

# Family Members' Knowledge and Attitude Toward Life-Sustaining Treatment Decisions for Patients in the Intensive Care Unit

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The decision to withhold or withdraw life-sustaining treatment (LST) lies sometimes in the hands of intensive care unit patients' families. Since 2018, family members of dying patients in South Korea have had the legal right to make decisions for the patients. This study aimed to examine knowledge and attitude toward LST among the family members of patients under intensive care since the foundation of the new legislation. Their perceptions of the roles of nurses were also explored. In this cross-sectional study, 89 participants completed survey questionnaires on demographic characteristics, relationship to patient, reason for admission, length of stay, awareness of the new legislation, knowledge and attitude toward LST, and perception of the role of nurses. The results indicated that knowledge was significantly associated with attitude and was, in fact, the only predictor of attitude toward LST ( $P = .021$ ). Explaining the disease and prognosis in detail and relieving patients of their physical pain were the roles of nurses most valued by family members. The findings suggest that it is crucial for nurses to support family members and provide information about critical changes and medical options for collaborative decision making according to the patients' wishes during the dying process.

## KEY WORDS

attitude, family, intensive care unit, life support care, perception

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Life-sustaining treatment (LST) enabled by the development of modern medical technologies has resulted in meaningless medical care for life prolongation when there is no possibility of recovery.<sup>1</sup> Recently, the withdrawal and withholding of LST has increased, particularly for terminally ill patients in intensive care units (ICUs).<sup>2</sup> The prevalence of LST withholding or withdrawal for patients who died in the ICUs ranged from 10.1% to 82.8%, with a mean (SD) of 51.5% (22.7),<sup>3</sup> whereas the overall mortality rate of adult ICU patients ranged from 10% to 29%.<sup>2</sup> It is notable that the withholding of LST is more frequent than withdrawal in the ICUs.<sup>3</sup>

Family members of critically ill patients often find themselves in difficult situations wherein they must make LST decisions for their loved ones.<sup>4</sup> In particular, the task can be extremely painful and overwhelming for the families of patients without advance directives or who have previously not expressed their preferences for end-of-life care options.<sup>5-8</sup> Life-sustaining treatment decisions may vary depending on individual factors such as age, religious beliefs, severity of illness, and economic status.<sup>8-10</sup> Previous studies reported that cultural and statutory factors also influence LST decisions.<sup>3,11-13</sup> In South Korea, family-oriented culture is reflected by the high level of involvement in patients' illness progress and treatment decisions. Life-sustaining treatment decisions are considered as a family matter rather than the individual decisions of the patient.<sup>7,8</sup> Furthermore, the views on LST and the legislations on it vary globally, although dying with dignity and minimizing suffering are commonly valued.<sup>12-15</sup>

In South Korea, there was an increased demand for establishing a legal basis to exercise the right to die with dignity by withdrawal or withholding of futile medical treatments.<sup>11</sup> Therefore, the "Hospice, Palliative Care, and LST Decision-making Act" (also known as the Well-Dying Act) was enacted in 2018. The contents that were amended partially in 2019 have been put to practice.<sup>16</sup> A recent study reported that among patients with terminated LST, only 29% made the decisions themselves, whereas 71% needed family members to make the decision after the enforcement of the act.<sup>11</sup> Even so, in hospitals and in daily life, talking about advance care planning—such as treatment



options and LST decisions—is taboo, until death is imminent.<sup>6,11</sup> Although the goal of the act is to assure the right of an individual patient in making decisions regarding medical treatments at the end of life, the decisions are often made by family members because they seemingly know the patient's preferences and have the best interest of the patient.<sup>4,8</sup>

Despite their best intentions, family members may insist on aggressive medical treatments even if patients are close to death. Previous studies indicated that LST decisions made by family members may be inconsistent with patients' wishes.<sup>7,8</sup> Furthermore, because laws and public policies related to LST and end-of-life care options are newly enacted and often amended, family members may not be fully informed of the legal basis and rights to make LST decisions in a timely and appropriate manner. It is important for nurses to provide detailed and tailored information and support the families during the LST decision-making process.

Before the implementation of the new act in South Korea, the number of decisions to withhold or withdraw LST were low, although ICU patients' family members had a negative attitude toward the use of LST for life prolongation.<sup>7</sup> Literature indicates that knowledge may influence attitude toward the use of LST for patients.<sup>17-19</sup> However, little is known about knowledge and attitude of ICU patients' family members since the enactment of the act.

Therefore, this study aimed to assess knowledge of LST and examine factors that influence attitude toward LST among family members of ICU patients. Their perceptions of the roles of ICU nurses were also explored.

## METHODS

### Study Design and Participants

This study used a cross-sectional design with convenience sampling. The study participants were spouses, parents, children, or siblings of family members of critically ill patients who were admitted to the ICUs of a tertiary general hospital in Seoul, South Korea. The power analysis was performed using the G\*Power 3.1 program to ensure that the sample size for the study was large enough to detect a statistically significant difference. A minimum of 82 participants were required, with  $\alpha = .05$ ,  $\beta = .30$ , effect size = 0.3, and 12 predictors. A total of 91 study participants were enrolled in the study. They were asked to complete survey questionnaires. Because of 2 incomplete questionnaires, 89 participant surveys were used for data analysis.

### Measurements

The survey questionnaires measured study variables, including knowledge of and attitude toward LST, along with perceptions of the role of ICU nurses. The general characteristics assessed were age, sex, marital status, religion,

education level, relationship to patient, length of stay in the ICU (days), reason for admission, and awareness of the new act regarding the LST decision.

Knowledge of LST was assessed using a 15-item questionnaire originally developed for advance directives of elderly living in the community.<sup>18</sup> The questionnaire consisted of items about medical treatments at the dying stage, including LST. The participants were asked to answer each item and received either 1 for a correct answer or 0 for an incorrect answer. The total score ranged from 0 to 15, with higher scores indicating higher level of knowledge of LST. The reliability of this questionnaire was acceptable (Cronbach  $\alpha = .99$ ).

Attitude toward LST was measured using instruments developed by Park<sup>20</sup> and modified by Byun et al.<sup>21</sup> Each item was assessed using a 5-point Likert scale. The score ranged from 0 to 60, with a higher total score indicating a positive attitude toward the decision to withhold or withdraw LST. The reliability of this questionnaire was acceptable (Cronbach  $\alpha = .85$ ).

The perceptions of the roles of nurses were assessed using 12 questions modified from items developed by Byun et al.<sup>21</sup> Eleven of the questions were scored on a 5-point Likert scale, whereas the last item was an open-ended question. Each scored item was categorized by clinical nurse roles,<sup>22</sup> as perceived by the family members of ICU patients. The last question was an open-ended question that asked the participants to list in the order of importance the 3 most crucial roles from the previous 11 questions. Scores for the 11 items ranged from 0 to 55, with higher total scores indicating a more positive active role of ICU nurses in the decision-making process of LST discontinuation. A previous study reported Cronbach  $\alpha = .88$ , whereas this study showed Cronbach  $\alpha = .72$ .

### Data Collection

The data were collected from July 30 to October 7, 2019, after approval from the institutional review board (IRB) was obtained. The study participants were recruited from the ICUs of a tertiary university hospital in Seoul, South Korea. The families of ICU patients who met the study criteria were invited to participate in the study. The waiting room or the visitors' room of the ICU was used for meetings with potential participants. The first author, who had undergone training of human subjects protection in biomedical research, explained the study's purpose and procedures while providing sufficient information and answering the participants' questions. Participants who agreed to participate in the study provided their written consent and completed the study questionnaires. Assistance, such as reading the questions for individuals who had difficulty completing the questionnaires, was provided to participants. It took approximately 15 to 30 minutes for each individual to complete the questionnaire. All personally



identifiable information was removed from data through the use of a code. The research data were securely stored in a locked cabinet. Throughout data collection and management, voluntary participation and confidentiality of the collected data were ensured.

### Statistical Analysis

The data were analyzed using descriptive statistics, an independent *t* test, analysis of variance, Pearson correlation coefficients, and multiple regression using the R Version 3.5.1 statistical program. Descriptive analyses included frequency, percentage, mean, and standard deviation. Analysis of variance, *t* test, and Scheffe test were used to evaluate the differences in knowledge, attitude, and perception of nurses' roles according to the general characteristics of the participants. The correlation between the study variables was analyzed using Pearson correlation. Multiple regression analyses were conducted to identify the factors affecting attitude toward LST of ICU patients' family members. The independent variables that showed a significant association with attitude statistically were selected for the regression model.

### Ethical Considerations

This study was conducted upon the approval from the IRB for Medical Research Ethics of the study hospital (IRB no. 1907-117-1048). Intensive care unit managers assisted in the recruitment of study participants.

The study participants were informed about the purpose and procedures of this study, confidentiality, benefits, and disadvantages of participating in the study. All the questions were answered. After the explanation of the study, the survey questionnaires were distributed to those individuals who agreed to participate in the study and signed the consent form. Participation in the study was voluntary and could be discontinued at any time during the study. All the participants were informed that the data were collected and managed anonymously and confidentially. The results were not used for purposes other than the study.

### RESULTS

The participants were aged 52 years on average, and 66.3% were women. Regarding educational background, 58.4% graduated from college or higher. Other demographics included religion (63% identified as having a religion), marital status (75.3% were married), and relationship with the patient (47.2% were the patient's adult children). A total of 62.9% of patients were admitted for less than 7 days, and 33.7% were admitted for ventilator care. Most of the participants (73%) were aware of the new act. The demographic characteristics of the study participants are summarized in Table 1.

The scores for knowledge ranged from 1 to 14 (mean [SD], 8.88 [2.80]). The item "The patient has the right to allow or reject LST" received the most correct answers (94.4%). Conversely, the item with the lowest percentage of correct answers (11.2%) was "If there are no physician orders for LST or advance directives and the patient is unable to express his or her will, at least four family members

Characteristics	Categories	n
Age	<40	20
	40–59	41
	>60	28
Sex	Male	30
	Female	59
Education level	≤High school	37
	>High school	52
Religion	Have	63
	None	26
Marital status	Unmarried	22
	Married	67
Relationship to patient	Spouse	28
	Parent	12
	Child	42
	Sibling	7
Length of stay in the ICU (days)	>7	56
	≤7	33
Reason for admission to ICU	Cardiac arrest	7
	Ventilator care	30
	Application of CRRT	10
	Postoperation	33
	Others	9
Aware of the Act on decisions on LST	Yes	65
	No	24

*Abbreviations: ICU, intensive care unit; CRRT, continuous renal replacement therapy.*



need to unanimously state the patient's wishes regarding LST, which were expressed during ordinary times. Then, the statement from the four family members needs to be checked by the doctor in charge and a specialist in the relevant field.” In general, the items related to actual law enforcement received more unknown or negative answers compared with other items.

On an average, the participants had a negative attitude toward the decision to withhold or withdraw LST, with scores ranging from 22 to 56 (mean [SD], 41.20 [7.52]). The item stating “The patients have the right to decide death for themselves” had the highest mean score (mean [SD], 4.12 [0.93]), whereas the item stating “If incurable patients are hospitalized, standard medications (eg, fluids and antibiotics) should be administered” had the lowest mean score (mean [SD], 2.55 [1.08]).

The mean (SD) score of perception about ICU nurses' roles was 45.42 (4.28), with a range of 34 to 55 points.

The item with the highest mean score of 4.51 (0.61) was “The ICU nurse should explain the disease and prognosis to the patient and their family members in detail,” indicating ICU nurses' role as educators in the LST decision-making process for the families of ICU patients. Detailed results regarding their perceptions of the role of ICU nurses are presented in Table 2; each item is presented in the order of highest mean score.

The differences in knowledge, attitude, and the perception of nurses' roles by general characteristics are presented in Table 3. Knowledge of LST differed according to the length of ICU stay ( $t = 3.527, P < .001$ ) and awareness of the new act ( $t = 3.806, P < .001$ ). Attitude toward LST differed significantly according to age ( $F = 4.7954, P = .0106$ ), length of ICU stay ( $F = 2.3998, P = .00191$ ), and awareness of the new act ( $t = 2.2588, P = .0301$ ). There was no difference in their perceptions of nurses' roles according to the general characteristics.

**TABLE 2 Perception of ICU Nurses' Roles (N = 89)**

Rank	Role	Items	Mean (SD)
1	Educator	The ICU nurse should explain in detail the disease and prognosis to the patient and their family members.	4.51 (0.61)
2	Pain controller	In cases where the patient's physical pain is severe, pain relief should be given priority.	4.46 (0.60)
3	Supporter of family members	ICU nurses should provide necessary information from an objective and professional standpoint and respect the judgment of the family members.	4.43 (0.56)
4	Spiritual hospice caregiver	Even when the patient has decided to discontinue life-sustaining treatment, ICU nurses should continue to provide optimal care.	4.31 (0.68)
5	Spiritual hospice care giver	ICU nurses should help patients finish their lives comfortably.	4.26 (0.67)
6	Emotional supporter	ICU nurses should provide emotional support to patients and their family members.	4.17 (0.50)
7	Spiritual hospice caregiver	Consideration should be given to terminally ill patients so that they can stay with family members.	4.17 (0.69)
8	Supporter of family members	ICU nurses should act as consultants to patients or their family members.	4.12 (0.67)
9	Coordinator	ICU nurses should act as coordinators between doctors and the family members of patients.	3.90 (0.83)
10	Emotional supporter	ICU nurses should help the patients or their family members gain religious support if desired.	3.58 (0.95)
11	Spiritual hospice caregiver	The decision to discontinue life-sustaining treatment is made by the patient or patient's family members. Therefore, ICU nurses do not participate in the decision. <sup>a</sup>	3.49 (1.29)
		Item mean score (SD)	4.12 (0.39)

Abbreviation: ICU, intensive care unit.

<sup>a</sup>Reverse item.



**TABLE 3** Differences in Knowledge, Attitude, and Perceptions of Nurses' Roles According to Participants' Characteristics (N = 89)

Characteristics		Knowledge		Attitude		Perception of Nurses' Role	
		Mean (SD)	t or F	Mean (SD)	t or F	Mean (SD)	t or F
Age	<40 <sup>a</sup>	8.9 (4.3)	0.29	38.3 (8.5)	4.80*	45.5 (3.9)	0.004
	40–59 <sup>b</sup>	9.1 (2.4)		43.7 (6.2)	a < b	45.4 (4.1)	
	>60 <sup>c</sup>	8.5 (2.7)		39.6 (7.7)		45.4 (4.9)	
Sex	Male	9.1 (3.2)	-0.41	42.7 (6.8)	-1.41	44.9 (3.7)	-0.19
	Female	8.8 (2.9)		40.4 (7.8)		45.7 (4.6)	
Education level	≥High school	8.5 (3.1)	-0.89	40.4 (7.7)	-0.89	45.1 (4.6)	-0.58
	<High school	9.1 (2.9)		41.8 (7.4)		45.7 (4.1)	
Religion	Have	9.0 (3.0)	0.69	41.0 (8.3)	-0.39	45.9 (4.2)	1.46
	None	8.5 (2.9)		41.6 (5.4)		44.4 (4.4)	
Marital status	Unmarried	8.3 (3.8)	-0.86	39.1 (6.5)	-1.63	43.9 (4.3)	-1.87
	Married	9.1 (2.7)		41.9 (7.8)		45.9 (4.2)	
Relationship to patient	Spouse	8.8 (2.7)	0.99	40.2 (8.3)	1.28	46.1 (4.8)	0.84
	Parents	8.4 (3.1)		38.3 (8.2)		44.2 (5.4)	
	Child	9.3 (3.1)		42.6 (6.8)		45.1 (3.7)	
	Siblings	7.4 (2.8)		42.0 (6.8)		46.6 (3.2)	
Length of stay in the ICU (days)	>7	9.7 (2.6)	3.53**	42.6 (7.4)	2.39*	45.8 (4.3)	0.99
	≤7	7.5 (3.1)		38.8 (7.2)		44.9 (4.2)	
Reason for admission	Cardiac arrest	8.6 (3.6)	1.60	41.0 (4.9)	0.51	44.4 (3.1)	1.09
	Ventilator care	8.9 (2.6)		40.1 (7.5)		44.8 (4.0)	
	CRRT	10.6 (3.4)		43.8 (5.3)		44.0 (2.4)	
	Postoperation	8.8 (3.2)		41.7 (8.7)		46.2 (4.2)	
	Others	7.2 (1.7)		40.3 (7.1)		46.9 (7.0)	
Awareness of the Act	Yes	9.6 (2.8)	3.81**	42.4 (6.9)	2.26	45.3 (4.3)	-0.49
	No	7.0 (2.8)		38.1 (8.2)		45.8 (4.2)	

Abbreviations: ICU, intensive care unit; CRRT, continuous renal replacement therapy.  
 \*P < .05.  
 \*\*P < .001.

The results of the correlational analysis showed that knowledge of LST had significant positive correlations with attitude toward LST ( $r = 0.46, P < .001$ ). There was no correlation between the perception of the roles of nurses and other variables.

Multiple regression analyses using Enter method were conducted to examine factors that influenced attitude toward LST. General characteristics that had a significant association with attitude toward LST were included as confounding variables. Age, length of ICU stay, awareness



**TABLE 4** Factors Influencing Attitude Toward LST (N = 89)

Factors	B	SE	$\beta$	t	P
(Constant)	36.404	8.941		4.072	<.001
Age	0.039	0.052	.077	0.761	.449
Length of stay in the ICU	-2.082	1.592	-.134	-1.308	.195
Awareness of the Act	-1.255	1.836	-.074	-.683	.496
Knowledge of LST	0.702	0.297	.278	2.362	.021 <sup>a</sup>
Perception of nurses' role	0.011	0.173	.006	0.061	.952

Abbreviations: LST, life-sustaining treatment; ICU, intensive care unit.

$R^2 = 0.2857$ , adjusted  $R^2 = 0.2334$ ,  $F = 5.466$ ,  $P < .001$ .

<sup>a</sup> $P < .05$ .

of the new act, knowledge of LST, and perception of nurse roles were included in the regression model. Before carrying out regression analysis, the Durbin-Watson test was used to confirm that the residual analysis was close to 2 at 1.5257 and had no autocorrelation among the selected variables. The results of the regression analysis showed that knowledge of LST ( $\beta = .278$ ,  $P = .021$ ) was the only predictor of attitude toward LST. The selected variables described 23.34% of the attitudes toward LST; the regression model was statistically significant ( $F = 5.466$ ,  $P < .001$ ), as presented in Table 4.

## DISCUSSION

The findings of the study showed that knowledge of LST among the family members of ICU patients was higher than that of community-dwelling older adults.<sup>18</sup> The correct answer percentage for knowledge of LST in this study was 59.2%, whereas it was 39.3% in the previous study. The literature shows that community-dwelling older adults have a poor understanding of the concepts of end of life, advance directives, LST, and do-not-resuscitate orders. Advance care planning, including discussions on LST, should be started early while older adults live independently in the community. This will later help in realizing their decisions on LST, including self-determination for a dignified death.

In this study, the participants had a low percentage of correct answers for questions about LST and the new act, indicating that the provided information related to LST may have been inadequate. Further, there may also have been a lack of interest among the participants. Family members' knowledge about legal protection on the decision to withdraw or withhold LST may allow the patients to access palliative care and maintain physical and psychospiritual integrity until the end of life.<sup>23-26</sup>

Therefore, it is important to improve awareness of the act and develop educational programs on LST for the family members of ICU patients.

Regarding the attitude of family members toward LST, the highest scored item in this study was "The patients have the right to decide death for themselves." The results confirmed the affirming attitude of family members toward the patient's dignity and self-determination. This was in line with the primary purpose of the act: ensuring the patients' right to self-determination and dignity. The item with the lowest score was "If incurable patients are hospitalized, standard medications (eg, fluids and antibiotics) should be administered." These findings indicated that family members wanted to continue routine treatment and management, because they had a concomitant desire for recovery.<sup>8</sup> In South Korea, although patients make their own decision, most final decisions tend to consider the decision of the family.<sup>6</sup> Patients, family members, and medical staff should work together to ensure that LST decisions can be made to fully reflect the intentions of both patients and their families because medical uncertainty and differences in individual values and preferences exist.<sup>17,27,28</sup>

The participants in this study perceived ICU nurses as health educators. It is critical that nurses support the families of ICU patients by providing detailed and tailored information during the LST decision-making process. Relieving the physical pain of the patient was the second most highly rated role of ICU nurses. Pain is considered as one of the most demanding difficulties that terminally ill patients experience.<sup>19</sup> In the LST decision-making process, the role of nurses is vital. Nurses who are most aware of the condition of the patient are expected to perform various roles while supporting patients and their family caregivers during the end-of-life process. The challenges for nurses include being present, providing and interpreting information, and assisting family members to make



end-of-life decisions aligned with the wishes of the patients.<sup>23-25,28</sup> Effective communication is key for resolving conflicts and differences to ensure that the family is satisfied with the care provided.<sup>17,24,26</sup> Ongoing education opportunities may help improve nurses' competency in end-of-life care.<sup>17,24,27</sup> Further studies should develop effective interventions for the family members of ICU patients in the process of end of life, as well as improve the competencies of the expected role of nurses in the LST decision-making process in clinical practice.

The generalizations of the study are limited given that convenience sampling was used to select individuals from the ICUs of a tertiary university hospital in Seoul. Future studies are necessary to include ICUs from various regions and hospitals with a large sample size. Subsequent studies may explore the causal relationships between knowledge, attitude, and behaviors regarding LST decisions of the families of critical ill patients. Further research should focus on the effects of the involvement of family members in decision making in LST and on the development of interventions for advance care planning that includes patients, their families, and their medical staff. Finally, it is necessary to explore the time and approaches for discussing LST termination in clinical practice.

## CONCLUSION

This study increased the understanding of knowledge and attitude regarding LST of the families of ICU patients since the enactment of the new act in South Korea. Provision of relevant information to the families of critical patients is significantly associated with their attitude toward LST. Increased knowledge and improved attitude may lead to making decisions in clinical practice regarding meaningless LST for patients. Follow-up studies are necessary to develop LST-related intervention programs and evaluate the effects on the families of ICU patients.

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