



Participation and Influencing Factors in the Decision-Making of Life-Sustaining Treatment: A Focus on Deceased Patients with Hematologic Neoplasms

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Purpose: This study aimed to investigate the involvement of patients who died from hematologic neoplasms in the decision-making process surrounding the withdrawal of life-sustaining treatment (LST). **Methods:** A total of 255 patients diagnosed with hematologic neoplasms who ultimately died following decisions related to LST during their end-of-life period at a university hospital were included in the study. Data were retrospectively obtained from electronic medical records and analyzed utilizing the chi-square test, independent t-test, and logistic regression. **Results:** In total, 42.0% of patients participated in the decision-making process regarding LST for their hematologic neoplasms, while 58.0% of decisions were made with family involvement. Among these patients, 65.1% died in general wards and 34.9% in intensive care units (ICUs) as a result of decisions such as the suspension of LST. The period from the LST decision to death was longer when the decision was made by the patient (average, 27.15 days) than when it was made by the family (average, 7.48 days). Most decisions were made by doctors and family members in the ICU, where only 20.6% of patients exercised their right to make decisions regarding LST, a rate considerably lower than 79.4% observed in general wards. Decisions to withhold or withdraw LST were more commonly made by patients themselves than by their families. **Conclusion:** The key to discussing the decision to suspend hospice care and LST is respecting the patient's self-determination. If a patient is lucid prior to admission to the ICU, considerations about suspending LST should involve the patient input.

Key Words: Hematologic neoplasms, Palliative care, Patient self-determination act, Resuscitation orders, Terminal care

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INTRODUCTION

1. Background

Hematologic neoplasms are malignant conditions characterized by abnormal proliferation and differentiation due

to irregular hematopoietic processes. This category includes diseases such as leukemia, multiple myeloma, myelodysplastic syndrome, and malignant lymphoma [1]. While less prevalent than solid tumors, the incidence and prevalence of hematologic neoplasms have been steadily rising. For instance, in South Korea, the incidence of hematologic neoplasms rose by 56.2%

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in 2019 compared to 2009 [2]. Patients with hematologic neoplasms were found to be more likely than those with solid tumors to visit the emergency room, be hospitalized for 30 days before death, and have higher rates of admission to and death in the intensive care unit (ICU). They were also more likely to undergo chemotherapy and targeted chemotherapy. Consequently, these patients were less likely to receive hospice care associated with active end-of-life care compared to those with solid tumors [3].

In a study focusing on patients aged 60 years or older with acute leukemia, it was found that 90% of patients believed they could fully recover from acute leukemia, while hematologic oncologists only estimated a 31% chance of complete recovery [4]. This significant discrepancy between patient and health-care professional perceptions of the disease and prognosis may influence critical medical decision-making. Therefore, it is crucial to enhance patient understanding of the disease and prognosis, enabling patients with hematologic neoplasms to make more informed decisions about their cancer treatment [5].

Hematologic neoplasms pose a life-threatening risk due to complications such as acute renal failure caused by tumor lysis syndrome, sepsis during treatment, or hospitalization in the ICU due to organ bleeding and ischemia. Treatment outcomes for patients with hematologic neoplasms in the ICU are typically poor, with mortality rates ranging from 46~70% [6]. Referral to hospice care is often considered for patients with hematologic neoplasms nearing the end of life, and this decision can significantly impact the initiation and quality of hospice care [7]. The Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life, enforced on February 4, 2018, was enacted with the intention to uphold patient dignity and value by respecting their decision-making rights and ensuring their best interests. This law also provides healthcare professionals with a legal basis for life-sustaining treatment (LST) [8,9]. To ascertain patients' intentions, the South Korean Act includes provisions for an advance directive (AD) and physician orders for life-sustaining treatment (POLST) [10]. From February 4, 2018, to January 28, 2019, 35,431 patients decided to withhold or withdraw LST, with 67.7% making this decision based on the consistent statements of two or more family members, or the consensus of all family members [10].

According to Article 2 of the Act on Decisions on Life-Sustaining Treatment, the end-of-life process refers to a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly, and it should be determined by the judgment of an attending physician and one medical specialist in the relevant field [8,11]. Patients with hematologic neoplasms show a hyperacute course corresponding to stage IV of solid tumors at diagnosis and should undergo special treatments including continuous chemotherapy and hematopoietic stem cell transplantation for complete recovery. After transplantation, continuous management of complications is required, including graft-versus-host disease. Furthermore, resilience is low, which requires nursing management different from that of solid tumors [12]. Decision-making regarding LST of patients with hematologic neoplasms should be made through clinical context, reversibility of acute medical diseases, and multidisciplinary discussions considering the patient's preferences and values [13]. In a study conducted in 2021, the ICU mortality rate for patients with hematologic neoplasms was 44.7% [14]. In a previous study that analyzed 44 studies, the survival rate of patients with hematologic neoplasms admitted to ICUs was closer to 40%, but the survival rate after cardiopulmonary resuscitation was only 6~8% [15]. Therefore, in ICU treatments, death can occur in an environment where patients lose their dignity, are not able to express their will, and suffer from psychological and physical pains due to social isolation. For most terminally ill patients, information on what to expect at the end of life influences their places of care and death [16]. Since healthcare professionals do not want patients to lose hope and family members are reluctant to mention the patient's death, patients lose an opportunity to choose a dignified death [17].

In a study on 235 terminal cancer patients in South Korea, China, and Japan, what patients wanted in LST was the same proportion of decision-making between the patients and their families, and the patients wanted to participate in decision-making regarding LST and be directly informed about issues related to their death from a physician [18]. In a study on decision regret and psychological stress of family members who made decisions on LST on behalf of terminal cancer patients, understanding the patient's values on LST was an important measure to reduce stress in the decision-making of families [19].

As dignified beings, humans have the inherent right to make decisions about their own legal interests and to freely make choices without unjust interference from others [20]. The most ideal approach is for patients to make advance decisions that reflect their personal values, thereby avoiding the administration of futile LST when they are dying [21]. However, in intensive care units (ICUs), discussions about withdrawing LST typically occur when the patient's condition becomes critical. Consequently, in many instances, patients are excluded from end-of-life care decision-making, and their opinions are not reflected in the treatment plan [22]. In other words, in the ICU, it is often the patient's family, not the patient, who makes decisions about LST and determines the extent of treatment. Although family members are often the most trusted individuals for the patient, they may also have vested interests in the patient's death, such as inheritance and medical cost considerations. Therefore, while unanimous agreement among all family members can benefit the patient, it could also harm them [23].

With this context, the aim of this study was to examine the current status of decision-making regarding LST among patients with hematologic neoplasms who died with LST and to evaluate their participation in LST decisions. This was done with the goal of providing a basis for the LST decision-making process for these patients.

2. Purpose

The specific objectives of this study were to evaluate the participation of patients with hematologic neoplasms who died in LST decision-making and identify influencing factors. The specific goals are as follows:

First, to identify the participation of patients in LST decisions according to the general characteristics of patients with hematologic neoplasms who died with LST.

Second, to identify the status of participation of patients with hematologic neoplasms who died with LST decisions in LST decision-making in both wards and ICUs.

Third, to compare the details of the implementation documents of decisions on withholding or withdrawing LST for patients with hematologic neoplasms who died with LST decisions.

Fourth, to identify factors influencing the participation of

patients with hematologic neoplasms who died with LST decisions in the decision-making process.

METHODS

1. Study design

This retrospective study was conducted to examine the involvement of patients with hematologic neoplasms who died after having made LST decisions in decision-making related to LST, as well as the factors influencing this involvement, using electronic medical records.

2. Study sample

Data were collected from January 2020 to May 2022 for 280 patients, aged 19 years or older, diagnosed with hematologic neoplasms. These patients died following LST decisions in both the hematology wards and hematology ICUs at C University Hospital in Seoul, South Korea. Patients who had ADs and family consents were excluded from the study because it was challenging to discern whether the decisions were made by the patients themselves or by their families. Additionally, patients who had withdrawn their LST decisions were also excluded. Ultimately, data from a total of 255 patients were collected for the study.

3. Study tools

1) General characteristics

The patients' general characteristics taken into consideration included age, sex, marital status, clinical department, ward, diagnosis, hematopoietic stem cell transplantation status, duration of disease, the time span from the date of LST decision to death, and recurrence.

2) Implementation document of decisions on withholding or withdrawing life-sustaining treatment

The implementation document of decisions on withholding or withdrawing LST (Form No. 13), as per the Act on Decisions on Life-Sustaining Treatment, was utilized for this study. Referring to this form, medical records were scrutinized to determine whether to withhold or execute LST decisions. These decisions encompassed cardiopulmonary cerebral resuscitation

(CPCR), the use of ventilators, hemodialysis, chemotherapy, extracorporeal membrane oxygenation (ECMO), blood transfusion, and inotropics.

3) Patient's intention for life-sustaining treatment

The patient's preference for LST was determined using the legal forms associated with the Act on Decisions on Life-Sustaining Treatment. When a patient was conscious, their preference was established through POLST (Form No. 1) and AD (Form No. 10). If a patient was unconscious, the intention was confirmed through 1) a statement by two family members for POLST (Form No. 11) when a patient's intention could be assumed or 2) the consensus by all family members for POLST (Form No. 12) when a patient's intention could not be assumed (Figure 1). Form Nos. 1 and 10 were written by the patient, and Form Nos. 11 and 12 were written by the family, although they included assumptions about the patient's intentions.

4. Data collection

Data were retrospectively collected from the electronic medical records of patients with hematologic neoplasms who passed away following LST decisions. These patients were in the hematology wards and hematology ICUs at C University Hospital from January 2020 to May 31, 2022. Prior to analysis, this study received approval from the Data Review

Committee and the institutional review board. From June 1 to August 31, 2022, co-researchers were given access to the electronic medical records. Data were collected using a standardized case report form, and a principal investigator cross-verified their findings.

5. Data analysis

The data collected in this study were analyzed using SPSS for Windows version 24.0 (IBM Corp., Armonk, NY, USA). Descriptive statistics, including frequencies, percentages, means, and standard deviations, were used to analyze the general characteristics of the participants. The chi-square test and independent t-test were conducted to examine differences in the implementation document of decisions on withholding or withdrawing LST, and confirmation of intention on LST decisions of patients in wards and ICUs. Factors influencing patients' decision-making regarding LST were analyzed using multiple logistic regression.

6. Ethical considerations

This study was conducted with the approval of the Data Review Committee and institutional review board (No. KC22RI-SI0656). As the study was based on medical record reviews, obtaining consent was deemed unnecessary. This study did not cause any additional pain, financial burden, or disadvantages to patients. Personal information and the confidentiality of

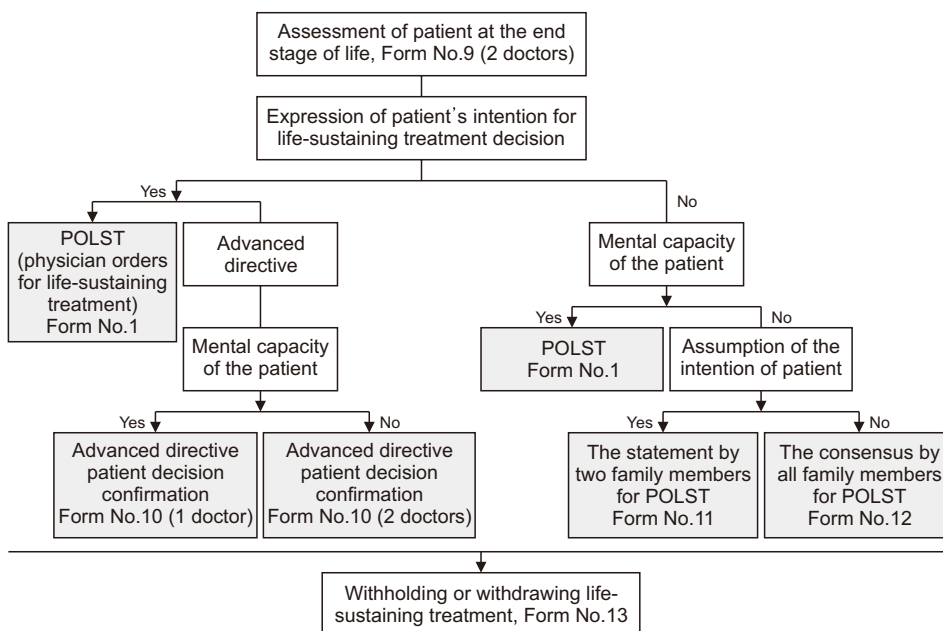


Figure 1. Procedural diagram of life-sustaining treatment plans.

Source: Korean Law Information Center. Act on Decisions on Life-sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life [Internet]. Sejong: Ministry of Health and Welfare; 2022 [cited 2022 Oct 31]. Available from: <https://www.law.go.kr/%EB%B2%95%EB%A0%B9/%EC%97%B0%EB%AA%85%EC%9D%98%EB%A3%8C%EA%B2%B0%EC%A0%95%EB%B2%95>.

collected data were protected, and the data were not used for any purpose other than research. Identifiable personal information such as names and hospital registration numbers were not collected. Instead, data were anonymized by assigning a separate number to prevent the exposure of personally identifiable information. To further protect personal information, data files were password-protected and only the principal investigator had access. All research-related records will be retained for three years following the conclusion of the research, after which they will be appropriately disposed of.

RESULTS

1. Participation in decision-making regarding life-sustaining treatment by patients with hematologic neoplasms according to their general characteristics

Out of 255 patients with hematologic neoplasms who consented to suspend LST, 107 patients (42.0%) made decisions independently, while the families of 148 patients (58.0%) participated in decision-making. There were 139 males (54.5%) and 116 females (45.5%), with an average age of 60.88 ± 14.32 years. A majority of the patients were between 51 to 70 years old ($n=135$, 52.9%), followed by those aged 71 years or older ($n=67$, 26.3%). Most patients were married ($n=233$, 91.4%). The most common diagnosis was acute myeloid leukemia ($n=100$, 39.2%), followed by lymphoma ($n=53$, 20.8%). Twelve patients (4.7%) were confirmed to have COVID-19, 99 patients (33.8%) had undergone hematopoietic stem cell transplantation, and 94 patients (36.9%) had experienced recurrence. A total of 169 patients (66.3%) made LST decisions in wards or an outpatient department, and 86 patients (33.7%) made their decisions in ICUs. Among those who made decisions in the ICU, fewer patients made decisions themselves ($n=20$, 18.7%) compared to those whose families were involved in decision-making ($n=66$, 44.6%) ($\chi^2=18.64$, $P<0.001$).

In total, 166 patients (65.1%) passed away in wards and 89 patients (34.9%) passed away in the ICU. Among those who died in the ICU, 22 patients (20.6%) participated in LST decision-making, which was fewer than the 67 patients

(45.3%) whose families were involved in the LST decision-making ($\chi^2=16.69$, $P<0.001$). The average duration from LST decisions to death was 15.73 days. This duration was longer when patients made the decisions themselves (mean, 27.15 days) than when families made the decisions (mean, 7.48 days) ($t=-2.08$, $P=0.039$). The mean time from diagnosis to LST decision-making was 927.35 days, and 92 patients (71.9%) preferred hospice care. When patients desired hospice care, they were more likely to make the LST decisions themselves ($n=76$, 87.4%) than have their families make the decisions ($n=16$, 39.0%) ($\chi^2=32.20$, $P<0.001$). There was no significant difference in LST decision-making between patients and their families based on sex, age, marital status, diagnosis, COVID-19 infection, hematopoietic stem cell transplantation status, relapse, and duration from diagnosis to LST decision-making (Table 1).

2. Participation in decision-making of life-sustaining treatment by patients with hematologic neoplasms in wards and intensive care units

Given the significant difference in the confirmation of patients' and their families' intentions for LST depending on the place of death (wards or ICUs), an examination was carried out to ascertain if there were differences in the documents confirming patients' intentions based on these locations. The documents pertaining to LST decision-making were categorized based on whether the patients were in wards or ICUs. ADs (Form No. 10), written by patients, were obtained from 23 patients (9%), with more from ICUs ($n=14$, 15.7%) than wards ($n=9$, 5.4%) ($\chi^2=7.50$, $P=0.006$). POLST (Form No. 1) were obtained from 85 patients (33.3%), with more from wards ($n=77$, 46.4%) than ICUs ($n=8$, 9.0%) ($\chi^2=36.46$, $P<0.001$). The consensus by all family members for POLST (Form No. 12) were obtained from 97 patients (38.0%), and the proportion of patients in the ICU (46 out of 89 patients, 51.7%) was higher than that of patients in wards (51 out of 166 patients, 30.7%) ($\chi^2=10.80$, $P=0.001$). Statement by two family members for POLST (Form No. 11) were obtained from 58 patients (22.7%), with no significant difference between wards and ICUs (Table 2).

Table 1. General Characteristics of Life-sustaining Treatment according to Patients' Participation in Decision-making (N=255).

Characteristics	Participation in decision-making			χ^2 or t	P
	Total (n=255)	Patients (n=107)	Families (n=148)		
	n (%)				
Sex					
Male	139 (54.5)	65 (60.7)	74 (50.0)	2.89	0.089
Female	116 (45.5)	42 (39.3)	74 (50.0)		
Age (yr)					
19~30	9 (3.5)	2 (1.9)	7 (4.7)	7.79	0.051
31~50	44 (17.3)	22 (20.6)	22 (14.9)		
51~70	135 (52.9)	48 (44.8)	87 (58.8)		
≥71	67 (26.3)	35 (32.7)	32 (21.6)		
M±SD	60.88±14.32	61.57±14.49	60.39±14.22	-0.65	0.515
Married					
Yes	233 (91.4)	98 (91.6)	135 (91.2)	0.11	0.917
No	22 (8.6)	9 (8.4)	13 (8.8)		
Diagnosis					
ALL	17 (6.7)	4 (3.7)	13 (8.8)	4.42	0.620
AML	100 (39.2)	43 (40.2)	57 (38.5)		
MM	30 (11.8)	11 (10.3)	19 (12.8)		
MDS	27 (10.6)	12 (11.2)	15 (10.1)		
Lymphoma	53 (20.8)	22 (20.6)	31 (20.9)		
CML	6 (2.4)	3 (2.8)	3 (2.0)		
Aplastic anemia etc.	22 (8.6)	12 (11.2)	10 (6.8)		
COVID-19 infection					
Yes	12 (4.7)	5 (4.7)	7 (4.7)	0.00	>0.999
No	243 (95.3)	102 (95.3)	141 (95.3)		
Hematopoietic stem cell transplantation status					
Yes	99 (38.8)	36 (33.6)	63 (42.6)	2.08	0.149
No	156 (61.2)	71 (66.4)	85 (57.4)		
Recurrence					
Yes	94 (36.9)	34 (31.8)	60 (40.5)	2.05	0.152
No	161 (63.1)	73 (68.2)	88 (59.5)		
Decision-making place of LST plan					
Ward or OPD	169 (66.3)	87 (81.3)	82 (55.4)	18.64	<0.001
ICU	86 (33.7)	20 (18.7)	66 (44.6)		
Death place					
Ward	166 (65.1)	85 (79.4)	81 (54.7)	16.69	<0.001
ICU	89 (34.9)	22 (20.6)	67 (45.3)		
Interval from decision-making of LST to death	15.73±64.38	27.15±96.66	7.48±16.16	-2.08	0.039
Interval from diagnosis to decision-making of LST	927.35±1296.56	983.49±1327.20	886.76±1276.95	-0.58	0.560
Hospice use intention					
Yes	92 (71.9)	76 (87.4)	16 (39.0)	32.20	<0.001
No	36 (28.1)	11 (12.6)	25 (61.0)		

ALL: acute lymphoblastic leukemia, AML: acute myelocytic leukemia, CML: chronic myelocytic leukemia, ICU: intensive care unit, LST: life-sustaining treatment, MDS: myelodysplastic syndrome, MDS: multiple myeloma, OPD: outpatient department.

Table 2. Confirmation of the Patient's Intention to Discontinue Life-sustaining Treatment (N=255).

Participation in decision-making	Death place			χ^2	P
	Total (n=255)	Ward (n=166)	ICU (n=89)		
	n (%)				
Patients					
Advanced directive (patient) No.10					
Yes	23 (9.0)	9 (5.4)	14 (15.7)	7.50	0.006
None	232 (91.0)	157 (94.6)	75 (84.3)		
Physician orders for life-sustaining treatment (patient) No.1					
Yes	85 (33.3)	77 (46.4)	8 (9.0)	36.46	<0.001
None	170 (66.7)	89 (53.6)	81 (91.0)		
Families					
The consensus by all family members for POLST (family) No.12					
Yes	97 (38.0)	51 (30.7)	46 (51.7)	10.80	0.001
None	158 (62.0)	115 (69.3)	43 (48.3)		
Statement by two family members (family) No.11					
Yes	58 (22.7)	37 (22.3)	21 (23.6)	0.06	0.812
None	197 (77.3)	129 (77.7)	68 (76.4)		

No: Number.

3. Details of implementation of life-sustaining treatment decisions

In the analysis of documents regarding decisions to withhold or withdraw LST, there was no significant difference in withholding or withdrawing CPR between decisions made by patients (n=106, 99.1%) and families (n=148, 100%). Decisions to withhold or withdraw ventilation were more frequently made by patients (96 out of 107 patients, 89.7%) than by families (107 out of 148 patients, 72.3%) ($\chi^2=11.61$, P=0.001). Likewise, decisions to withhold or withdraw hemodialysis were more often made by patients (97 out of 107 patients, 90.7%) than by families (119 out of 148 patients, 80.4%) ($\chi^2=5.04$, P=0.025). Decisions to withhold or withdraw blood transfusion were more frequently made by patients (38 out of 107 patients, 35.5%) than by families (34 out of 148 patients, 23.0%) ($\chi^2=4.82$, P=0.028), representing the least frequent type of withholding or withdrawal of LST. There was no significant difference in withholding or withdrawing chemotherapy and ECMO between decisions made by patients and those made by families. Withholding or withdrawing inotropics did not show a significant difference between decisions made by patients (n=55, 51.4%) and families (n=62, 41.9%), and it represented the second-least frequent withholding or withdrawal among

LST (Table 3).

4. Factors affecting participation in decision-making by patients with hematologic neoplasms

Factors influencing patient involvement in LST decision-making were analyzed using logistic regression, yielding statistically significant findings ($\chi^2=40.27$, P<0.001). Nagelkerke's coefficient of determination indicated an explanatory power of 37.8%, and the classification accuracy was 68.0%. The participation of patients in decision-making increased by 1.02 times (odds ratio [OR]=1.02, 95% CI 1.00~1.04; P=0.013) when the period from LST decision-making to death lengthened, but decreased by 0.29 times (OR=0.29, 95% CI 0.16~0.51; P<0.001) when the LST decision was made in the ICU. Patients' participation was 0.31 times lower (OR=0.31, 95% CI 0.18~0.55; P<0.001) when a patient died in the ICU, but increased by 10.80 times (OR=10.80, 95% CI 4.43~26.31; P<0.001) when patients expressed an intention to use hospice care. Patient participation in decision-making decreased by 0.30 times (OR=0.30, 95% CI 0.15~0.62; P=0.001), 0.42 times (OR=0.42, 95% CI 0.20~0.91; P=0.028), and 0.54 times (OR=0.54, 95% CI 0.31~0.94; P=0.029) when the patients were on ventilators, underwent CPR, and received blood transfusions, respectively (Table 4).

Table 3. Withholding or Withdrawing Life-sustaining Treatment according to Patient Decision-making (N=255).

Characteristics	Withholding or withdrawing	Participation in decision-making			χ^2	P
		Total (n=255)	Patients (n=107)	Families (n=148)		
		n (%)				
CPCR	Yes	254 (99.6)	106 (99.1)	148 (100.0)	11.61	0.001
	No	1 (0.4)	1 (0.9)	0 (0.0)		
Ventilator	Yes	203 (79.6)	96 (89.7)	107 (72.3)	5.04	0.025
	No	52 (20.4)	11 (10.3)	41 (27.7)		
Hemodialysis	Yes	216 (84.7)	97 (90.7)	119 (80.4)	3.23	0.072
	No	39 (15.3)	10 (9.3)	29 (19.6)		
Chemotherapy	Yes	175 (68.6)	80 (74.8)	95 (64.2)	0.14	0.711
	No	80 (31.4)	27 (25.2)	53 (35.8)		
ECMO	Yes	207 (81.2)	88 (82.2)	119 (80.4)	4.82	0.028
	No	48 (18.8)	19 (17.8)	29 (19.6)		
Blood transfusion	Yes	72 (28.2)	38 (35.5)	34 (23.0)	2.26	0.133
	No	183 (71.8)	69 (64.5)	114 (77.0)		
Inotropics	Yes	117 (45.9)	55 (51.4)	62 (41.9)		
	No	138 (54.1)	52 (48.6)	86 (58.1)		

CPCR: cardiopulmonary cerebral resuscitation, ECMO: extracorporeal membrane oxygenation.

*The Fisher exact test was performed as a non-parametric test for continuous and categorical variables.

Table 4. Factors Affecting the Participation of Patients in Decision-making for End-of-life Care (N=255).

Variable	B	SE	Wald	P	OR	95% CI	
						Minimum	Maximum
Interval from decision-making of LST to death	0.02	0.01	6.12	0.013	1.02	1.00	1.04
Decision-making for LST plan in ICU	-1.25	0.30	17.68	<0.001	0.29	0.16	0.51
Death in ICU	-1.16	0.29	15.98	<0.001	0.31	0.18	0.55
Hospice use intention	2.38	0.45	27.40	<0.001	10.80	4.43	26.31
Ventilator continuation	-1.21	0.37	10.79	0.001	0.30	0.15	0.62
CRRT continuation	-0.86	0.39	4.83	0.028	0.42	0.20	0.91
Blood TF continuation	-0.61	0.28	4.76	0.029	0.54	0.31	0.94

Nagelkerke $R^2=0.378$, $\chi^2=40.27$, $P<0.001$, Hit ratio=68.0%
Hosmer-Lemeshow Goodness of fit $\chi^2=0.52$, $P=0.77$

The OR and 95% CI were statistically significant ($P<0.05$).

Univariate logistic regression analyses with decision-making place (ICU=1, Ward or OPD=0), death place (ICU=1, Ward=0), hospice use intention (yes=1, no=0) as explanatory variables.

CI: confidence interval, df: degrees of freedom, LST: life-sustaining treatment, OR: odds ratio.

DISCUSSION

This study aimed to examine how decision-making regarding LST for patients with hematologic neoplasms was approached, particularly focusing on the patient's perspective. By investigating the details of LST decision-making and its implementation for patients with hematologic neoplasms, this research provides foundational data for enhancing the decision-making process for these patients' LST.

Given that LST decision-making is a critical matter shaping how one confronts their own mortality, there is a consensus that patients should make these decisions independently. However, in this study, only 22 patients (20.6%) participated in LST decision-making in the ICU, which is fewer than the 67 patients (45.3%) where families were involved in the decision-making. According to a study by Park et al. [24] on LST decision-making among 71,327 patients, only 33.5% of the patients made their own decisions. Similarly, Kim et al. [25]

reported that only 29% of 809 patients made their own decisions. Thus, patient involvement in LST decision-making is still insufficient, particularly in the ICU.

In this study, a greater percentage of patients in the ICU (15.7%) wrote ADs (Form No. 10) than those in wards. This finding suggests that even patients with existing ADs could be admitted to ICUs and receive intensive care if physicians deemed they were not in the end-of-life stage and required medical treatments. Although end-of-life patients are typically the focus of LST decision-making [20], Article 16 of the Act on Decisions on Life-Sustaining Treatment mandates that the determination of whether a patient is in the end-of-life stage should be made by the attending physician, in consultation with a specialist [20]. Hence, the physician's determination of the end-of-life stage greatly influences LST decision-making. Consequently, some patients who have written ADs may still die in intensive care before they are officially recognized as being at the end of life. Furthermore, more patients in wards wrote ADs than those in the ICU, indicating a significant difference between the two groups. ICU patients showed remarkably lower participation in decision-making than those in wards. In principle, to justify LST decisions, patients themselves must make these decisions [20].

There was a difference in the consensus by all family members for POLST (Form No. 12) between the two groups, with more of these plans originating in the ICU than in the wards. Given that patients write both the patient POLST and ADs, while family members write both the statement by two family members and the consensus by all family members for POLST, it appears that patients are less likely to participate in decision-making in the ICU, while families are more likely to do so. This result is consistent with an 8-year retrospective study by Lee et al. [26] involving 1,818 US patients who were hospitalized and treated for six months or less before death in the ICU. The study found that only 22% received comfort treatments, 78% received limited or full treatments, and 38% received treatments not aligning with LST decisions. Baek et al. [27] suggested that the direction of LST should be determined in a way that reflects the patient's wishes, to minimize pointless treatments. Taking into account the patient's wishes is an aspect that needs further consideration when determining LST in the ICU.

In the analysis of implementation documents detailing decisions on withholding or withdrawing LST, patients typically chose to withhold or withdraw treatments like ventilators, hemodialysis, inotropics, and blood transfusions. However, blood transfusions were more commonly maintained rather than withheld or withdrawn, suggesting that patients and their families do not consider blood transfusions to be part of LST. Nonetheless, given that blood components are precious and limited resources, and the overall economic impact of transfusion dependency can be significant [28], patients and families may need to reconsider their perspectives when deciding on LST. Furthermore, since the implementation documents of decisions on withholding or withdrawing LST conflate the withdrawal of current treatments and the withholding of necessary treatments, it may be beneficial to create separate forms for withholding and withdrawing LST. While the clinical field has had numerous discussions about do-not-resuscitate (DNR) orders, more recent conversations are centered on decision-making regarding LST [29]. It has become increasingly important to make decisions about LST in advance.

In the analysis of factors influencing patient decision-making around LST, the likelihood of patients participating in the decision-making process was 10.80 times higher when they intended to use hospice care. This finding aligns with a study by Kim [30], which suggested that respecting the patient's decision-making is critical in discussions about withdrawing hospice care and LST.

While this study, conducted at a university hospital, has limitations in generalizability, it holds significance in the field of nursing. It serves as a foundation for investigating the decision-making process around LST for patients with hematologic neoplasms in both wards and ICUs. Given that decision-making about LST constantly navigates the crossroads between dignified death and respect for life, it is essential to establish clear guidelines through further research and to make these available to healthcare professionals and patients.

In conclusion, in ICUs, only 20.6% of patients were involved in decision-making concerning LST, a percentage much lower than the 79.4% found in wards. This finding indicates that the majority of decisions in the ICU were made by physicians and family members. Moreover, of the patients who participated in decision-making, a substantial 87.4% expressed a desire to

be transferred to hospice wards. The most commonly utilized form for LST decision-making was the consensus by all family members for POLST (Form No. 12), completed by 97 out of 255 patients. When making decisions, patients were more inclined to withdraw or withhold treatments like ventilators, continuous hemodialysis, blood transfusions, and the use of inotropics, compared to their families. Interestingly, patients showed a preference for maintaining blood transfusions rather than discontinuing them. Respect for the patient's autonomy is paramount when discussing decisions to suspend hospice care and LST. Given that a diagnosis of hematologic neoplasms is equivalent to stage IV of solid tumors, it is vital to review decision-making concerning LST when patients are conscious, prior to ICU admission, as is the case with other patients with solid tumors.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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AUTHOR'S CONTRIBUTIONS

Conception or design of the work: all authors. Data collection: all authors. Data analysis and interpretation: all authors. Drafting the article: all authors. Critical revision of the article: JEJ, JMR, DYK. Final approval of the version to be published: all authors.

SUPPLEMENTARY MATERIALS

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REFERENCES

- Han Y, Kim YJ, Kim MJ, Byun JM, Youk T, Yoon HS, et al. Gradual increase in hematologic malignancy in Korea from 2005 to 2015 based on the national health insurance service data. *Lab Med Online* 2020;10:144-51.
- National Cancer Center. Cancer registration statistics press release in Korea 2019 [Internet]. Goyang: National Cancer Center; 2021 [cited 2022 Oct 31]. Available from: <https://ncc.re.kr/cancerStatsView.ncc?bbsnum=578&searchKey=total&searchValue=&pageNum=1>.
- Hui D, Didwaniya N, Vidal M, Shin SH, Chisholm G, Roquemore J, et al. Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. *Cancer* 2014;120:1572-8.
- El-Jawahri A, Nelson-Lowe M, VanDusen H, Traeger L, Abel GA, Greer JA, et al. Patient-clinician discordance in perceptions of treatment risks and benefits in older patients with acute myeloid leukemia. *Oncologist* 2019;24:247-54.
- El-Jawahri A, Nelson AM, Gray TF, Lee SJ, LeBlanc TW. Palliative and end-of-life care for patients with hematologic malignancies. *J Clin Oncol* 2020;38:944-53.
- Lee J, Jeong DS, Jeon H, Kim JH, Kim DY. Factors affecting intensive care unit nurses' care burden of patients with hematologic neoplasm. *Asian Oncol Nurs* 2022;22:235-44.
- Manitta VJ, Philip JA, Cole-Sinclair MF. Palliative care and the hemato-oncological patient: can we live together? A review of the literature. *J Palliat Med* 2010;13:1021-5.
- Kim Y, Lim C, Sim T, Huh J, Oh D, Ko Y. The influence of new legislation on the withdrawal of life-sustaining treatment on the perceptions and experiences of residents in a tertiary hospital in Korea. *Korean J Med Ethics* 2020;23:279-99.
- Korean Law Information Center. Act on Decisions on Life-sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life [Internet]. Sejong: Ministry of Health and Welfare; 2022 [cited 2022 Oct 31]. Available from: <https://www.law.go.kr/%EB%B2%95%EB%A0%B9/%EC%97%B0%EB%AA%85%EC%9D%98%EB%A3%8C%EA%B2%B0%EC%A0%95%EB%B2%95>.
- Ko BJ. Comparative study of Korean law and US law about the regulation of withdrawing life-sustaining treatment. *Law Policy Rev* 2019;25:1-25.
- Kim DK. Patient end-of-life decision act and bio-power-forgoing life-sustaining treatment from perspective of Foucault's bio-power. *Philos*

- Thought Cult 2022;38:177-97.
12. Hong JH, Kwon JH, Kim IK, Ko JH, Kang YJ, Kim HK. Adopting advance directives reinforces patient participation in end-of-life care discussion. *Cancer Res Treat* 2016;48:753-8.
 13. Hill QA. Intensify, resuscitate or palliate: decision making in the critically ill patient with haematological malignancy. *Blood Rev* 2010;24:17-25.
 14. Judickas S, Stasiunaitis R, Zucenka A, Zvirblis T, Serpytis M, Sipylaite J. Outcomes and risk factors of critically ill patients with hematological malignancy. Prospective single-centre observational study. *Medicina (Kaunas)* 2021;57:1317.
 15. Kwak SY, Byeon YS. Factors influencing resilience of patients with hematologic malignancy. *Korean J Adult Nurs* 2013;25:95-104.
 16. Ml Verschuur E, M Groot M, van der Sande R. Nurses' perceptions of proactive palliative care: A Dutch focus group study. *Int J Palliat Nurs* 2014;20:241-5.
 17. Piers RD, van Eeoud IJ, Van Camp S, Grypdonck M, Deveugele M, Verbeke NC, et al. Advance care planning in terminally ill and frail older persons. *Patient Educ Couns* 2013;90:323-9.
 18. Ivo K, Younsuck K, Ho YY, Sang-Yeon S, Seog HD, Hyunah B, et al. A survey of the perspectives of patients who are seriously ill regarding end-of-life decisions in some medical institutions of Korea, China and Japan. *J Med Ethics* 2012;38:310-6.
 19. Kim S. Family surrogates' decision regret and psychological stress about end-of-life cancer treatments: Path analysis. *J Korean Acad Nurs* 2018;48:578-87.
 20. Na DS. A study on the discussion surrounding the right of the self-determination of discontinuing life sustaining treatment. *Dankook Law Review* 2014;38:97-123.
 21. DS. Patient autonomy and advance directives in Korea. *J Korean Med Assoc* 2009;52:865-70.
 22. Jung S, Lee H, Lee S. Characteristics of end of life sustaining treatment and attitudes towards advance directives among geriatric patients. *J East West Nurs Res* 2014;20:103-11.
 23. Park SH. Some legal issues of the withdrawal of life-sustaining treatment - Focused on constitutional basis, scope and the confirmation of patient's intention. *Ajou Law Review* 2018;11:176-208.
 24. Park SY, Lee B, Seon JY, Oh IH. A national study of life-sustaining treatments in South Korea: what factors affect decision-making? *Cancer Res Treat* 2020;53:593-600.
 25. Kim JS, Yoo SH, Choi W, Kim Y, Hong J, Kim MS, et al. Implication of the life-sustaining treatment decisions act on end-of-life care for Korean terminal patients. *Cancer Res Treat* 2020;52:917-24.
 26. Lee RY, Brumback LC, Sathitratanacheewin S, Lober WB, Modes ME, Lynch YT, et al. Association of physician orders for life-sustaining treatment with ICU admission among patients hospitalized near the end of life. *JAMA* 2020;323:950-60.
 27. Baek SK, Chang HJ, Byun JM, Han JJ, Heo DS. The association between end-of-life care and the time interval between provision of a do-not-resuscitate consent and death in cancer patients in Korea. *Cancer Res Treat* 2017;49:502-8.
 28. Howard DS, Pawlik TM. Withdrawing medically futile treatment. *J Oncol Pract* 2009;5:193 - 5.
 29. McPherson K, Carlos WG 3rd, Emmett TW, Slaven JE, Torke AM. Limitation of life-sustaining care in the critically ill: a systematic review of the literature. *J Hosp Med* 2019;14:303-10.
 30. Kim DK. Hospice-palliative care and law. *Korean J Med* 2017;92:489-93.