Variable	Patients (n = 46)		Families (n = 54)		t	P
	Mean	SD	Mean	SD		
Parents	1	2.2	4	7.4	1.432	0.231
Relatives/sibling	1	2.2	1	1.9	0.013	0.909
Health professionals	27	58.7	26	48.1	1.109	0.292
Others	1	2.2	0	0	1.186	0.276
When recovery is impossible, do you agree to discontinue LST?						
Yes	32	69.6	47	87	4.571	0.102
No	6	13	3	5.6		
Depends on situation	8	17.4	4	7.4		
Who should make the decision about LST for those without immediate family						
Primary physician	21	45.7	21	38.9	10.17	0.070
Hospital ethics committee	1	2.2	5	9.3		
Doctor and ethics committee	15	32.6	26	48.1		
Appointed social worker	4	8.7	1	1.9		
Appointed guardian	2	4.3	1	1.9		
Others responsible for the patient	4	8.6	1	1.9		

about LST decisions based on survey data. Analyzing the EMR data indicated that 78.4% of the patients had signed a DNAR form, but only 5.6% had a written decision to discontinue LSTs. Health professionals, and patients and their family members were generally aware of the Act, though there were some discrepancies among them about the timing and who should make the decision.

When to discuss the suspension of LSTs

During the legislative process, the Act aimed to improve the end-of-life care environment for patients who chose to discontinue LSTs; hospice palliative care and LST decisions for patients at the end of life were then integrated into the combined law [17]. According to the law, predictions for end-of-life in patients were classified as imminent end-of-life or terminal state of disease in clinical practice, causing confusion [9, 17]. Our study found that 27.6% of the patients who were subject to LSTs or DNAR forms had not completed them until 1–2 days before they died. The median period from admission to DNAR-order signed was 3 days, from DNAR-order signed to death was 2 days, and from the completion of the LST decision form to death was 1 day.

Health professionals, patients, and their families agreed that the best time to discuss discontinuing LSTs was when the patient was critically ill but conscious. According to a previous survey by the National Institute for Life-Sustaining Treatment, participants wanted to be informed of their end-of-life status 6 months before their expected time of death [17]. LST decisions and implementation should, therefore, be discussed much earlier than they are in the present clinical environment. Even in a stable end-stage condition, a patient may rapidly deteriorate with repeated exacerbations and improvements, making it difficult to determine the end-of-life or terminal stage of the disease. Rather than suggest the timing of end-of-life for implementing the LST Act, the preparation of an LST plan should be permitted when explicit decision-making is possible to respect the right of self-determination.

The preparation of various types of forms according to the time period defined by the Act also revealed numerous practical difficulties, such as the use of confusing terminology and procedure complexity [4]. In our study, 78.4% of patients completed only the DNAR form, while 10.2% completed duplicated forms of LSTs and DNAR. To reduce anxiety about legal responsibility in an emergency situation in which the condition of the patient worsens, it is common to fill out a DNAR consent form together while preparing a statement about LST discontinuation. The present study results suggested that the LST plan should be discussed or drafted on the day that the patient is admitted to the hospital, and the

implementation form should be drafted while the patient is deteriorating but still conscious.

Awareness gaps in the LST act among health professionals, patients, and families

In the survey on LST awareness conducted before the Act took effect [18], 61% of health professionals and 33% of patients and their families said they were aware of LST decisions. In the present study, 90% of health professionals and more than 70% of patients and their families were aware of the Act, indicating that the level of awareness had improved. However, the perceptions of LSTs differed among the groups. In the clinical setting, health professionals reported that the decision-making about LST suspension was mostly performed by family members (65.5–83.7%), with the patients being involved in far fewer cases (9.6–23.6%). Nevertheless, most patients and family members believed that LST decisions should be made by the patient.

While health professionals know that LST decisions must be made by the patient, they experience moral difficulties and burnout when their decision is not adhered to in the clinical setting [19, 20]. The possibility of recovery was the most important factor when deciding about terminating LSTs for health professionals. The attending physician and relevant specialists can order LST procedures when they deem it medically necessary, even if they prolong the dying process without causing therapeutic benefit. In terms of “meaningless life-sustaining treatment,” there may be differences among groups [21]. Because there are no objective or valid criteria for determining futility, it is extremely difficult to determine which patients are receiving meaningless treatment and assess their terminal stage. Most patients and their families considered patient suffering to be the most important reason for the discontinuation of LSTs. Only 17.4% of patients and 24.1% of their families considered the possibility of recovery as an important reason. At the end of life, patients and their families value a comfortable and painless death (good dying) over-treating the disease, indicating a clear distinction in perceptions. Life-sustaining treatment can be withheld or withdrawn legally based on a medical judgment about the potential for recovery [7]. However, it is not desirable to evaluate solely from the perspective of healthcare professionals since views about patient benefit and futility may vary. Evaluations should consider the values, preferences, priorities, and desires of patients and their families [22].

Decision to discontinue LSTs for persons with no relatives

The Act was passed to protect the dignity and values of patients at the end of their lives. However, some situations are exempt from the law, such as when a person lives alone and does not have any first-degree relatives.

Furthermore, despite being considered a legal family under the current law, it is difficult to implement the Act to protect the dignity and respect the autonomy of patients when there is an inappropriate relationship of interest that would represent the intentions of the patient or where a family cannot be reached because of a breakdown in the relationship [17]. Most health professionals (55–65%) suggested that decisions about LST discontinuation for people without relatives should be made by the ethics committee of the medical institution, along with the primary physician. This clearly indicates that those who decide to suspend LSTs in this situation bear a legal and ethical burden. It is recommended that the ethics committee of the medical institution and the primary physician be involved in the decision-making process about LSTs for people without relatives. This requires that the role of ethics committees is established in legislation. Furthermore, guidelines should be developed to standardize the qualifications of ethics committee members.

Raising awareness and publicity for a good dying culture

Advance care planning (ACP) is reflected in the Korean Act on Decisions on Life-Sustaining Treatment, but the term “ACP” is not explicitly defined. The term ACP encompasses a broad concept of hospice and palliative care, respect for autonomy, Advance Directives, and physician orders for LST. However, it is still unfamiliar to health professionals in Korea [23]. Nevertheless, the domestic law protects human dignity and respects patient autonomy in accordance with ACP, and LST is the form of documentation to reflect ACP. Despite efforts to improve detailed operational procedures through legal amendments, there are still fundamental limitations in ensuring a dignified death for patients. As part of the Act, Advance Directives (AD) and Physician Orders for LST are mandatory, but in clinical practice, completing legally mandated documents takes precedence over conducting ideal ACP consultations [23]. In addition, the Act focuses primarily on whether a decision is made, as well as legal requirements for life-sustaining treatment, thus not adequately addressing various dilemmas relating to the decision-making process, end-of-life care, and environment. A complex legal application process and the unique circumstances of a terminal stage often result in decisions being made without sufficient time to accept a dignified death and discuss the options [24]. It is necessary to promote and educate clinical practitioners about ACP, along with supporting legal and institutional mechanisms in Korea [23].

The experience and knowledge of health professionals act as major factors in the process of determining the prognosis of a patient at the end of their life. However, when communication between health professionals and

patients is not effective, the timing of discussions about end-of-life care would be delayed, resulting in family members instead of the patient making decisions about LSTs [25]. Previous studies found that more patients made the decision about their end-of-life care, and the timing of decision-making for LSTs was also faster since the Act was implemented. Nevertheless, examining LST decision documents revealed that only about 30% were filled out by the patients themselves, while the remaining 70% were completed by their family members [15, 25, 26]. In the case of a surrogate decision made by a family member, the average time from filling out the form to the death of the patient is less than 2 days due to death being more imminent than when the patient makes the decision [26, 27]. Many critical factors are required to initiate discussions on LST decisions for patients at an early stage, including medical, legal, and ethical knowledge, effective communication, and changes in the awareness of health professionals [25, 27, 28]. The process of making life-sustaining treatment decisions should, therefore, be supplemented by providing enough time for patients and their families to discuss their prior preferences regarding end-of-life care and documenting them as evidence when necessary [24].

The Act requires the intention of the patient to be explicitly confirmed through an LST statement or plan in advance. If the patient is unable to do so, the decision can be made by the agreement of family members including spouse and first-degree descendants [1]. Different entities involved in life-sustaining treatment decisions have varying levels of knowledge and perception, which creates ethical dilemmas for families who must decide whether to withhold or withdraw LST procedures from a cultural perspective. In Asian cultures, including South Korea, where family is rooted in culture and values, discussion of death is taboo and there is a tendency to think that not directly mentioning death is for the sake of patients. This delays discussions about end-of-life, and LST decisions are often made by the family instead of the patient, as it is recognized as a duty that the family must endure [2, 29, 30].

Patients, healthcare professionals, and their families would be affected by cultural factors when making decisions about life-sustaining treatments. Rather than relying solely on medical judgment, decisions to withhold or withdraw life-sustaining treatment are discussed among healthcare providers, patients along with family members, taking a sociocultural perspective into consideration. In the present study, healthcare professionals identified the opinions of the family as the most influential factor in life-sustaining treatment decisions. While patients and families prioritize the patient's opinion, they also acknowledge the family's role in the decision-making process. The practice is in line with the dominant

family-centered culture, which takes into account the role of family members in caring for patients at the end of life and in bearing the burden of medical costs. For example, withdrawing life-sustaining treatment can facilitate the death of the patient, causing a strong feeling of guilt among the family members in spite of the patient's critical condition. Family members often make the decision to continue life-sustaining treatments even when those procedures are no longer beneficial to the patients because East Asian cultures place a strong emphasis on filial piety [31]. In this sociocultural context, it would be more challenging for health professionals to discuss the patient's preferences for end-of-life care [32, 33]. Therefore, it is necessary to develop educational and promotional programs that can be applied to patients and their families that consider cultural differences in order to increase understanding of the LST decision process. The clinical guidelines based on the Act must take into account the sociocultural context in order to serve as an effective model for guaranteeing the rights of patients under legal provisions pertaining to self-determination along with family decision-making regarding medical treatment.

Since this study was conducted in selected general hospitals, there are limitations in generalizing the results to clinical environments of different sizes and different disease severity. There are also limitations in this study to exploring individual or socio-economic factors that may influence the decision process of LST implementation. Further studies should be conducted in diverse clinical environments, and a future prospective cohort study of the LST decision process undertaken by patients and their families is also required.

Conclusions

The Act was implemented 5 years ago, yet there is still confusion about it in clinical practice, and a significant discrepancy exists in the perceptions of LST decisions among health professionals, patients, and their families despite the high awareness of the Act. As a result of the ambiguity regarding the timing of terminating LSTs, as well as the discrepancy between patients and their families, the implementation of the Act makes it difficult for patients to exercise their right to self-determination for a dignified end-of-life. Further effort is needed to improve public awareness of LSTs and to clarify the ambiguity of document preparation timing among patients and health professionals. Publicity on LST decisions should be given to the community to change perceptions of LSTs. The legal standards and authority of the ethics committees of medical institutions should also be clarified, and the competency standards of committee members should be strengthened. It is necessary to give ethics committees a role in the LST decision process by strengthening their

establishment in medical institutions. In South Korea, the Act on Life-Sustaining Treatment Decisions reflects both the perspectives of Asian culture and the universal values of dignity and autonomy. Consequently, evaluating how the Act reflects Korea's current situation and proposing improvements to the Act could serve as a basis for developing and revising laws and systems concerning end-of-life care around the world.

Abbreviations

LST	Life sustaining treatment.
EMR	Electronic medical records.
DNAR	Do-not-attempt-resuscitation.
ANOVA	Analysis of variance.
IRB	Institutional review board.
SD	Standard deviation.
WHWD	Decision to withhold/withdraw life-sustaining treatment.
EWS	Early-warning score.

Supplementary Information

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Supplementary Material 1

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Author contributions

RS, ES, DS, and JoL designed the study. DS, JoL, SY, ME, SO, HL, and JiL were involved in data collection and reviewed the data accuracy. RS, DS, SY, ME, and SO conducted analysis and prepared the tables and figures. RS, DS, ES, and JoL wrote the main manuscript text, and all authors reviewed it. All authors met authorship criteria and approved the final manuscript.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was conducted following the Declaration of Helsinki. The study protocol was approved by the Institutional review board (IRB) from Chungnam National University Hospital, where the researchers were affiliated (IRB no. CNUH-2022-07-006). During the phase 2 survey, a written informed consent form was obtained from the respondents before interviews were initiated.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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