



Comparing Perceptions, Determinants, and Needs of Patients, Family Members, Nurses, and Physicians When Making Life-Sustaining Treatment Decisions for Patients with Hematologic Malignancies

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Purpose: This descriptive study compared the perceptions, determinants, and needs of patients, family members, nurses, and physicians regarding life-sustaining treatment decisions for patients with hematologic malignancies in the hematology-oncology department of a tertiary hospital in Seoul, Korea. **Methods:** In total, 147 subjects were recruited, gave written consent, and provided data by completing a structured questionnaire. Data were analyzed using analysis of variance, the chi-square test, and the Fisher exact test. **Results:** Nurses ($F=3.35$) and physicians ($F=3.57$) showed significantly greater familiarity with the Act on Decisions on Life-Sustaining Treatment than patients ($F=2.69$) and family members ($F=2.59$); ($F=19.58$, $P<0.001$). Many respondents, including 19 (51.4%) family members, 16 (43.2%) physicians, and 11 (29.7%) nurses, agreed that the patient's opinion had the greatest effect when making life-sustaining treatment decisions. Twelve (33.3%) patients answered that mental, physical, and financial burdens were the most important factors in life-sustaining treatment decisions, and there was a significant difference among the four groups ($P<0.001$). Twenty-four patients (66.7%), 27 (73.0%) family members, and 21 (56.8%) nurses answered that physicians were the most appropriate people to provide information regarding life-sustaining treatment decisions. Unexpectedly, 19 (51.4%) physicians answered that hospice nurse practitioners were the most appropriate people to talk to about life-sustaining treatment ($P<0.001$). **Conclusion:** It is of utmost importance that the patient and physician determine when life-sustaining treatment should be withdrawn, with the patient making the ultimate decision. Doctors and nurses have the responsibility to provide detailed information. The goal of end-of-life planning is to ensure patients' dignity and respect their values.

Key Words: Perceptions, Terminal care, Life support care, Decision making, Hematologic neoplasms, Palliative care, Communication

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INTRODUCTION

1. Introduction

Hematologic malignancies progress rapidly and, unless proactive treatment is performed, most patients die within 2~3 months of diagnosis. Because of this difficult diagnosis, treatment process, and outcome, patients and their families experience extreme physical, psychological, social, and spiritual pain and are in considerable shock [1,2]. Developments in contemporary medicine have made it possible to prolong the life of dying patients, but it is also common to see patients at the end of their life still on chemotherapy and other meaningless life-sustaining treatment, without possibility of recovery [3]. It becomes important to recognize when life-sustaining treatment is no longer necessary for delaying death but has become a futile and painful treatment process. Treatment during the dying process is performed as a part of maintaining the individual's dignity and valuing their quality of life. In particular, it is necessary to be aware of the patient's right to self-determination when making treatment decisions [4].

Life-sustaining treatment refers to "medical treatment by cardiopulmonary resuscitation, hemodialysis, administering chemotherapy, and mechanical ventilation to a patient at the end of life which merely extend the duration of the end-of-life process without curative effect" according to the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life (hereafter referred to as the Act on Decisions on Life-Sustaining Treatment), enforced on February 4, 2018, for the purpose of prescribing "matters necessary for hospice and palliative care and life-sustaining treatment decisions for patients at the end of life and the implementation thereof, and thereby to protect the dignity and value of human beings by assuring the best interests of the patients and by respecting their self-determination" [5]. In other words, the Act on Decisions on Life-Sustaining Treatment provides an opportunity for patients at the end of life to end their lives with dignity by respecting self-determination [3].

Ethical and legal issues arise regarding the opinion that withdrawal of life-sustaining treatment respects human dignity, such as defining the criteria for decision-making and the withdrawal of life-sustaining treatment, deciding which treat-

ment are to be stopped, and who participates in the decision-making. Although patients have the right to autonomously make life-sustaining treatment decisions [6], in South Korea (hereinafter, Korea), it is common for families to make decisions for terminal patients excluding the patients themselves, even when death is imminent [7] and especially when a patient has difficulty expressing his or her opinions accurately [8]. Families of terminal patients often believe that proactive treatment is necessary for patients and withdrawal of treatment is only necessary to alleviate pain caused by the treatment. Diseases are considered a family matter rather than an individual patient's concern in Korea and it is the family that traditionally makes the final decisions, often excluding the patient from the decision process [9]. Although the family may make the decisions regarding the continuation or withdrawal of life-sustaining treatment, the experience and opinions of nurses and physicians have a decisive effect on the family's decision-making [2,10].

When it comes to education about life-sustaining treatment, most patients want to communicate honestly with their nurses and physicians about terminal treatment options. However, they believe that nurses and physicians should raise the topic first, making nurses and physicians responsible for initiating the communication in a timely manner [11]. Nurses often communicate patients' thoughts and feelings to physicians on the patients' behalf, as well as encouraging patients to participate in the decision-making process [12]. Successful decision-making for life-sustaining treatment requires close communication among patients, family members, nurses, and physicians [12].

In Korea, studies on life-sustaining treatment have mainly focused on patients with cancer and their caregivers [7,13] or on medical professionals [2,14], but few studies have included patients, family members, nurses, and physicians. In addition, there have been studies on attitudes about withdrawal of medical treatment for terminal patients [15], experiences of decision-making on withdrawal of life-sustaining treatment [16], and perceptions of a good death [3], but studies including the perceptions, determinants, and needs of patients regarding life-sustaining treatment are few. Therefore, this study aimed to investigate the perceptions, determinants, and needs of patients, family members, nurses, and physicians

when dealing with decision-making regarding life-sustaining treatment in patients with hematologic malignancies, which progress rapidly and for which proactive treatment is provided immediately after diagnosis. This study will contribute to understanding the issue of life-sustaining treatment and provide basic data useful to nurses when involved in a life-sustaining treatment decision-making process that respects the patient's self-determination.

2. Purpose

The purpose of this study was to compare the perceptions, determinants, and needs of patients, family members, nurses, and physicians when dealing with decision-making for life-sustaining treatment in patients with hematologic malignancies, in order to enhance understanding of life-sustaining treatment, facilitate best decision-making, and provide basic data useful for end-of-life planning which respects the patient's self-determination.

The specific purposes are as follows:

- 1) To identify differences in perceptions among patients, family members, nurses, and physicians who were dealing with decision-making for life-sustaining treatment in patients with hematologic malignancies
- 2) To identify differences in determinants among patients, family members, nurses, and physicians who were dealing with decision-making for life-sustaining treatment in patients with hematologic malignancies
- 3) To identify differences in needs among patients, family members, nurses, and physicians who were dealing with decision-making for life-sustaining treatment in patients with hematologic malignancies

METHODS

1. Study design

This was a descriptive study to compare the perceptions, determinants, and needs of patients, family members, nurses, and physicians when dealing with decision-making for life-sustaining treatment in patients with hematologic malignancies.

2. Participants

The participants of the study were patients, family members, nurses, and physicians in the hematology-oncology department of a tertiary hospital in Seoul, Korea. To collect data, participants were recruited through convenience sampling. The participants were 19 years old or older, able to communicate, and consented to participate in the study.

The specific inclusion and exclusion criteria were as follows:

- 1) Patients: Patients with hematologic malignancies who were admitted to the hematology-oncology ward and were aware of their disease were included. Patients who were transferred to an intensive care unit, were unresponsive, or were not able to communicate were excluded.
- 2) Family members: The patient's spouse, immediate family, and siblings who knew the diagnosis were included. Unrelated caregivers and relatives outside the immediate family were excluded.
- 3) Nurses: Nurses working in a hematology-oncology ward and caring for patients with hematologic malignancies were included. Nurses with less than 6 months of clinical experience were excluded since they were training in team nursing and did not perform functional nursing.
- 4) Physicians: Residents and hematologists in charge of patients in a hematology-oncology ward were included. Interns were excluded due to limited knowledge of patients with hematologic malignancies since they rotate departments every two weeks.

The number of participants was calculated using the G*Power 3.1 program by applying one-way analysis of variance (ANOVA) with an effect size of 0.3, significance level of 0.05, and power of 0.8. The calculated number of participants was 128. Considering a dropout rate of 20%, a total of 152 participants were recruited and surveyed with the questionnaire. Five participants were excluded due to incomplete responses or inappropriate completion of the questionnaire, leaving a total of 147 participants (36 patients, 37 family members, 37 nurses caring for patients with hematologic malignancies, and 37 physicians) in the study.

3. Data collection

The data were collected from November 2011 to May 2020. After receiving institutional review board approval, the principal researcher directly explained the purpose and methods of the study to the patients who were recruited at C tertiary hospital in six hematology–oncology wards. After obtaining consent, the data were collected using an anonymous questionnaire and medical records without patients' names.

Two types of questionnaires (15 items each) for medical professionals (nurses and physicians) and general public (patients and family members) about perceptions, determinants, and needs for life–sustaining treatment decision–making were used to collect the data. The disease–related characteristics of patients including diagnosis, admission date, discharge date, length of hospital stay, treatment phase, duration of illness, comorbidities, relapse experience, admission in an intensive care unit, decisions on the dying process, and hospice referral were collected using medical records.

4. Study tools

1) General characteristics of participants

The collected demographic data were as follows: sex, age, religion, marital status, education status, economic status, occupation, and type of household for the general public (patients and family members), and sex, age, religion, marital status, education status, economic status, position, and length of clinical career for medical professionals (nurses and physicians).

2) Perceptions, determinants, and needs in decision–making for life–sustaining treatment

A structured questionnaire was used. The researchers used the tool developed by Hwang and Yang [13] after receiving approval from the original authors via email. Among the 16 items in the questionnaire, 2 items ('the necessity of enactment of the law related to life–sustaining treatment' and 'Does application of hospice palliative care mean withdrawing life–sustaining treatment?') were deleted since they were related to the enactment of the Act on Decisions on Life–Sustaining Treatment, and 1 additional item ('I am well aware of the Act on Decisions on Life–sustaining Treatment' was included. Finally, a total of 15 items matched the purposes of this study

on perceptions, determinants, and needs of patients, family members, nurses, and physicians on making life–sustaining treatment decisions. The perceptions of making life–sustaining treatment decisions consisted of 5 items assessing the degree of perception on decision–making for life–sustaining treatment, and measured on a 4–point Likert scale (1: not at all, 4: strongly agree). The higher score was associated with a higher degree of perceptions, and an average score was calculated. The five items on determinants for making life–sustaining treatment decisions were about the criteria for decision–making and withdrawal of life–sustaining treatment, such as which treatment(s) to stop, what influences the decision, and who participates in the decision–making. The participants were asked to answer the items that applied to them. The need for education on making life–sustaining treatment decisions included 5 items on the necessity of the education, appropriate educators, appropriate education methods, appropriate timing of education, and appropriate timing of decision–making for life–sustaining treatment. Again, the participants were asked to answer the items that applied to them. Six experts (1 nursing professor, 3 unit managers with clinical experience of 20 years or more, and 2 specialists) were consulted on the validity of the tool. The items with content validity of 0.8 or over were selected and the content validity index was 0.99. In the previous study, Cronbach's α , as a measure of reliability was not presented. However, in the present study, the Cronbach's α for perceptions on making life–sustaining treatment decisions, as measured on a Likert scale, was 0.62.

5. Ethical considerations

This study was conducted after receiving approval from the institutional review board (IRB) (No. KC19QESI0765) of C hospital. The purpose of the study, confidentiality protocols, and that the collected data were only used for research purposes were explained to the participants. They were also informed that they can refuse or discontinue participation at any time and written consents were signed. The questionnaires were identified only by numbers. Contact information for the IRB was given to the participants if they had inquiries about their rights or other inquiries, concerns, or complaints that had not been answered by the researchers. A small gift was provided after completing the data collection.

Table 1. General Characteristics of Patients and Family Members (N=73).

Characteristics	Categories	n (%)		Mean ± SD (min~max)
		Patients (n=36)	Family members (n=37)	
Sex	Female	22 (61.1)	26 (70.3)	
	Male	14 (38.9)	11 (29.7)	
Age (yr)	<50	12 (33.3)	14 (37.8)	
	50~59	11 (30.6)	13 (35.1)	
	60~69	12 (33.3)	7 (18.9)	
	≥70	1 (2.8)	3 (8.2)	
	Mean ± SD	52.5 ± 13.0	49.9 ± 12.0	
Marital state	Single	4 (11.1)	4 (10.8)	
	Married	30 (83.3)	32 (86.5)	
	Others	2 (5.6)	1 (2.7)	
Religion	Yes	21 (58.3)	18 (48.6)	
	None	15 (41.7)	19 (51.4)	
Educational status	University	20 (55.6)	20 (54.0)	
	High school	12 (33.3)	14 (37.8)	
	Middle	4 (11.1)	3 (8.2)	
Economic status	Good	3 (8.3)	1 (2.7)	
	Fair	24 (66.7)	29 (78.4)	
	Poor	9 (25.0)	7 (18.9)	
Occupation	Yes	14 (38.9)	12 (32.4)	
	None	22 (61.1)	25 (67.6)	
Household status	With family	32 (88.9)	-	
	Alone	4 (11.1)	-	
Family members	Husband or wife	-	24 (64.9)	
	Parents	-	5 (13.5)	
	Sons and daughters	-	8 (21.6)	
Live with patient	Yes	-	30 (81.1)	
	No	-	7 (18.9)	
Patient responsibility for hospital fee	All or most	-	13 (35.1)	
	Shared equally	-	13 (35.1)	
	Less than others	-	3 (8.2)	
	None	-	8 (21.6)	
Diagnosis	Leukemia	12 (33.4)	-	
	Multiple myeloma	9 (25.0)	-	
	Myelodysplastic syndromes	2 (5.5)	-	
	Lymphoma	10 (27.8)	-	
	Severe aplastic anemia	2 (5.5)	-	
	Castleman disease	1 (2.8)	-	
Phase of treatment	Chemotherapy	24 (66.7)	-	
	PBSCT post care	5 (13.9)	-	
	Supportive care	4 (11.1)	-	
	PBSC collection	3 (8.3)	-	
Relapse	None	21 (58.3)	-	
	Yes	15 (41.7)	-	
Admission to intensive care unit	None	33 (91.7)	-	
	Yes	3 (8.3)	-	
Comorbidities	None	22 (61.1)	-	
	Yes	14 (38.9)	-	
Length of hospital stay (days)		-	-	26.3 ± 16.8 (7~76)
Duration of illness (days)		-	-	1196.9 ± 780.4 (418~4437)

PBSCT: Peripheral blood stem cell transplant, PBSC: Peripheral blood stem cell.

6. Data analysis

The data were analyzed using SPSS version 22.0 (IBM Corp., Armonk, NY, USA).

1) The general and disease-related characteristics of the participants were analyzed as real numbers, percentages, averages, and standard deviations.

2) The perceptions of the participants on making life-sustaining treatment decisions were analyzed as average and standard deviation, and the differences of perception between the groups were analyzed using ANOVA and the Scheffé post hoc test.

3) The differences in the determinants and needs among the four groups were analyzed using the chi-square test and verified by the Fisher exact test.

RESULTS

1. General characteristics of patients and family members

Of the total 147 participants, 36 were patients and 37 were family members. More than half of the participants were women (21 patients, 61.6%; 26 family members, 70.3%). Twelve patients (33.3%) were younger than 50 years old, 11 (30.6%) were in their 50s, 12 (33.3%) were in their 60s, and 1 (2.8%) patient was in their 70s. The age of family members were younger than 50 years old (n=14, 37.8%), in their 50s (n=13, 35.1%), in their 60s (n=7, 18.9%), and in their 70s (n=2, 5.6%). Thirty patients (83.3%) and 32 family members (86.5%) were married. Thirty-two patients (88.9%) lived with their family members and the most common relationship between patient and family member was spouse (n=24, 64.9%).

Leukemia was the most common disease in the participating patients (12 patients, 33.4%). Twenty-four patients (66.7%) were receiving chemotherapy, followed by 5 patients (13.9%) receiving post-care after peripheral blood stem cell transplantation. Twenty-one patients (58.3%) had not experienced relapse of the disease, and 33 patients (91.7%) had not been admitted to an intensive care unit. The average length of hospital stay was 26.3 days and the average duration of illness was 1196.9 days (Table 1).

2. General characteristics of nurses and physicians

Of the total 147 participants, 37 were nurses and 37 were physicians. The age of most nurses and physicians ranged from 21 to 40 years (23 nurses, 62.1%; 31 physicians, 83.8%), and 28 nurses (75.7%) were single. Twenty-two (59.5%) physicians were specialists, clinical instructors, or higher, and 15 were residents (40.5%). The nurses included 4 (10.8%) unit managers, chief nurses, or higher, while most (n=33, 89.2%) were staff nurses. The career experiences varied from 1 year to 11 years or longer (Table 2).

3. Perceptions of patients, family members, nurses, and physicians on life-sustaining treatment decision-making

For the item ‘I am well aware of the Act on Decisions on Life-sustaining Treatment,’ measured on a 4-point Likert

Table 2. General Characteristics of Physicians and Nurses (N=74).

Characteristics	Categories	n (%)	
		Nurses (n=37)	Physicians (n=37)
Sex	Male	0 (0.0)	24 (64.9)
	Female	37 (100.0)	13 (35.1)
Age (yr)	≤30	21 (56.8)	6 (16.2)
	31~40	10 (27.0)	17 (45.9)
	≥41	6 (16.2)	14 (37.8)
Marital status	Single	28 (75.7)	17 (45.9)
	Married	9 (24.3)	20 (54.1)
Religion	Yes	27 (73.0)	26 (70.3)
	None	10 (27.0)	11 (29.7)
Educational status	Doctor of philosophy	1 (2.7)	14 (37.8)
	Master’s	5 (13.5)	18 (48.6)
	Bachelor’s	31 (83.8)	5 (13.6)
Economic status	Good	2 (5.4)	16 (43.2)
	Fair	33 (89.2)	20 (54.1)
	Poor	2 (5.4)	1 (2.7)
Position	Medical specialist	-	22 (59.5)
	Resident	-	15 (40.5)
	Unit manager	4 (10.8)	-
	Staff nurse	33 (89.2)	-
Total clinical career (yr)	≤2	13 (35.1)	12 (32.4)
	3~10	16 (43.2)	12 (32.4)
	≥11	8 (21.6)	13 (35.1)
	Mean ±SD	7.24 ± 7.53	10.05 ± 10.18

scale, the average score was higher in nurses (3.35 points) and physicians (3.57 points) than patients (2.69 points) and family members (2.59 points) with a statistically significant difference ($F=19.58$; $P<0.001$). There was also a statistically significant difference ($F=40.03$; $P<0.001$) in the average score for the item 'I have thought about death as related to the patient's disease', with higher scores among nurses (3.54 points) and physicians (3.70 points) than patients (2.58 points) and family members (2.24 points). The average score for the item 'The patient and family are having honest conversations about decision-making' showed a statistically significant difference ($F=20.06$; $P<0.001$), with higher scores for patients (3.14 points) and family members (3.08 points) than for nurses (2.00 points) and physicians (2.32 points). The average score of the item 'The family truly knows the patient's values and wishes regarding life-sustaining treatment' was higher in physicians (3.05 points) than patients (2.42 points), family members (2.54 points), and nurses (2.19 points) and showed a statistically significant difference ($F=7.33$, $P<0.001$) (Table 3).

4. Determinants of patients, family members, nurses, and physicians on life-sustaining treatment decision-making

For the item 'What would you do if the medical treatment did not cure the disease,' half of patients (18 patients, 50%) responded that they would consider withdrawing life-sustaining treatment, but the most common response in physicians and nurses was that the patient would 'try to find alternative

treatments with the family' (24 physicians, 64.9%; 23 nurses, 62.2%), and there was a statistically significant difference ($P<0.001$). For the item 'reasons to withdraw life-sustaining treatment,' the largest number of patients ($n=16$, 44.4%) and family members ($n=17$, 45.9%) responded that 'prolonging the life of a patient with pain has become futile,' and the mental, physical, and financial burden was considered second among patients ($n=9$, 25.0%). Meanwhile, 15 physicians (40.5%) and 12 nurses (32.4%) responded that 'despite all efforts, a cure is unachievable,' a statistically significant difference ($\chi^2=17.60$, $P=0.040$).

For the item 'Why is it hard to make life-sustaining treatment decisions?', the most common response in patients and family members was 'hope or uncertainty in medicine' (23 family members, 62.2%; 18 patients, 50%), but 'guilt and feeling sorry about withdrawing treatment' and 'disagreements between patient and family' were most common among nurses ($n=17$, 45.9%) and physicians ($n=22$, 59.5%), a statistically significant difference ($P<0.001$). Statistically significant differences ($P<0.001$) were found for the item 'What are the most important factors involved in making life-sustaining treatment decisions?', the patient's opinion was the highest response in family members ($n=19$, 51.4%) followed by physicians ($n=16$, 43.2%) and nurses (11 nurses, 29.7%), while 12 patients (33.3%) responded that the mental, physical, and financial burden was greatest (Table 4).

Table 3. Comparison of Perceptions among Patients, Family Members, Physicians and Nurses Who Make Life-Sustaining Treatment Decisions for Patients with Hematologic Malignancies.

Variables	Mean \pm SD					P	Scheff
	Patients (n=36)	Family members (n=37)	Nurses (n=37)	Physicians (n=37)	Total (n=147)		
I am well aware of the Act on Decisions on Life-sustaining Treatment	2.69 \pm 0.62 ^a	2.59 \pm 0.83 ^b	3.32 \pm 0.58 ^d	3.57 \pm 0.55 ^c	3.05 \pm 0.77	<0.001	
I have thought about the death as related to the patient's disease	2.58 \pm 0.94 ^a	2.24 \pm 0.80 ^b	3.54 \pm 0.51 ^d	3.70 \pm 0.46 ^c	3.02 \pm 0.93	<0.001	a, b<c, d
The person who should talk about everything regarding patient is himself/herself	3.36 \pm 0.49	3.08 \pm 0.83	3.27 \pm 0.73	3.19 \pm 0.57	3.22 \pm 0.67	0.328	a, b<c, d
The patient and family are having honest conversations about decision-making	3.14 \pm 0.68 ^a	3.08 \pm 0.68 ^b	2.00 \pm 0.78 ^d	2.32 \pm 0.88 ^c	2.63 \pm 0.90	<0.001	
The family truly knows the patient's values and wishes regarding life-sustaining treatment	2.42 \pm 0.81 ^a	2.54 \pm 1.02	2.16 \pm 1.09 ^d	3.05 \pm 0.70 ^c	2.54 \pm 0.97	<0.001	a, b<c, d

Table 4. Comparison of Determinants among Patients, Family Members, Physicians and Nurses Who Make Life-sustaining Treatment Decisions for Patients with Hematologic Malignancies.

Variables	n (%)					χ^2/P
	Patients (n=36)	Family members (n=37)	Nurses (n=37)	Physicians (n=37)	Total (n=147)	
What would you do if medical treatment could not cure the disease?						
Never give up treatment	4 (11.1)	8 (21.6)	0 (0.0)	1 (2.7)	13 (8.8)	<0.001*
Consider withdrawing life-sustaining treatment	18 (50.0)	11 (29.7)	14 (37.8)	12 (32.4)	55 (37.4)	
Try to find alternative treatments with the family	4 (11.1)	11 (29.7)	23 (62.2)	24 (64.9)	62 (42.2)	
Do not think about that	10 (27.8)	7 (18.9)	0 (0.0)	0 (0.0)	17 (11.6)	
Reasons to withdraw life-sustaining treatment						
For death with dignity	3 (8.3)	9 (24.3)	11 (29.7)	10 (27.0)	33 (22.4)	17.60/0.04
Prolonging the life of a patient has become futile	16 (44.4)	17 (45.9)	9 (24.3)	7 (18.9)	49 (33.3)	
Despite all efforts, a cure is unachievable	8 (22.2)	6 (16.2)	12 (32.4)	15 (40.5)	41 (27.9)	
Mental, physical and financial burden	9 (25.0)	5 (13.5)	5 (13.5)	5 (13.5)	24 (16.3)	
Why is it hard to make life-sustaining treatment decisions?						
Hope or uncertainty in medicine	18 (50.0)	23 (62.2)	10 (27.0)	9 (24.3)	60 (40.8)	<0.001*
Guilt and feeling sorry about withdrawing treatment	5 (13.9)	12 (32.4)	18 (48.6)	3 (8.1)	38 (25.9)	
Disagreements between patient and family	2 (5.6)	0 (0.0)	7 (18.9)	22 (59.5)	31 (21.1)	
Lack of information on the Act on Life-Sustaining Treatment Decisions	8 (22.2)	2 (5.4)	2 (5.4)	3 (8.1)	15 (10.2)	
Financial reasons	3 (8.3)	0 (0.0)	0 (0.0)	0 (0.0)	3 (2.0)	
What are the most important factors involved in making life-sustaining treatment decisions?						
Patient's opinion	11 (30.6)	19 (51.4)	11 (29.7)	16 (43.2)	57 (38.8)	<0.001*
Family's opinion	1 (2.8)	1 (2.7)	10 (27.0)	10 (27.0)	22 (14.9)	
Mental, physical and financial burden	12 (33.3)	7 (18.9)	10 (27.0)	8 (21.6)	37 (25.2)	
Recommendation of healthcare providers	7 (19.4)	9 (24.3)	6 (16.2)	0 (0.0)	22 (15.0)	
Information about making life-sustaining treatment decisions	5 (13.9)	1 (2.7)	0 (0.0)	4 (5.4)	9 (6.1)	
The most important person involved in making life-sustaining treatment decisions						
Patient himself/herself	32 (88.9)	28 (75.7)	35 (94.6)	35 (94.6)	130 (88.4)	0.080*
Family	0 (0.0)	4 (10.8)	1 (2.7)	1 (2.7)	6 (4.1)	
Health care providers	4 (11.1)	5 (13.5)	1 (2.7)	1 (2.7)	11 (7.5)	

*Fisher exact test.

5. Needs of patients, family members, nurses, and physicians in life-sustaining treatment decision-making

All groups agreed that there was a need to provide information on making life-sustaining treatment decisions to patients and family members during the treatment of hematologic malignancies (average 3.48 points) Written guidelines and in-person review of the guidelines was felt to be the best way to provide that information. Physicians were the most appropriate people to provide that information according to family members (n=27, 73%), followed by patients (n=24, 66.7%), and nurses (n=21, 56.8%). Meanwhile, more than half of physicians (n=19, 51.4%) responded that this information should

be provided by hospice nurse practitioners (P<0.001). The most appropriate time to provide information on decision-making for life-sustaining treatment was when the patient was diagnosed with terminal cancer according to 21 patients (58.3%), followed by 18 family members (48.6%), 15 physicians (37.8%), and 13 nurses (35.1%). Fourteen physicians (37.8%) responded that the early stage of treatment was the second most appropriate time, and 8 nurses (21.6%) responded that the early stage of treatment and disease relapse were equally appropriate second choice times (P=0.030). The most appropriate time to discuss making life-sustaining treatment decisions was when the patient was diagnosed with terminal cancer according to 20 family members (54.1%), 19 patients (52.8%), 12 physicians (32.4%), and 11 nurses (29.7%) in de-

Table 5. Comparing Needs among Patients, Family Members, Physicians and Nurses Who Make Life-Sustaining Treatment Decisions for Patients with Hematologic Malignancies (N=147).

Variables	n (%)					P
	Patients (n=36)	Family members (n=37)	Physicians (n=37)	Nurses (n=37)	Total (n=147)	
Provide information about making life-sustaining treatment decisions						
Strongly agree	13 (36.1)	14 (37.8)	24 (64.9)	31 (83.8)	82 (55.8)	<0.001*
Agree	18 (50.0)	20 (54.1)	12 (32.4)	6 (16.2)	56 (38.1)	
Disagree	4 (11.1)	2 (5.4)	0 (0.0)	0 (0.0)	6 (4.1)	
Strongly disagree	1 (2.8)	1 (2.7)	1 (2.7)	0 (0.0)	3 (2.0)	
Mean ± SD	3.19±0.75	3.27±0.69	3.59±0.64	3.84±0.37	3.48±0.68	
Appropriate way to provide information on the Act on Life-Sustaining Treatment Decisions						
Provision of written guidelines	2 (5.6)	2 (5.4)	3 (8.2)	2 (5.4)	9 (6.1)	0.930*
Provision of written guideline with in-person explanation	17 (47.2)	18 (48.6)	18 (48.6)	20 (54.1)	73 (49.7)	
National campaigns and promotions	11 (30.6)	6 (16.2)	9 (24.3)	8 (21.6)	34 (23.1)	
Arrange an appointment with the relevant department	6 (16.7)	11 (29.7)	7 (18.9)	7 (18.9)	31 (21.1)	
Appropriate person to provide information						
Physician	24 (66.7)	27 (73.0)	15 (40.5)	20 (54.1)	86 (58.5)	<0.001*
Nurse	4 (11.1)	3 (8.1)	1 (2.7)	0 (0.0)	8 (5.4)	
Hematology-oncology nurse practitioner	6 (16.7)	5 (13.5)	1 (2.7)	1 (2.7)	13 (8.8)	
Hospice nurse practitioner	2 (5.6)	2 (5.4)	19 (51.4)	16 (43.2)	39 (26.5)	
Family member	0 (0.0)	0 (0.0)	1 (2.7)	0 (0.0)	1 (0.7)	
Appropriate time to provide information on making life-sustaining treatment decisions						
Early stage of treatment	2 (5.6)	4 (10.8)	14 (37.8)	8 (21.6)	28 (19.0)	0.030*
During chemotherapy (or chemo-radiotherapy)	1 (2.8)	1 (2.7)	0 (0.0)	2 (5.4)	4 (2.7)	
When the disease progresses.	3 (8.3)	4 (10.8)	4 (10.8)	8 (21.6)	19 (12.9)	
When the patient's condition deteriorates rapidly	8 (22.2)	10 (27.0)	4 (10.8)	6 (16.2)	28 (19.0)	
When the patient is diagnosed with terminal cancer	21 (58.3)	18 (48.6)	15 (40.5)	13 (35.1)	67 (45.6)	
While the patient is healthy	1 (2.8)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.7)	
Appropriate time to make life-sustaining treatment decisions						
Early stage of treatment	1 (2.8)	2 (5.4)	11 (29.7)	10 (27.0)	24 (16.3)	<0.001*
During chemotherapy (or chemo-radiotherapy)	0 (0.0)	2 (5.4)	3 (8.1)	0 (0.0)	5 (3.4)	
When the disease progresses	3 (8.3)	3 (8.1)	7 (18.9)	7 (18.9)	20 (13.6)	
When the patient's condition deteriorates rapidly	13 (36.1)	10 (27.0)	4 (10.8)	9 (24.3)	36 (24.5)	
When the patient is diagnosed with terminal cancer	19 (52.8)	20 (54.1)	12 (32.4)	11 (29.7)	62 (42.2)	

*Fisher exact test.

scending order. The second most appropriate time was when the patient's condition deteriorates rapidly according to patients (n=13, 36.1%) and family members (n=10, 27%), while the early stage of treatment was the second most appropriate time according to physicians (n=11, 29.7%) and nurses (n=10, 27%) (P<0.001) (Table 5).

DISCUSSION

Nurses and physicians are more familiar with life-sustaining treatment for patients with hematologic malignancies than pa-

tients and family members. The role of nurses and physicians is to help patients and family members understand life-sustaining treatment and help them make end-of-life care decisions by providing accurate insights and information. Similar to the results of this study, Park et al. [10] reported that 60% of patients with cancer and their family members were not aware of advance directives, while 60% or more physicians and nurses were aware of advance directives. Since the condition of patients with hematologic malignancy deteriorates rapidly after diagnosis, it may be necessary for nurses and physicians to have accurate perceptions and provide information on making

life-sustaining treatment decisions.

In a study by Cho et al. [17], 70.6% of family members responded that they communicated well about making life-sustaining treatment decisions, while 52% of physicians responded that family members did not fully reflect the patients' opinions, similar to the results of this study. The results of this study showed that physicians felt that disagreement between patients and family members was the greatest factor making it difficult to make life-sustaining treatment decisions. These conflicts result in disagreement between patients and family members, difficulties in mediation, and the inability to make decisions that reflect the patient's wishes. These results were also consistent with the study by Jang et al. [18], which showed low scores for the question 'When patients and families disagree regarding advance directives preparation, I advocate for patients.'

In this study, the majority of participants (50%) considered making life-sustaining treatment decisions when curative treatment was no longer possible. This result corresponds with the study by Sun et al. [19] on patients with terminal cancer on a hospice ward, finding that most patients with terminal cancer (n=119, 88.8%) did not want cardiopulmonary resuscitation, placing more importance on death with dignity than a meaningless life with life-extending technology. In a study by Lee et al. [20] on strategies for dying well, a high percentage of participants responded that 'not burdening others' was an important factor for a good death. Ruijs et al. [21] reported that 19~65% of patients with cancer experienced negative emotions and pain from the thought that caregivers were exhausted and that the patient was a burden to them. Kim et al. [22] also reported that the second-highest response (21.1%) was 'not being a burden to the family,' similar to the results of this study. In particular, patients with hematologic malignancies have higher financial costs for treatment than patients with other diseases due to expensive antibiotics, chemotherapeutic drugs, immunotherapy, and peripheral blood stem cell transplants. Therefore, as the treatment period proceeds, the financial factor becomes a burden [23].

In this study, nurses and physicians had higher responses to 'try to find alternative treatments with the family' than patients and family members. This result was similar to the study by Choi and Song [2], reporting that nurses want life-sustaining

treatment more for their family members than for themselves. Kirby et al. [24] also reported that nurses can feel strong emotions when coping with a patient's death and had negative experiences and felt a high burden of emotional responsibility while caring for patients who had a difficult death. These results show that nurses experience conflict and ethical concerns about maintaining a patient's life versus withdrawing life-sustaining treatment.

When analyzing the factors that influence life-sustaining treatment decisions, family members, nurses, and physicians responded that the patient's opinion was the most important factor, with the family's opinion second most important. This may be due to the cultural characteristics of Korea where family culture is predominant and the opinions of family members (who may be in charge of medical costs) cannot help but be respected [9]. This result corresponds with a study by Hwang and Yang [13] that the patient's opinion (68.9%) was the greatest factor influencing decisions on life-sustaining treatment. It was also consistent with a study by Kwon et al. [15] on treatment discontinuation for patients with terminal disease which showed that 71.4% of patients responded that they knew best about making life-sustaining treatment decisions for themselves. Park et al. [10] also stated that the final decision was made by the patient when patients and family members had conflicting opinions and most of the nurses (92.0%), physicians (84.0%), patients (74.0%), and family members (64.0%) responded that the patient was the final decision-making authority. This also corresponds to the results of this study.

Patients, family members, and nurses responded that the most appropriate person to provide information on decision-making and life-sustaining treatment was the physician. In a study by Kwon et al. [15], 77.5% of patients wanted to hear information on withdrawal of life-sustaining treatment directly, while 63.0% of family members responded that they should provide this information to the patient, a significant difference. Park et al. [10] found that patients required the help of physicians with medical knowledge in order to make the best decision about life-sustaining treatment, and that a patient's self-determination and consent without such explanations was meaningless. In a study by Hwang and Yang [13], 71.1% of patients felt that the physician was the appropriate person to explain life-sustaining treatment and more patients wrote

advance directives when the physician recommended it [25]. In this study, however, physicians responded that hospice nurse practitioners should provide the information. The reason for this may be that physicians were confused about the timing of transfer to hospice and palliative care with providing the information on life-sustaining treatment, which is usually given when the physician notifies the patient of their terminal stage. Although the physician in charge usually knows the patient's condition best and has built a relationship with them, related professionals (e.g., a hospice nurse practitioner) may provide information on life-sustaining treatment and provide appropriate detailed information. Moreover, the demand for professional medical staff to provide end-of-life care is impacted by the unfortunate medical reality in Korea that there is limited time to explain decision-making for life-sustaining treatment due to a lack of personnel [25].

Few patients and family members responded that the appropriate time to provide information on making life-sustaining treatment decisions was in the early stage of treatment, during chemotherapy, or as the disease progresses. This reflects a culture that feels mentioning life-sustaining treatment in advance is inappropriate because of the perception that life-sustaining treatment is closely related to death [23]. In addition, although nurses and physicians did feel that information on decision-making and life-sustaining treatment should be provided during initial treatment, patients and family members felt that information should be provided at the time the patient was diagnosed with terminal cancer. This result is contrary to a study by Hwang and Yang [13] in which 40% of patients responded that they wanted to receive this information when they were healthy. Sun et al. [19] reported that cancer patients in a hospice ward responded that they wanted this information when they were near death, in the terminal stage, or when metastasis was diagnosed. In a study by Lee et al. [26], hospitalized patients and medical professionals in a general hospital wanted this information to be provided immediately after admission for a terminal disease. Although there were differences in study participants, these results were similar to our study.

Furthermore, in this study nurses and physicians responded evenly that the appropriate timing for providing information was when patients were diagnosed with terminal cancer, at the early stage of treatment, and during progression of the disease,

indicating differences when compared with patients and family members. Medical professionals want to support the patient's opinions by providing information on life-sustaining treatment while the patient can make decisions. It is necessary to correct the perception of patients and family members that withdrawal of life-sustaining treatment is giving up medical care and reinforce that decision-making for life-sustaining treatment is a system meant to enhance the patient's quality of life. These results suggest that medical professionals should establish treatment protocols for both the full recovery of patients and for situations where treatment is no longer possible.

This study identified the perceptions, determinants, and needs of patients, family members, nurses, and physicians making life-sustaining treatment decisions for patients with hematologic malignancies. The most important authority to make decisions on life-sustaining treatment is the patient. Nurses should provide information that helps patients make appropriate decisions while understanding the differing opinions between groups, and support patients who are making life-sustaining treatment decisions while respecting the patient's right to self-determination and right to die with dignity.

Medical professionals should have training in medical ethics and the legal system and receive continuing education on advance directives with a proactive approach. This training is essential for helping patients with hematologic malignancies prepare for a good death in situations where medical judgments are uncertain or mixed or where making objective judgments about life-sustaining treatment is difficult because of variance in the characteristics of disease. The role of a hospice ethics committee is to promote and support decision-making about life-sustaining treatment in a therapeutic environment so that such decisions are not delayed, creating treatment hardships, and so that consensus can be reached that provides broad support for the patient's dignity.

Since this study was conducted with patients, family members, nurses, and physicians in a tertiary hospital, the study results cannot be generalized to the whole population and we suggest that future studies should be expanded to include multi-center samples and more participants. The study tool (questionnaire) was modified by the researcher to incorporate the perceptions, determinants, and needs for making life-sustaining treatment decisions appropriate for patients with

hematologic malignancies. Therefore, the reliability of the tool is relatively low and the tool was not validated. Verification of the tool is recommended for repeated use in the future. In addition, we suggest an intervention study that compares the realistic implementation of life-sustaining treatment decisions with the perceptions, determinants, and needs related to life-sustaining treatment decisions, as well as the patient's disease and general characteristics. A qualitative study with focus groups is also suggested to study in depth the complex factors of life-sustaining treatment decision-making.

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: SK, EHH, DYK. Data collection: all authors. Data analysis and interpretation: SK, EHH, DYK, SNJ. Drafting the article: all authors. Critical revision of the article: SK, DYK. Final approval of the version to be published: all authors.

SUPPLEMENTARY MATERIALS

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REFERENCES

1. Kwak SY, Byeon YS. Factors influencing resilience of patients with hematologic malignancy. *J Korean Acad Soc Adult Nurs* 2013;25:95-104.
2. Choi YN, Song Y. Life-sustaining treatment choices and related factors involving hospital nurses. *J Korean Public Health Nurs* 2018;32:167-80.
3. Kim SN, Kim HJ. Recognition of good death, attitude towards the withdrawal of life-sustaining treatment, and attitude towards euthanasia in nurses. *Korean J Hosp Palliat Care* 2016;19:136-44.
4. Atkinson Smith M, Torres L, Burton TC. Patient rights at the end of life: The ethics of aid-in-dying. *Prof Case Manag* 2020;25:77-84.
5. Law No. 18627 : Act on Decisions on Life-sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life [Internet]. Seoul: The National Assembly of the Republic of Korea; 2021. Dec 21 [cited 2021 Dec 21]. Available from: <https://www.law.go.kr>.
6. Yun YH, Rhee YS, Nam SY, Chae YM, Heo DS, Lee SY, et al. Public attitudes toward dying with dignity and hospice palliative care. *Korean J Hosp Palliat Care* 2004;7:17-28.
7. Kang JS, Kim HO. The effect of video education on cancer patient advance directive writing. *AON* 2020;20:39-49.
8. Jung HJ, Park JY. Life-sustaining treatment in end-stage liver disease patients: Patients' decisions and results. *Korean J Hosp Palliat Care* 2020;23:85-92.
9. Kim MH, Kang EH, Kim MY. Family decision-making to withdraw life-sustaining treatment for terminally-ill patients in an unconscious state. *Korean J Hosp Palliat Care* 2012;15:147-54.
10. Park AR, So HS, Chae MC. Recognition of patients, families, nurses, and physicians about clinical decision-making and biomedical ethics. *AON* 2014;14:23-31.
11. Visser M, Deliens L, Houttekier D. Physician-related barriers to communication and patient- and family-centred decision-making towards the end of life in intensive care: a systematic review. *Critical Care* 2014;18:604.
12. Kim Y. Signification and challenges of the act on life-prolongation determination - with focus on patient-oriented medical care. *Korean J Health Community* 2018;13:53-61.
13. Hwang HY, Yang SJ. A comparative study on the perceptions of elderly patients and their caregivers toward life-sustaining treatment. *Korean J Med Ethics* 2016;19:484-503.
14. Choi SY, Kim KH. The influence of moral sensitivity, knowledge of advanced directives, good death Perception on nurses' attitudes toward

- the withdrawal of life-sustaining treatment in a general hospital. *Korean J Rehabil Nurs* 2020;23:120–31.
15. Kwon BG, Koh YS, Yun YH, Heo DS, Seo SY, Kim HC, et al. A study of the attitudes of patients, family members, and physicians toward the withdrawal of medical treatment for terminal patients in Korea. *Korean J Med Ethics* 2010;13:1–16.
 16. Lee SJ, Kim HY. Attitude, role perception and nursing stress on life sustaining treatment among intensive care unit nurses. *KJAN* 2017;29:131–42.
 17. Cho KH, Park YK, Suh SR. Comparison of the death anxiety and preferences for care near the end of life between nurses and physicians. *Korean J Med Ethics* 2017;20:276–86.
 18. Jang NS, Park HS, Kim MR, Lee JY, Cho YW, Kim KM, et al. Knowledge, confidence, and learning needs regarding advance directives among hospital nurses. *J Korean Crit Care Nurs* 2018;11:35–45.
 19. Sun DS, Chun YJ, Lee JH, Gil SH, Shim BY, Lee OK, et al. Recognition of advance directives by advanced cancer patients and medical doctors in hospice care ward. *Korean J Hosp Palliat Care* 2009;12:20–6.
 20. Lee SH, Shin DE, Sim JA, Yun YH. Public perception and acceptance of the national strategy for well-dying. *Korean J Hosp Palliat Care* 2013;16:90–7.
 21. Ruijs CD, Kerkhof AJ, van der Wal G, Onwuteaka-Philipsen BD. The broad spectrum of unbearable suffering in end-of-life cancer studied in dutch primary care. *BMC Palliative Care* 2012;11:12.
 22. Kim KS, Kim SM, Hong SW, Kim JS. The evaluation of the Korean Advance Directives (K-AD). *Korean J Hosp Palliat Care* 2016;19:109–18.
 23. Shin DW, Lee JE, Cho BL, Yoo SH, Kim SY, Yoo JH. End-of-life communication in Korean older adults: with focus on advance care planning and advance directives. *Geriatr Gerontol Int* 2016;16:407–15.
 24. Kirby E, Broom A, Good P. The role and significance of nurses in managing transitions to palliative care: a qualitative study. *BMJ Open* 2014;4:e006026.
 25. Jo KH, An GJ, Kim GM. A factor analysis of the impediments to end-stage medical decision-making as perceived by nurses and physicians in South Korea. *Korean J Med Ethics* 2011;14:427–42.
 26. Lee SR, Shin D, Choi Y. Perceptions of caregivers and medical staff toward DNR and AD. *Korean J Hosp Palliat Care* 2014;17:66–74.