

# Difficulties doctors experience during life-sustaining treatment discussion after enactment of the Life-Sustaining Treatment Decisions Act: A cross-sectional study

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## Research article

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# Abstract

## Background

In the Republic of Korea, life-sustaining treatment (LST) for patients at the end of life should be legally discussed by a doctor according to the LST Decisions Act, which was enacted in February 2018. However, little is known about challenges doctors experience during LST discussion. This study aims to investigate the perceived difficulties of doctors during LST discussions after enactment of the new Act.

## Methods

A cross-sectional survey was conducted in a tertiary hospital in August 2019 and included 686 doctors (432 attending physicians, 141 clinical fellows, and 295 residents) who care for seriously ill patients. The doctors were given a structured questionnaire, and difficulties during the discussion process were examined.

## Results

A total of 132 doctors answered the questionnaire. Most (86.4%) experienced considerable difficulties during LST discussions (mean score,  $7.4 \pm 1.6/10$ ). The two most common difficulties were communication with patients and family and determining when to discuss LST. Two-thirds of doctors found direct discussions with the patient difficult and said they would initiate LST discussions only with family. LST discussions were actually initiated later than considered appropriate. When medically assessing whether the patient is imminently dying, 56% of doctors experienced disagreements with other doctors, which could affect their decisions.

## Conclusion

In the present study, most doctors experienced serious difficulties during LST discussions. To alleviate these difficulties, further institutional support is needed.

## Introduction

Maintaining their own dignity and having meaningful time with their family with proper end-of-life (EOL) care is important for patients in a dying state (1). Conversely, people who do not prepare for dying receive life-sustaining treatment (LST) until near death and EOL care is impossible (2, 3). Therefore, patients need to communicate with their family members and healthcare providers regarding treatment preferences for future care if they are unable to make their own decisions. This process is called advance care planning.

However, in the Republic of Korea, the use of advance care planning is restricted to whether the patient would undergo or forgo the LST when imminently dying, which is different from Western countries. Decisions for LST in Korea are mostly discussed within a few days or weeks before death (4–6). Family members usually write a do-not-resuscitate document as surrogate decision makers for family members near death (5–8). Furthermore, patients in the terminal stage are more likely to receive aggressive treatment with little curative effect (9–11).

Although these situations lower the quality of life at the EOL, legal regulations or policies regarding LST discussions were nonexistent before the LST Decisions Act for patients in hospice and palliative care or at the EOL was enacted on February 4, 2018 (12). The Act aims to assure the best interest of the patients and to respect their self-determination rights. Based on the Act, doctors can discuss LST decisions with patients and document the patient's intention for LST.

The Act is expected to facilitate LST discussions between patients and their doctors, however, there have been concerns that doctors might be intimidated by the Act and issue defensive decisions (13). In addition, the challenges doctors' experience during LST discussions after the Act remain unclear. Therefore, in the present study, the difficulties perceived by doctors during LST discussions in clinical practice after the enactment of the Act were examined.

## **Material And Methods**

### **Design and Participants**

This cross-sectional study was conducted between August 16, 2019 and August 31, 2019 in the Seoul National University Hospital (SNUH). The SNUH is a 1,779-bed tertiary referral hospital in the Republic of Korea, where 1,400 doctors work mainly in acute and specialized care but without an inpatient hospice-palliative care unit. The SNUH has an institutional Ethics Committee which deliberates on matters requested by a patient at the EOL and manages controversial ethical issues relating to LST decisions. Multi-specialty doctors who care for seriously ill patients in SNUH were enrolled in the present study. The study included attending physicians, clinical fellows, and residents who agreed to participate in the study and work in internal medicine, pediatrics, general surgery, obstetrics and gynecology, neurology, neurosurgery, thoracic surgery, or emergency medicine departments. Among 432 attending physicians, 141 fellows, and 295 residents, a total of 132 participants answered the questionnaire and the response rate was 15.2%.

### **Questionnaire**

The study questionnaire was developed by the authors after literature review. After a pilot test with a sample of five doctors, the final questionnaire and explanation for the study in an online link (URL) were sent *via* text message and email to the participants. The questionnaire assessed 1) overall difficulties doctors encounter in LST discussions, 2) difficulties in LST discussions with patients and facilitating

strategies, 3) the appropriate and actual time for initiating LST discussion, 4) difficulties in medical assessment of the patient in the EOL process and their influence on LST decisions, 5) LST implementation in ambiguous cases, and 6) demographic and clinical variables (sex, duration of clinical experience, clinical position, specialty, and whether to see cancer patients). The EOL term has several meanings (14), such as irreversible decline before death or several months or less of life expectancy. However, in the questionnaire, the term EOL process was used as a state of imminent death in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly, which is defined in the Act. According to the Act, the term patient at the EOL indicates a person who is in the EOL process as assessed by the doctor in charge and a medical specialist in the relevant field.

## **Statistical analysis**

The demographic and clinical data of the respondents were analyzed using descriptive statistics. Continuous variables are expressed as median with ranges. Categorical variables are presented as numbers and percentages. The questions assessing attitude toward facilitating strategies were answered using four responses (strongly agree, agree, disagree, or strongly disagree). The responses were divided into two groups: agree (strongly agree or agree) and disagree (disagree or strongly disagree). All analyses were performed using STATA SE, version 15 (StataCorp LP, College Station, TX, USA).

## **Results**

### **Participant characteristics**

A total of 132 doctors answered the questionnaire. The characteristics of the participants are described in Table 1. Among subjects, 42% were male, the median duration of clinical experience was 4 years (range, 0.4–30 years), and half of participants were residents. The most common specialty was internal medicine, followed by pediatrics, emergency medicine, general surgery, neurology, obstetrics and gynecology, thoracic surgery, and neurosurgery.

Table 1  
Clinical characteristics of the participants

	n	%
<b>Sex</b>		
Male	55	42
Female	77	58
<b>Clinical experience</b>		
Median (range), year	4	0.4–30
<b>Clinical position</b>		
Attending physician	26	20
Clinical fellow	35	27
Resident	71	54
<b>Specialty</b>		
Internal medicine	58	44
Pediatrics	20	15
Obstetrics and Gynecology	9	7
General surgery	12	9
Emergency medicine	13	10
Neurology	11	8
Neurosurgery	4	3
Thoracic surgery	5	4
<b>Seeing cancer patients</b>		
Yes	112	85
No	20	15

## Difficulties experienced by doctors during LST discussions

Most of the participants (86.4%, n = 114) had difficulties discussing LST. The mean severity score was  $7.4 \pm 1.6$  (range, 2–10). Items the participants found difficult are listed in Table 2. The two most difficult items were communication with patients and family members followed by determining when to discuss LST decisions.

Table 2  
Items the participants found difficult during LST discussions

Item	1st choice	2nd choice	Scores <sup>a)</sup>	order
Communication with patients and family members	56	28	224	1
Determining when to discuss decisions on LST	24	29	130	2
Diagnosing the patient in the EOL process	18	15	84	3
Determining whether a treatment is LST	8	17	78	4
Choosing among the right documents (e.g., LST plan, Advance Directives)	6	21	60	5
Communication with other doctors	2	4	14	6
Abbreviations: 1st, first; 2nd, second; LST, life-sustaining treatment; EOL, end-of-life				
a) Scores are calculated by 3 × the number of the first choice plus 2 × number of the second choice				

## Difficulties in discussing LST with patients and facilitating strategies

When examining with whom the doctors initiate LST discussions, 10.6% (n = 14) answered they initiate discussion with the patient first, 66.7% (n = 88) with the family member first, and 22.7% (n = 30) with both. Among participants, 67.4% (n = 89) of doctors answered LST discussions with patients were difficult. As shown in Table 3, the most common reason was inability of the patient to communicate and to show intention for LST due to lack of mental capacity. The second most common reason was severe physical symptoms and/or mental distress of the patient, and the third most common reason was the family avoids directly discussing LST with the patient. Most of the participants had a positive attitude regarding the three strategies for facilitating LST discussion with the patient; 97% (n = 129), 99.2% (n = 131), 94.7% (n = 125) agreed that LST discussion can be facilitated by increasing education and information regarding LST decisions for patients, building an environment that enables patients to communicate honestly about death with family or other people, and providing education to doctors about communication skills for LST discussions, respectively.

Table 3

Reasons for difficulties during LST discussions with patients (multiple responses permitted; n = 89)

Reasons	n	%
The patient is unable to communicate and to show his/her intention for LST due to lack of mental capacity at the time of discussion	52	58.4
The patient has severe physical symptoms and/or is mentally distressed at the time of discussion	45	50.6
The family protects the patient from directly discussing EOL care plan with the doctor	26	29.2
The patient may refuse necessary medical treatments before dying	16	18.0
The doctor does not know how to initiate LST discussions with the patient	12	13.5
The patient does not want to discuss decisions regarding LST	7	7.9
Other <sup>a)</sup>	6	6.7
Abbreviation: LST, life-sustaining treatment; EOL, end-of-life		
<sup>a)</sup> Other included the patient is under 19 years of age (n = 5) and communication with the patient at the time of discussion is not easy (n = 1).		

## The appropriate time for initiating LST discussions and the actual time of discussion

The participants were asked when would be an appropriate time for initiating LST discussions and when they would actually initiate LST discussions (Fig. 1A). Most participants answered that an appropriate time for initiating LST discussions was when patients were in a healthy condition, diagnosed with a critical illness, or expected to have poor prognosis despite current active treatment. However, the actual time when LST discussions were mostly initiated was when the patient was expected to have poor prognosis despite current active anti-disease treatment or unable to receive active anti-disease treatment. In addition, none of the participants answered the appropriate time was when death is imminent, however, 12.9% (n = 17) answered they had initiated the discussion when death was imminent.

The attitude toward the two strategies to facilitate LST discussions at an earlier time were investigated (Fig. 1B). Among the participants, 75% (n = 99) agreed that LST discussions are necessary when the patient visits an emergency room or has unplanned hospitalization and 83% (n = 110) of participants agreed to include the explanation for LST discussion in the consent form before a procedure or an operation with risk of death.

## Difficulties in medical assessment of the patient in the EOL process and their influence on LST decision making

According to the Act, to implement the decision to withdraw or withhold LST, medical assessment of the patient in the EOL process should be performed. Among participants, 18.2% (n = 24), 22.7% (n = 30), 40.9% (n = 54), and 18.2% (n = 24) reported they assess the patient is in the EOL process 1–3 days before death, 4–7 days before death, several days to several weeks before death, and several weeks to several months before death, respectively. A discrepancy between when the patient or family thought the patient is in the EOL process and when the doctor assessed the patient was experienced by 93.2% (n = 123) of doctors (Fig. 2A). Among the participants who reported the discrepancy, 87.8% (n = 108) answered that doctors determine the EOL process earlier than patients/families.

Disagreement between doctors regarding the assessment of the EOL process was reported by 56% (n = 74) of doctors (Fig. 2B). Most of the participants stated these discrepancies between doctors and patients/family or disagreements between doctors in medical assessment of the EOL process influence the decision-making process for LST (Fig. 2C).

## **LST implementation in ambiguous cases**

Since the Act was revised in August 2017, the patient expresses the intention for LST in a conceptual sense in Advance Directives or LST Plan, and when the patient is thought to be at the EOL, the doctor in charge should determine which specific medical procedure is futile or regarded as LST based on the best interest of the patient. Without the patient's preference for the specific medical procedure, doctors may experience challenging cases in LST implementation. In the present study, the responses of doctors to LST implementation in two ambiguous cases in were investigated.

### **Case 1**

"If the patient is currently unable to express their intention, what would you do if the family wants a ventilator even though you consider it a medically inappropriate LST?" (Fig. 3)

For case 1, the responses of the doctors varied based on the patient's previous intention, although all doctors regarded the ventilator as an LST. Most of the doctors stated they explained the ventilator is an LST and refused the family's wish for a ventilator (17.4%, n = 23) or persuaded the family to not use or withdraw the ventilator (75%, n = 99). However, when the doctors were not aware of the patient's intention for LST, the number of doctors who answered they would follow the family's wishes increased from 6 (4.6%) to 62 (47%).

### **Case 2**

"You know that your patient has stated that he or she does not want LST but has no written Advance Directives or LST Plan yet. What would you do if the patient who was never determined to be in the EOL process had a sudden cardiac arrest?" (Fig. 4)

For case 2, although the doctors understood the patient's wishes, 62% (n = 82) of the participants said that cardiopulmonary resuscitation should be performed in situations that do not meet legal

requirements. Only 6% (n = 8) responded they would not perform cardiopulmonary resuscitation and 32% (n = 42) said that they would follow the family's wishes.

## Discussion

While a patient usually discusses with doctors various treatment options in addition to LST at the EOL during advance care planning in Western countries, determining LST in the Republic of Korea is possible only if he or she is in the EOL process according to the LST Decisions Act. Therefore, LST discussions are limited to the LST specified in the Act. We found that doctors experience a number of difficulties during LST discussions even after enforcement of the Act. The four major reasons causing the difficulties were the late timing of LST discussions, family-related barriers, lack of communication skills, and limitations of the Act that are not properly applied in clinical practice.

Discussions regarding LST with respect to the patient's self-determination right in the context of the Act is important. However, the present study results showed that many doctors had difficulty in discussing decisions regarding LST with patients and initiated LST discussions with the family. Due to the patient's poor status to communicate, which may result from the late timing of initiating LST discussions, the doctors found the situation difficult. The late timing of having LST discussions reflects the Korean culture of not having honest communications about death (15). Furthermore, in clinical practice, doctors are used to discussing LST with family members when the patient is near death (16), thus, this practice apparently remains after the Act. LST discussions should be performed when the patient can understand and communicate properly (17). In a previous study (18), 78.3% of Koreans thought the most appropriate person to make decisions regarding EOL care plans was themselves. Initiating LST discussions can be recommended at the time of diagnosis in some patients with advanced cancer (19) and should be initiated at least in terminal diagnosis cases. However, when the best time for LST discussions for patients with non-cancerous diseases is remains unclear (20, 21). In the present study, doctors had a positive attitude for initiating LST discussions when the patient visits the emergency room, has an unplanned admission, or is planning for a procedure or operation with risk of death. We suggest these strategies may help establish an early time for LST discussion.

In the present study, family was a considerable barrier in LST discussions with patients. In previous studies (22, 23), doctors regarded the family's reluctance to include the patient in discussion as a significant factor interfering with LST discussions. Patients are frequently protected by family members from being shocked or discouraged by bad news and the family may worry whether the patients may lose hope and decline necessary treatment (24). However, family's paternalistic decisions may not consider the patient's values or result in reasonable decisions respecting the self-determination right of the patient (25). In addition, family members could suffer from decisional burden and experience depression and grief (26, 27) due to surrogate decision making. The present study results showed that building an environment in which patients and family have open discussions and encouraging LST discussions with patients and family can be strategies to reduce family-related barriers.

The most common difficulty addressed by doctors during LST discussions was communication with patients and family. Lack of communication training has been reported as a barrier to prognostic disclosure in previous studies (28–30). Although the Act designates the doctor in charge as the person who should discuss decision making regarding LST, minimal guidance is provided for doctors about how to communicate with patients and family in this regard. Therefore, doctors may feel unhelpful, abandoned, and experience ethical conflicts in clinical practice (31, 32). Based on the present study results, education regarding communication skills for having LST discussions can help doctors overcome the difficulties encountered.

According to the Act, LST implementation should precede assessment of the EOL process (12). However, prognostic uncertainty due to the underlying disease fundamentally exists, causing difficulty for doctors to correctly assess the EOL process (33). Therefore, uncertainty in the medical assessment may complicate LST discussions and influence decision making (34). The fact that LST decision can only be determined at the EOL aggravates the difficulty of predicting medical prognosis and narrows the options for LST decision, making the decision making more complicated. Although the Act does not state any process to alleviate the uncertainty, further guidance and research to support medical assessment of the EOL process are needed.

Several limitations of the Act were observed in the present study which hinder proper application in clinical practice, especially during the implementation process. After the amendment of the Act, patients or families only document the expansive intention for LST (e.g., the patient does not want LST when in a state of imminent death), and doctors are required to determine which medical procedure is regarded as medically inappropriate LST based on the best interest of the patient in the EOL process. However, the survey from case 1 shows if the patient did not express any wishes or thoughts regarding LST, doctors tended to follow the family's wishes. Family members are designated as surrogate decision maker in the Act, but this does not mean that the family can always play a role as an ethically appropriate surrogate (35). Although the Act recognizes the patient's dignity and self-determination at the EOL and stipulates the purpose of the Act is to assure the best interests of the patient, guidelines regarding what the best interest of the patient is or how to address this issue is not provided. Thus, without knowing the patient's wishes, the best interest of the patient appears to depend on the family's decision. In case 2, doctors would make different decisions without the documented intention of the patient, even when they already know the verbal do-not-resuscitate status. In this gray area, one third of doctors prioritize the family's intentions. In these circumstances, which the Act does not address, decision making should be determined in a manner that respects the best interest of the patient, and institutional support for the doctor's decision is needed.

The present study had several limitations. First, the study was from a single tertiary hospital and included a small number of respondents, thus, the difficulties doctors experience during LST discussions after the Act cannot be generalized. Further studies with a larger sample size should be conducted in various institutional settings. Second, the study population included doctors that practice medicine in specific fields where they frequently experience LST discussions, which may cause selection bias. Third, the recall

bias may occur in asking when the doctors had LST discussion, how frequently they had LST discussions, and whether there were disagreements with family or between physicians.

Despite these limitations, the results showed most doctors experienced serious difficulties during LST discussions. To alleviate these difficulties, further institutional support is needed to improve the LST discussion between doctors, patients, and family.

## **Abbreviation**

EOL, end-of-life; LST, life-sustaining treatment; SNUH, Seoul National University Hospital;

## **Declarations**

## **Ethics approval and consent to participate:**

The study protocol was reviewed and approved by the institutional review board of the SNUH (no. H-1907-171-1050). The study was conducted in accordance with the Principles of the Declaration of Helsinki. Informed consent was obtained from all participants in the study.

## **Consent for publication:**

Not applicable

## **Availability of data and materials:**

The dataset used and/or analyzed during the current study is provided in the supplementary materials and additional materials are available from the corresponding author on reasonable request.

## **Competing interests:**

The authors declare that they have no competing interests

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## **Authors' contributions:**

Conception and design: SHY; Development of methodology: SHY, WC, YK, HYP; Acquisition of data: SHY, WC, YK; Analysis and interpretation of data: SHY, WC, YK; Administrative, technical, or material support: SHY, DSH; Study supervision: SHY, DSH; All authors read and approved the final manuscript.

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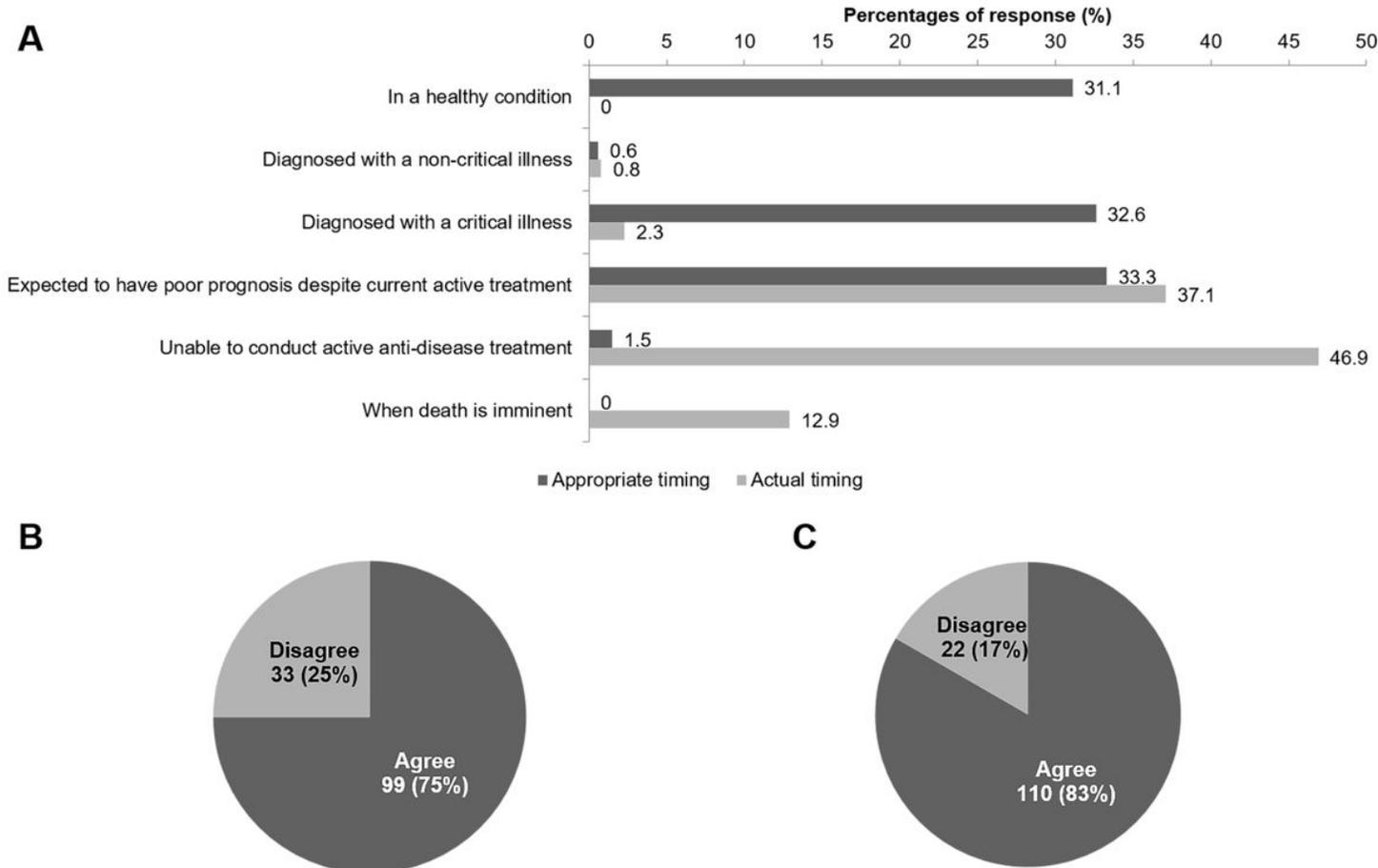
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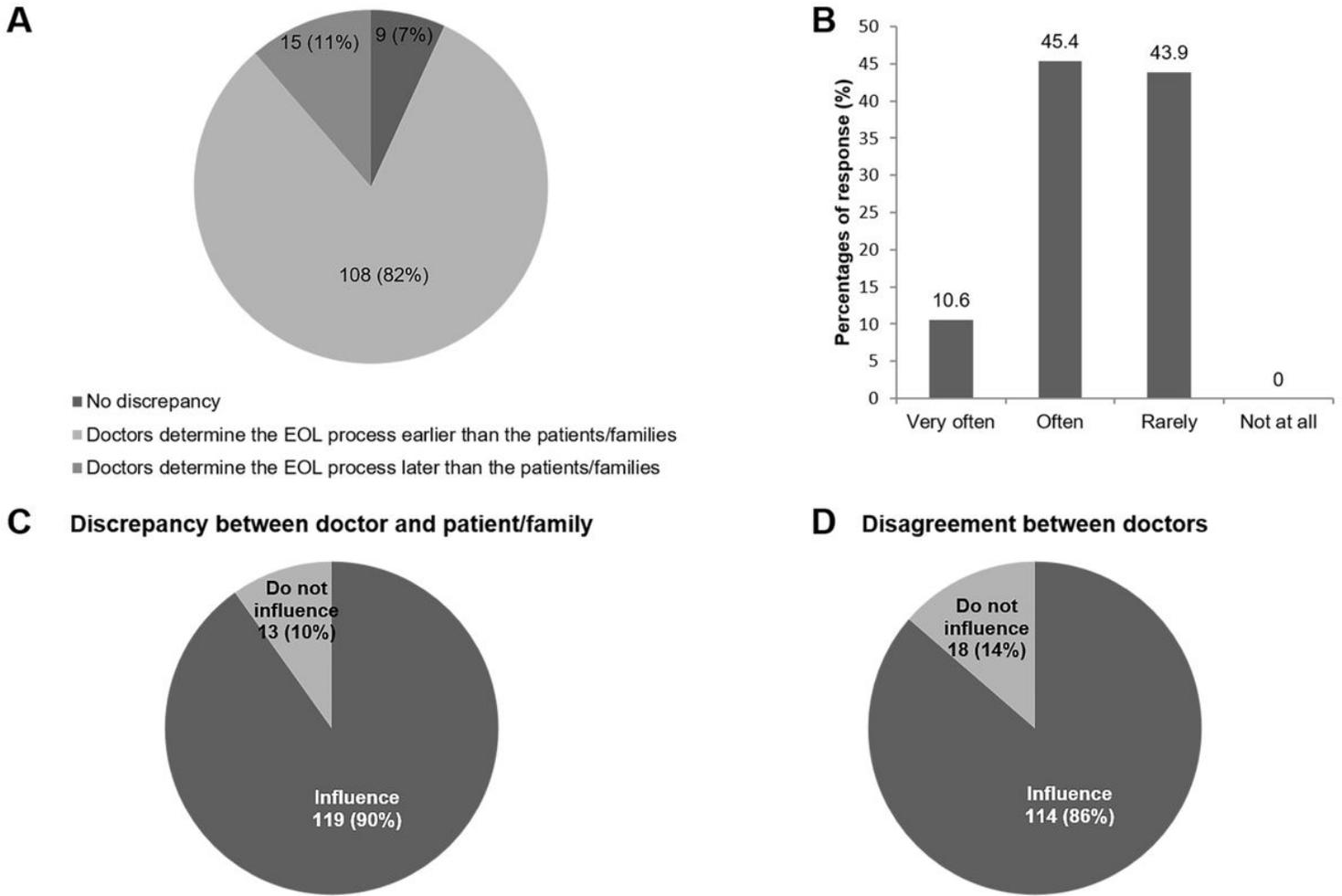
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## Figures



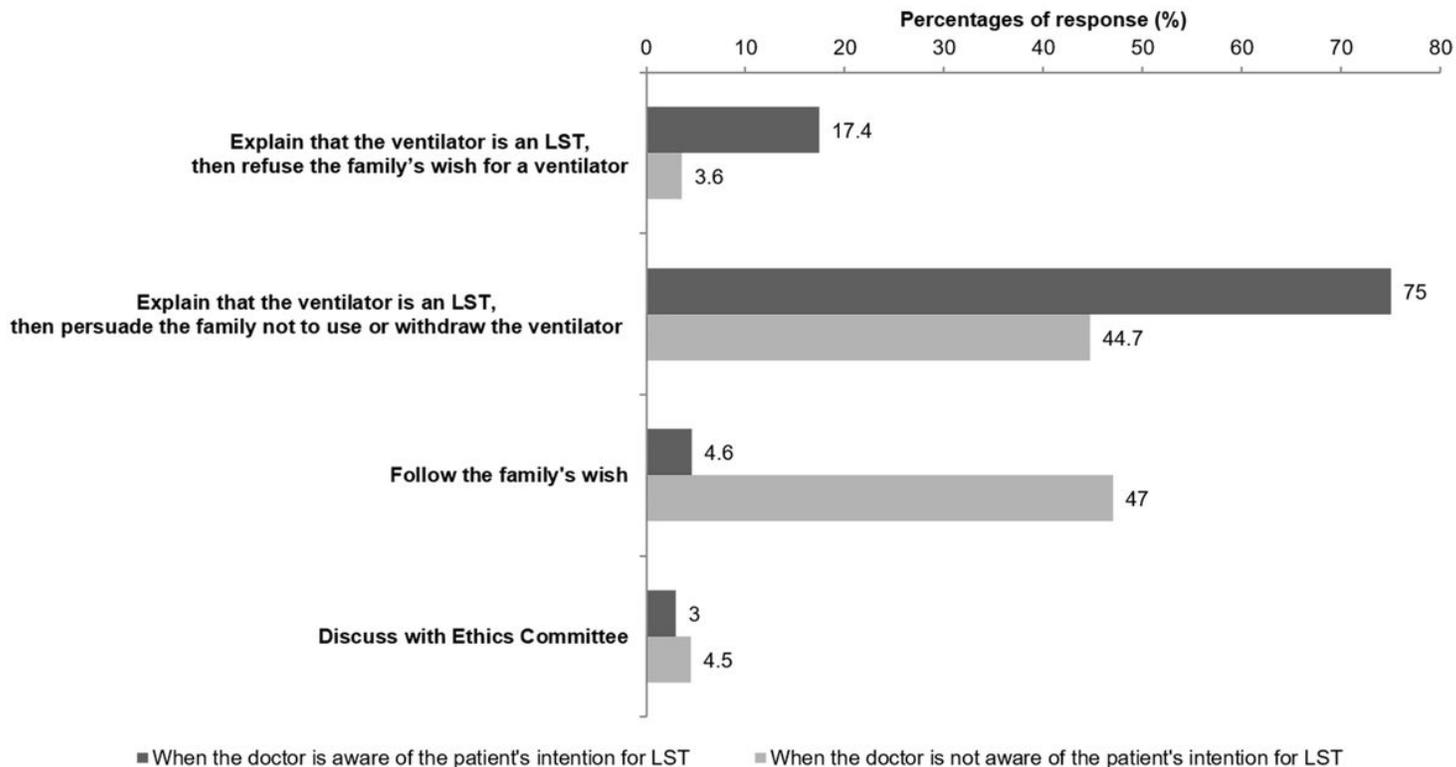
**Figure 1**

The timing of life-sustaining treatment (LST) discussions and strategies to facilitate the discussion at an earlier time. (A) The appropriate time for initiating LST discussions and the actual time of discussion. (B) Attitudes toward the strategy to necessitate LST discussions when the patient visits an emergency room or has unplanned hospitalization. (C) Attitudes toward the strategy to include the explanation for LST discussions in the consent form before a procedure or an operation with risk of death.



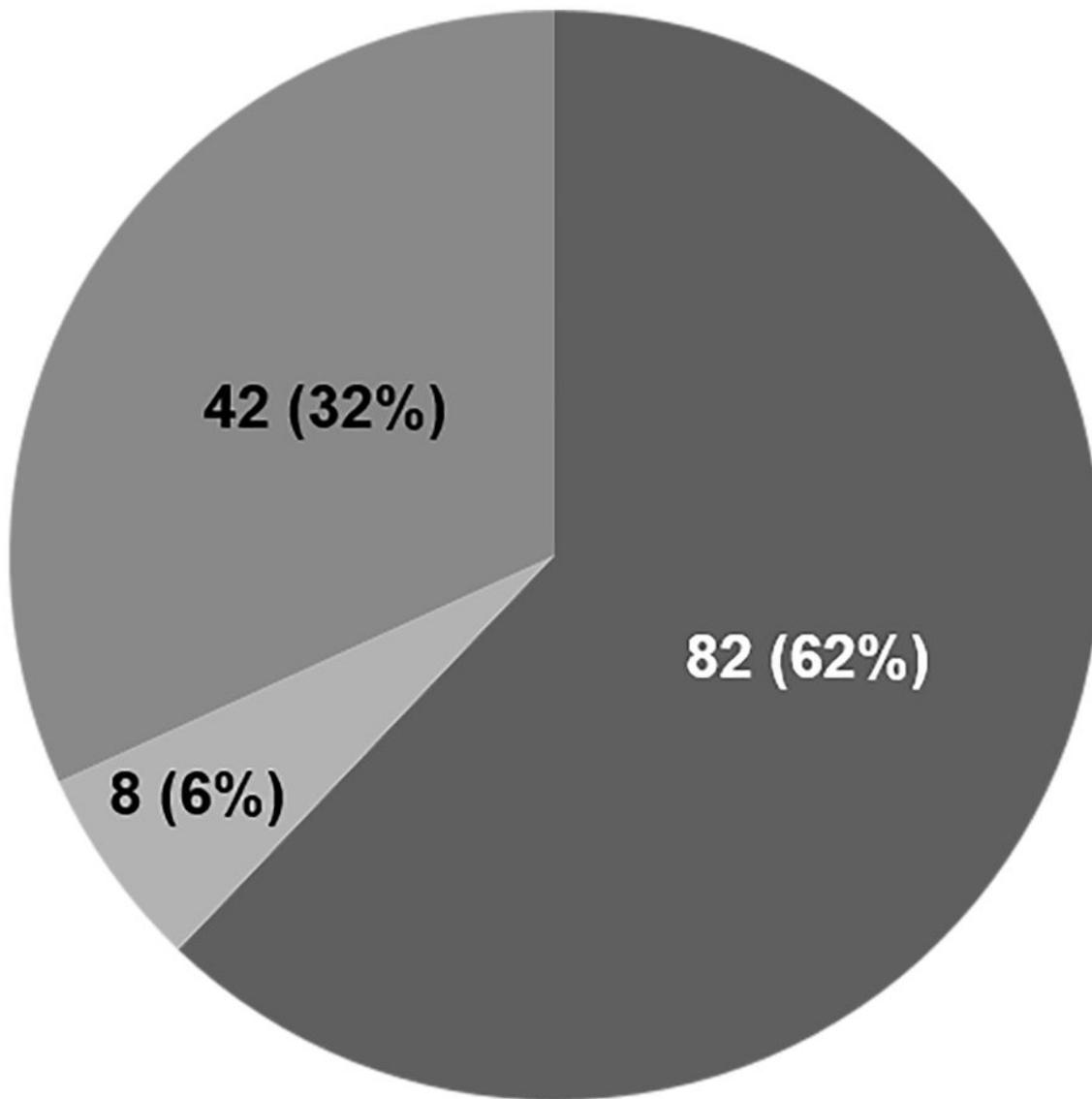
**Figure 2**

Discrepancy or disagreement in medical assessment of the patient in the end-of-life (EOL) process. (A) Response to the question “Is there a discrepancy between when the patient or family thought the patient is in the EOL process and the doctor’s assessment?” (B) Response to the question “How often do you experience disagreement with other doctors regarding medical assessment of the patient in the EOL process?” (C) The impact of discrepancy between doctor and patient/family and (D) the impact of disagreement between doctors on the decision-making process on life-sustaining treatment (LST).



**Figure 3**

Response to case 1 based on the previous intention of the patient: "In case the patient is currently unable to express their intention, what would you do if the family wants a ventilator even though you consider it a medically inappropriate life-sustaining treatment (LST)?"



- Perform cardiopulmonary resuscitation
- Do not perform cardiopulmonary resuscitation
- Follow the family's wish

**Figure 4**

Response to case 2: "You know that your patient has stated that he or she does not want life-sustaining treatment (LST) but has no written Advance Directives or LST Plan yet. What would you do if the patient who was never determined to be in the end-of-life process had a sudden cardiac arrest?"