



Problems Related to the Act on Decisions on Life-Sustaining Treatment and Directions for Improvement

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The Act on Decisions on Life-Sustaining Treatment has been in effect since 2018 for end-of-life patients. However, only 20~25% of deaths of terminally ill patients comply with the law, while the remaining 75~80% do not. There is significant confusion in how the law distinguishes between those in the terminal stage and those in the dying process. These 2 stages can be hard to distinguish, and they should be understood as a single unified “terminal stage.” The number of medical institutions eligible for life-sustaining treatment decisions should be legally expanded to properly reflect patients’ wishes. To prevent unnecessary suffering resulting from futile life-sustaining treatment, life-sustaining treatment decisions for terminal patients without the needed familial relationships should be permitted and made by hospital ethics committees. Adult patients should be permitted to assign a legal representative appointed in advance to represent them. Medical records can be substituted for a patient’s judgment letter (No. 9) and an implementation letter (No. 13) for the decision to suspend life-sustaining treatment. Forms 1, 10, 11, and 12 should be combined into a single form. The purpose of the Life-sustaining Medical Decisions Act is to respect patients’ right to self-determination and protect their best interests. Issues related to the act that have emerged in the 3 years since its implementation must be analyzed, and a plan should be devised to improve upon its shortcomings.

Key Words: Death, Palliative medicine, Hospice care, Terminal care, Patient self-determination act, Personal autonomy

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INTRODUCTION

The Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life (hereinafter referred to as the Act on Decisions on Life-Sustaining Treatment) passed in South Korea’s Congress in February 2016. The hospice and palliative care portion was

implemented first, beginning in August 2017, and covered preparations such as the expansion of existing infrastructure, education for medical personnel, and improvement of the public perception of the act. The portion relating to decisions on life-sustaining treatment was implemented in February 2018. The Act on Decisions on Life-Sustaining Treatment included hospice and palliative care so that patients could

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continue to receive hospice and palliative care even when they decided to withhold or withdraw life-sustaining treatment. Diverging from the intent of the legislation, the process required by law has only been followed by 20~25% of end-of-life patients. We aimed to analyze the problems following the implementation of the law and suggest strategies for improvement.

1. The situation after the implementation of the Act on Decisions on Life-Sustaining Treatment

1) Implementation of the Act on Decisions on Life-Sustaining Treatment

According to a study based on National Health Insurance billing data, in the 20 months from February 2018 to October 2019, 71,327 patients (42,796 patients in 1 year) wrote statements on the decision to suspend life-sustaining treatment [1]. This figure nearly matches the number of statements on the decision to suspend life-sustaining treatment reported in an annual report by the National Agency for Management of Life-Sustaining Treatment (33,390 in 2018, 48,470 in 2019, and 54,659 in 2020) [2].

Among the 136,555 patients who submitted statements between 2018 and 2020, a significantly larger proportion of patients at tertiary hospitals (61.2%) and general hospitals (35.9%) prepared statements compared to patients at primary hospitals (1.97%), long-term care hospitals (0.74%), and clinics (0.19%) [2]. According to data from a tertiary hospital, among the 1,198 patients who died in the past year, 809 (67.5%) were confirmed to have prepared statements [3]. Therefore, statements on the decision to suspend life-sustaining treatment are mostly written by patients at large hospitals such as tertiary and general hospitals.

According to an analysis by the National Agency for Management of Life-Sustaining Treatment of hospital statistics during the first year of implementation of the Act on Decisions on Life-Sustaining Treatment (February 4, 2018, to January 31, 2019), 59% out of 33,549 patients who prepared a statement (19,827 patients) were cancer patients [4]. However, in a study that analyzed National Health Insurance billing data on 50,838 cancer patients who died within the same time period, only 12,891 (25%) were found to have followed the process required by the Act on Decisions on Life-Sustaining Treat-

ment, while 37,947 (75%) did not [5].

According to data published by Statistics Korea, 75.6% of the 305,100 individuals who died in South Korea in 2020 died in a hospital, totaling 230,656 patients. However, an annual report by the National Agency for Management of Life-Sustaining Treatment reported that 54,659 patients submitted statements on the decision to suspend life-sustaining treatment [2]. Thus, 23.7% of patients who died in hospitals followed the process for making decisions about life-sustaining treatment outlined in the Act on Decisions on Life-Sustaining Treatment. The implementation of the act in the clinical field must be analyzed to understand the process undertaken by patients who died in hospitals and did not write statements on the decision to suspend life-sustaining treatment.

2) Frequency of self-determination

Among the 71,327 patients who submitted statements between February 2018 and October 2019, 33.5% (23,891 patients) completed the forms themselves. An advance directive for life-sustaining treatment was prepared for 1.2% of patients, and 32.3% had life-sustaining treatment plans. When other family members completed the forms, the decision was based on speculation about the patient's wishes for 31.5% of patients, and 33.6% were surrogate decisions based on a consensus among all family members [1].

In a 2017 study in which 336 terminal cancer patients were asked to prepare life-sustaining treatment plans for themselves, which preceded the Act on Decisions on Life-Sustaining Treatment, 105 patients (31.3%) decided to prepare statements. The main reasons patients did not complete the forms, as identified by medical personnel, were non-cooperation by family members (49.7%) and patient refusal (34.3%). According to patients, the reasons included a lack of information about decisions on life-sustaining treatment (65.1%) and emotional anxiety (63.5%) [6]. A study conducted 1 year after the implementation of the Act on Decisions on Life-Sustaining Treatment found that long-term cancer patients, young patients, patients who lived in the Seoul metropolitan area, and patients with a low income level were more likely to complete life-sustaining treatment plans and use hospice and palliative care institutions [5].

3) Withholding or withdrawal

The act does not distinguish between withholding and withdrawal. Thus, no data related to withholding and withdrawal are included in National Agency for Management of Life-Sustaining Treatment statistics. According to the results of an analysis of 809 patients at a tertiary hospital who made decisions to suspend life-sustaining treatment within the past year, 727 (90%) patients decided to withhold treatment, while 82 (10%) decided to withdraw treatment [3]. In another study, withholding was found to be much more common than withdrawal, at a ratio of 141:28 [7]. In a multi-institution study of Asian countries, when decisions about life-sustaining treatment for patients with only a small chance of survival were made, the number of critical care patients in South Korea who chose to withhold treatment was similar to that of critical care patients in Singapore, Hong Kong, the Philippines, Malaysia, and Thailand. However, a significantly lower proportion of South Korean patients chose to withdraw treatment [8]. Therefore, these findings indicate that doctors in South Korea prefer not to withdraw life-sustaining treatment.

2. Comparison to the legal systems of other countries

Cultures and legal systems differ by country. Decisions about life-sustaining treatment are only possible during the dying process in South Korea, but the law can be applied to anyone with a terminal illness in Taiwan and Japan and extended to patients in a persistent vegetative state. In countries where the law is extended to patients in a persistent vegetative state, the law applies to both patients in the dying process and patients with terminal illnesses.

1) Countries where decisions about life-sustaining treatment are only possible during the dying process

According to the Act on Decisions on Life-Sustaining Treatment, “end-of-life” indicates that a patient’s health status precludes the possibility of recovery and shows no signs of improvement despite treatment, suggesting that the patient is near death due to his or her rapidly deteriorating symptoms, and “terminal illness” indicates that an attending physician and a specialist in the relevant disease agree on a prognosis of approximately 1 month for a patient due to the impossibility of

recovery and worsening symptoms despite active treatment.

In the “Consensus Guidelines for the Definition of the End Stage of Disease, Last Days of Life, and Criteria for Medical Judgment” published in 2018, guidelines were suggested for each terminal disease, but the guidelines only consider patients to be at the dying process when their status deteriorates to the point at which they are only days or weeks away from expected death [9]. The terminal stage is defined in the guidelines as when patients with an irreversible disease are expected to die within months, while the dying process is defined as having only days or weeks left to live. However, in other countries, the dying process is not distinguished from the terminal stage.

2) Countries where patients with terminal illnesses can make decisions about life-sustaining treatment

The Palliative and Hospice Care Act implemented in Taiwan in 2000 and the Japanese national guidelines published in 2007 (“Guidelines on the Medical Decision-Making Process in the Final Stages of Life”) allow terminal patients to make decisions about life-sustaining treatment [10]. The law applies to patients in the dying process and terminal patients facing no possibility of recovery. Taiwan’s act used the expression “terminal,” and Japan’s policy used the terms “terminal” and “end-of-life stage.” However, neither policy mentions a specific amount of remaining time.

3) Countries where decisions about life-sustaining treatment can be made for patients in a persistent vegetative state

The US and the UK allow decisions about life-sustaining treatment for patients with terminal illnesses despite a lack of legislation via do-not-resuscitate (DNR) policies. Laws were drafted after the issue of decisions about life-sustaining treatment for patients in a persistent vegetative state became a social issue. In 1990, the Patient Self-Determination Act was passed federally in the US so that patients could make decisions about life-sustaining treatment not only when they had a terminal illness, but also when they were in a persistent vegetative state or had severe dementia [11]. The Mental Capacity Act was passed in 2005 in the UK [12], followed by similar acts in Germany in 2009 and Italy in 2017.

When decisions about life-sustaining treatment are made

for patients in a persistent vegetative state, as is permitted in the US and some European countries, the patient's right to self-determination is a necessary prerequisite in the face of uncertainty. Therefore, these decisions about life-sustaining treatment are only permitted when submitted by patients themselves. Advance directives play an important role and are strictly followed in a manner similar to the execution of a will. An individual designated by the patient in advance can participate in the decision-making process, but decisions by proxy are generally not allowed. A separate legal system applies to issues around euthanasia such as physician-assisted suicide. In cases of dementia, there is a possibility of conflict when determining the severity of the disease. Advance directives specifically for patients with dementia have been developed and implemented, but they are generally not recognized [13].

In addition to the Palliative and Hospice Care Act enacted in 2000 for patients with terminal illnesses, Taiwan introduced the Patient Self-Determination Act in 2019. This separate legislative act aimed to expand the eligibility criteria for decisions about life-sustaining treatment to patients in irreversible comas, in vegetative states, with severe dementia, and whose condition or pain is intolerable or lacks a solution based on the assessment of the hospital in charge [14].

TEXT

The main issues related to the implementation of the Act on Decisions on Life-Sustaining Treatment over the past 3 years in the clinical field are as follows. The possibility of executing decisions to suspend life-sustaining treatment under the Act on Decisions on Life-Sustaining Treatment in South Korea is limited since, among patients who are not expected to recover, it only applies to patients in the dying process. However, the issues primarily seem to stem from the strictly managed implementation process, similar to countries where decisions about life-sustaining treatment can be made for patients in a persistent vegetative state.

1. Timing of the implementation of decisions to suspend life-sustaining treatment

Withholding and withdrawal of treatment are considered when executing decisions on life-sustaining treatment. The

timing is clear for the withdrawal of treatment, but the timing for the withholding of treatment is less straightforward. For example, if a terminal patient is transferred from a tertiary hospital to a long-term care, hospice, or palliative care facility after the completion of a life-sustaining treatment plan that stated that he or she refuses treatment using a ventilator, the implementation of the decision to withhold life-sustaining treatment is not considered to have occurred at the time of completion of the life-sustaining treatment plan since the patient completed the plan while he or she was still considered a terminal patient rather than an patient in the dying process. Even if the beginning of the dying process is set as the time of withholding, there is still uncertainty since there are no strict criteria to determine the beginning of the dying process. Since a ventilator could be considered a life-sustaining measure at any point in the dying process from illness to death, withholding of the ventilator can be considered a cause of death. Therefore, even when the withholding process reflects the patient's will, it is difficult to strictly adhere to withholding measures as a guideline for behavior.

While there is clear diagnostic evidence to distinguish death from life, determining if a patient is in the dying process entails uncertainty. The Act on Decisions on Life-Sustaining Treatment was based on the assumption that two doctors could determine with certainty cases in which the dying process had begun. However, due to the development of medical technology, it is difficult to clearly identify when a patient is in the dying process in the clinical field. On one hand, some patients may be considered to have begun the dying process and recover, while, on the other hand, some patients may die even though they received aggressive treatment and were not considered to be in the dying process. In addition, when patients die after rapid deterioration of their condition, it can still be difficult to receive signatures from two doctors at small hospitals.

Patients who have been ill for a long time with a non-cancer chronic disease often go through periods of improvement and deterioration, making it more difficult to distinguish between the terminal stage and the dying process. Therefore, the window of time during which decisions about life-sustaining treatment must be made could be missed while waiting to determine ambiguous criteria for the dying process. In a South

Korean study of cancer patients, the period from terminal illness to death ranged from 4 to 11 weeks [15,16]. According to the Act on Decisions on Life-Sustaining Treatment, decisions about life-sustaining treatment can be executed only for patients in the dying process, and the dying process is defined as being close to death. However, in reality, many patients are referred to hospice care after submitting their statements, which indicates that there are many problems related to determining when the dying process has begun even though it is a prerequisite for the execution of a patient's will. According to a study of 169 patients at a tertiary hospital who died within the study period after they were classified as being in the dying process, the average survival time of patients who decided to withdraw life-sustaining treatment was 2.12 days. However, the average time period between the submission of a decision form and death for patients who decided to withhold treatment was 8.95 days [7]. A large-scale and systematic study of the total number of patients who completed decision forms is needed to understand how terminal illness and dying process diagnoses are made in clinical practice to improve policies so that patients can receive hospice and palliative care without delay.

A study of a South Korean tertiary hospital examined whether it was possible to distinguish terminal illness from the dying process. One case study described a 72-year-old male patient diagnosed with esophageal cancer whose disease continued to progress despite simultaneous radiation therapy and chemotherapy. During the third palliative chemotherapy session, he was admitted to the emergency room due to fever and shortness of breath. Septic shock caused by aspiration pneumonia was suspected, and a central venous catheter was inserted at the emergency room. Vasopressors were administered, and the patient's blood pressure was maintained. The patient was conscious but had severe respiratory failure. The patient understood his disease state and strongly refused intubation and ventilator treatment. The patient had not written an advance directive.

In response to a survey of residents at a hospital in the first year of the Act on Decisions on Life-Sustaining Treatment, in answer to the question, "Do you consider ventilator and intensive care unit treatment for this patient to be a life-sustaining treatment for a patient in the dying process?", 43.2% of resi-

dents answered that the patient was in the dying process, while 50.4% responded that the patient had a terminal illness. In the second year, 37.5% of residents responded that the patient was in the dying process, while 57% responded that the patient had a terminal illness [17]. Presented with the same scenario, doctors expressed different opinions about whether a patient had a terminal illness or was in the dying process.

The Supreme Court decision in South Korea about Grandmother Kim (case 2009Da17417) declared that, in "end-of-life cases without the possibility of recovery" in which the patient has no possibility of recovery and no possibility of recovering lost vital functions, and the possibility of dying in a short time frame is very clear based on the physical status of the patient, implementation of the decision to suspend life-sustaining treatment is permitted. However, in this case, the patient survived 201 more days after the suspension of ventilator treatment [18].

In most countries, patients with a life expectancy of less than 6 months are considered to have a terminal illness [19], and this definition is used for administrative processes. However, numerical predictions of the remainder of a patient's life can be inaccurate [20], and it is more accurate to diagnose patients with a terminal illness when they have no possibility of recovery and the progression of the disease can cause death in a short amount of time [21].

Since there is substantial uncertainty when predicting the remainder of a patient's life, it is unrealistic to distinguish terminal illness from the dying process based on this metric. Examples of legislation from other countries do not distinguish between the dying process and the terminal stage. In addition to the medical difficulty of distinguishing between the terminal stage and the dying process among patients with no possibility of recovery, it also causes administrative confusion. Therefore, the criteria to distinguish between terminal illness and the dying process in the Act on Decisions on Life-Sustaining Treatment should be combined so that they apply to all patients with terminal illnesses.

2. Hospitals under the jurisdiction of the act

Currently, the Act on Decisions on Life-Sustaining Treatment is only applicable in hospitals with a hospital ethics committee or hospitals in partnership with institutions with a

hospital ethics committee. For this reason, adherence to the act is difficult at small hospitals. As of August 2021, hospital ethics committees had been established at only 302 of South Korea's 3,239 hospitals (9.3%). Stratified by hospital type, the proportion of hospitals with a hospital ethics committee were 100% (45 out of 45) for tertiary hospitals, 53% (169 out of 319) of general hospitals, 1.5% (21 out of 1,409) of primary hospitals, and 4.6% (67 out of 1,466) of long-term care hospitals [2].

Prior to the Act on Decisions on Life-Sustaining Treatment, decisions about suspending life-sustaining treatment considered various factors including the opinions of patients and patients' family members, as well as the benefits to the patient at each hospital. Following the implementation of the act, it is unclear what guidelines should be followed for near-death patients at hospitals where the execution of decisions to suspend life-sustaining treatment is not possible.

When hospitals are unable to establish hospital ethics committees, they can instead establish memoranda of understanding (MOUs) with the hospital ethics committees of other hospitals or a public ethics committee. However, small hospitals face difficulties when taking these measures. Reasons can include 1) the high cost of MOUs, 2) perceived minimization of the need to implement the Act on Decisions on Life-Sustaining Treatment due to the established use of DNR forms, and 3) the frequent transfer of patients to tertiary hospitals right before death [22].

Decisions to suspend life-sustaining treatment in the clinical field are made in response to situations that change by the minute. Even with an MOU with a public ethics committee, when conflicts around decisions to suspend life-sustaining treatment occur, the process to resolve the conflict through a public ethics committee rather than the institution where the patient is receiving care is complicated and lengthy, making it difficult to apply in actual clinical practice.

Even when hospital ethics committees are in place, 34.9% of institutions have never conducted a review meeting despite the existence of a hospital ethics committee. Moreover, 68.3% of institutions responded that their main responsibilities were administrative and included registering forms related to decisions about life-sustaining treatment, indicating that hospital ethics committees are not practical [22].

With South Korea's aging population, many seniors complete

advance directives. As of January 2022, 1,180,000 advance directives were filed, and based on data on 9,000,000 individuals aged 65 years or above, 13% of advance directives were completed. However, advance directives are not legally effective unless an individual dies at a large hospital, and it is not currently possible to confirm using a digital database whether a patient completed advance directives.

The Patient Self-Determination Act in the US states that all facilities that treat patients with advanced diseases such as general hospitals, long-term care facilities, home visit nurse teams, remote medical institutions, and hospice and palliative care facilities are involved in decisions about life-sustaining treatment. In Taiwan, patients' statements concerning their decisions about life-sustaining treatment are saved and stored on their digital health insurance cards so that, even in emergencies, the wishes of the patient can be observed in real-time. Japan changed its regulations so that patients' decisions about life-sustaining treatment can be observed at home to prevent situations in which patients who return home for end-of-life care after being hospitalized do not receive unnecessary CPR when requesting help from an emergency department during a house call.

When the legal parameters are expanded to patients in a persistent vegetative state, it could be appropriate to limit the act to hospitals with a hospital ethics committee. However, given the current legal system in which decisions about life-sustaining treatment are only possible for those at the end-of-life stage, the Act on Decisions on Life-Sustaining Treatment should be amended so that it is generally applicable at any location where patients might die.

3. Decisions about life-sustaining treatment for those without next-of-kin

When family members cannot be identified and the patient does not complete any forms, it is impossible to make a decision about suspending life-sustaining treatment. According to 2019 data from Statistics Korea, 30.2% of all households are single-person households, totaling 6,140,000 individuals. A total of 1,676 individuals died without any known next-of-kin in 2015 based on family separation records. This number increased to 2,947 individuals in 2020 [23]. Even when next-of-kin can be identified, the number of patients from single-

person households and seniors who live alone who cannot see family members due to family separation and immigration-related issues is expected to increase. However, these individuals occupy a blind spot in the current legal system.

In the first draft of the Act on Decisions on Life-Sustaining Treatment, a hospital ethics committee or a public ethics committee could decide to suspend a patient's life-sustaining treatment by consensus for patients with no family members. Consensus is considered to have been reached when more than two-thirds of hospital ethics committee members were present and all present members voted in favor of suspending treatment. At least one member who does not work at the hospital and at least one member who is not a medical professional and was recommended by religious, legal, ethical, or grassroots groups must also be present [24].

However, on January 8, 2016, the Legislation and Judiciary Committee approved a version of the act (draft) that did not include the regulation about patients without next-of-kin, which passed in Congress on the same day without change. The decision that the constitutional court made about the Act on Dissection and Preservation of Corpses, which included a clause that declared it to be unconstitutional to use bodies of individuals without next-of-kin as cadavers for training at medical schools, could have had an effect [24].

The Palliative and Hospice Care Act from Taiwan states that, when patients do not have next-of-kin, they are referred to the hospital ethics committee, and a medical decision that is beneficial to the patient can be made. According to Japan's national guidelines, a palliative care team can determine the best course of treatment for patients. According to the United Kingdom's Mental Capacity Act, a proxy can be named to make decisions on behalf of a patient, and a proxy can also be designated by a court and an independent mental capacity advocate.

Family members recognized by the Act on Decisions on Life-Sustaining Treatment are sometimes individuals who are unable or unwilling to represent the patient's best interests. Medical professionals routinely discuss decisions about life-sustaining treatment, medical treatments, and end-of-life care with patients' caregivers in clinical practice. However, when forms have to be completed, medical personnel sometimes face an ethical conflict when they have to ask a family member

who is unable or unwilling to reflect the patient's best interests to complete the form. Policies should be improved so that the proxy named by the patient or the actual caregiver, even if they are not legally related to the patient, can act on behalf of the patient. Hospital ethics committees should also be permitted in South Korea to make decisions about the suspension of life-sustaining treatment for patients without next-of-kin.

4. Forms

When patients with no possibility of recovery reach the end-of-life stage, doctors must consult forms to implement the chosen process and must decide whether to provide life-sustaining treatment. The following three forms must be completed and recorded electronically.

First, an assessment to determine whether a patient is in the dying process must be made (No. 9).

Second, forms documenting the intentions of the patient or a family member of the patient about the decision to suspend life-sustaining treatment must be completed. The first of these forms either confirms the patient's decisions about the suspension of life-sustaining treatment (advance directive) (No. 10) or confirms the patient's life-sustaining treatment plan (No. 1). When patients cannot complete the forms themselves, a form must be completed to determine the patient's intentions based on the input of family members (No. 11) or to make a proxy decision (No. 12).

Third, a form must be completed to finally execute the patient's decisions about the suspension of life-sustaining treatment (No. 13).

However, since a significant amount of time is required to complete these administrative forms, check additional documents (such as family registration forms), and enter them into an electronic system, there is not always sufficient time to consult patients or their family members, and it can be difficult to follow this established process. An oncologist described the issue after the first year during which the act had been in effect as follows: "For the sake of the law and the completion of forms, the precious time at the end of patients' lives that should be spent on reducing patients' pain and sharing comfort was spent completing bureaucratic legal forms. Doctors in clinical practice had to forgo holistic care to abide by the requirements of the law, and even when we were fighting

for each second, completion of a legally correct form became a priority. We can console ourselves with a bitter smile that we provided treatment according to the law after our patients die.” [25]

The assessment of a patient in the dying process (No. 9) and the form to implement a patient’s decisions about the suspension of life-sustaining treatment (No. 13) can be replaced with medical records without having to complete and store separate forms. Forms 1, 10, 11, and 12 should also be integrated into a single form. Forms for patients with terminal illnesses in other countries, such as DNR forms and Physicians Orders for Life-Sustaining Treatment forms, have a simple structure and are only 1 or 2 pages in length.

Among the items listed on the implementation form, while CPR and treatment using a ventilator are common life-sustaining treatments, treatments such as extracorporeal life support and chemotherapy are only applicable for some patients. However, medical personnel must explain and ask consent for these items to patients and family members when completing the forms, increasing unnecessary confusion. Common treatments such as CPR and treatment using a ventilator should remain on the form, but other medical treatments should only be included if they are relevant based on the patient’s medical history. Moreover, additional administrative tasks should be reflected in the reimbursement system.

When the act was first implemented in 2018, forms listed individual treatments (CPR, ventilator, etc.) by name and required consent for each treatment, but the revised forms from 2019 are structured so that patients or the family members of patients listen to a comprehensive explanation of the execution of life-sustaining treatment, the decision to suspend life-sustaining treatment, and the option to receive hospice and palliative care and to refuse or suspend life-sustaining treatment. In order to uphold the purpose of the act so that patients receive information and make decisions on the basis of self-determination, each medical treatment should be listed, and patients should be allowed to select the treatments relevant to them and obtain a signature, as with advance directives or the physician orders for life-sustaining treatment forms used in the US and some European countries.

Specifically, non-medical specialists can explain and receive consent related to advance directives. In some cases, non-

specialists must explain the technology behind treatments such as extracorporeal membrane oxygenation and injection of chemotherapy that are even difficult for medical professionals to comprehensively understand and obtain consent for. Preparations to expand the parameters of decisions about life-sustaining treatment based on those used in the United States, United Kingdom, and Taiwan should reinforce advance directives through legal forms that correspond to patients’ wishes.

According to statistics from the National Agency for Management of Life-Sustaining Treatment, the proportion of forms completed by patients themselves has increased each year, from 32.4% in 2018, 35.8% in 2019, to 38.3% in 2020, and decisions about advance directives also increased from 0.8% in 2018, 2.3% in 2019, to 5.1% in 2020, which is a positive sign [2].

South Korea designed the Act on Decisions on Life-Sustaining Treatment to be limited to patients in the dying process, but the average survival of patients who decided to withdraw life-sustaining treatment in the dying process was 2.12 days while the average time between the completion of implementation forms to death for patients who decided to withhold treatment was 8.95 days [7]. Since decisions about life-sustaining treatment are always made just before death, the purpose of the act, which is to allow patients to withhold life-sustaining treatment and support the use of hospice and palliative care, is not being achieved. Given that the systems used by most other countries allow such decisions to be made 6 months before death, the debate concerning the timing of decisions about suspending life-sustaining treatment should be reopened.

The proportion of documents completed by patients themselves was estimated to be 6~10% based on the number of patients who died at hospitals. The proportion of documents completed by family members was 14~18%, and the remaining 75~80% of patients did not submit documents. There are several possible reasons for the low proportion of patients who submit documents according to the process outlined in the Act on Decisions on Life-Sustaining Treatment. First, if a patient dies according to the existing end-of-life care process based on an agreement between treatment providers and family members, many find it unnecessary to follow the complicated Act on Decisions on Life-Sustaining Treatment beyond the

institutional use of DNR forms [22]. Second, small hospitals such as long-term care hospitals are unable to make decisions about the suspension of life-sustaining treatment since they cannot establish hospital ethics committees. Finally, many people lack a sufficient understanding of the law. In a survey of 128 residents at a tertiary hospital during the second year of the law's implementation, only 64.8% of respondents answered that they were familiar with the content of the act. Large differences between departments were also observed [17].

Not every patient has to complete forms for decisions about suspending life-sustaining treatment, but most patients who were hospitalized long-term due to chronic illness must decide how much medical treatment they are comfortable with [7]. Further research on why many patients with severe illness do not follow the process of the Act on Decisions on Life-Sustaining Treatment is needed.

Life-sustaining treatment decisions for patients with terminal illnesses are not medically controversial, and, in most countries, this is backed by the principle that they benefit patients. The need for a third party in the life-sustaining treatment decisions of patients with terminal illnesses is commonly recognized. DNR forms and life-sustaining treatment plan forms reflect this need.

It is preferred for patients to complete the forms themselves, but when a patient is unable to sign a document, a family member or proxy is typically allowed to decide what is best for the patient based on consultations with treatment providers. However, the principle backing South Korea's Act on Decisions on Life-Sustaining Treatment is self-determination, and decisions made on behalf of a patient are only permitted via consensus among the patient's spouse and all other immediate family members. Those who fail to execute or violate a patient's decision to suspend life-sustaining treatment can be subject to a maximum of 1 year of incarceration or a fine of KRW 10,000,000. Falsification of records or leaking confidential information can result in a maximum of 3 years of incarceration. Taiwan, which has a similar law, only issues fines or license suspensions for a maximum of 1 year.

According to statistics from the past 3 years during which the Act on Decisions on Life-Sustaining Treatment was in effect, the intentions of patients could be clearly identified in forms 1 and 10 for only one-third of all patients. Speculation about a

patient's wishes by family members was possible for another one-third of patients, and decisions were made by family members on behalf of patients for the remaining one-third of patients. Therefore, in practice, family members participated in the decision-making process in two-thirds of all cases.

Although South Korea's Act on Decisions on Life-Sustaining Treatment only applies to patients at the end-of-life stage, the ensuing process and forms require strict adherence to the self-determination principle rather than the patient's best interests. Issues for which the best option for patients can be determined by providers and family members should be resolved according to the best interest principle, and the processes should be simplified accordingly.

Some researchers have suggested that a proxy system should be implemented. A designated proxy should be permitted to receive an attending physician's explanation of a patient's life-sustaining treatment plan. Therefore, designated proxies who can decide whether a patient receives hospice and palliative care should be limited to those who are named in the patient's advance directives [26].

If the law is expanded to encompass areas with higher degrees of uncertainty regarding a patient's status, such as for patients in a persistent vegetative state, the risk of conflict will increase. In such situations, a designated proxy can play a major role in reflecting a patient's preferences. In the United States, the Uniform Health-Care Decisions Act describes in detail the process of designating a proxy and the authority of the proxy [27]. In Taiwan, a designated proxy system was implemented via the Patient Self-Determination Act [14,28].

In various medical circumstances beyond terminal illness, such as when patients are in a persistent vegetative state, issues related to decisions about the suspension of life-sustaining treatment constantly occur in clinical practice. In Taiwan, the parameters of the law were expanded to encompass any patients facing no possibility of recovery, such as those in a persistent vegetative state, via the Patient Self-Determination Act [14]. The Supreme Court decision about Grandmother Kim in South Korea also concerned a patient who was in a persistent vegetative state rather than in the dying process, and although the Supreme Court decided that the patient's ventilator could be removed due to the patient's predicted death, the patient lived for 201 more days after the removal of the ventilator. As

life-sustaining treatment technology continues to develop, the level of treatment most appropriate and beneficial for patients will become a persistent social issue, and those in the medical field and health authorities should respond proactively. Therefore, the system should be reinforced to meet international standards, including permitting the use of a designated proxy based on patients' advance directives. The structure of advance directives does not currently enable these issues caused by complex medical situations to be resolved.

Lastly, there are still cases in which the Act on Decisions on Life-Sustaining Treatment is nicknamed the "Death with Dignity Act," and the Grandmother Kim case in 2009 is also frequently associated with the issue of death with dignity. In the United States, in the process of implementing laws to allow physician-assisted suicide in 11 states, the "Death with Dignity Act" was selected as the name for most of these pieces of legislation. Dignitas in Switzerland is a company that assists with legal euthanasia and has been criticized for marketing death trips using the word "dignity." "Death with Dignity Act" is widely used as the name of pieces of legislation that permit physician-assisted suicide. Since South Korea's Act on Decisions on Life-Sustaining Treatment does not allow physician-assisted suicide, it is incorrect to refer to it as the "Death with Dignity Act." Moreover, "life-sustaining treatment decisions" is a value-neutral term. However, expressions such as "death with dignity" reflect a subjective value system, increasing the risk of misunderstanding. Therefore, the use of categorizations and terms that allow for subjective interpretation should be limited.

CONCLUSION

Enactment of the Act on Decisions on Life-Sustaining Treat-

ment led to some improvements in the clinical practice environment. However, various systematic issues continue to cause difficulties for patients and providers when implementing the law. To reduce the degree to which terminal patients suffer unnecessary pain when they face no possibility of recovery, and to facilitate hospice and palliative care, the Act on Decisions on Life-Sustaining Treatment should be improved to address various issues.

CONFLICT OF INTEREST

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

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Conception or design of the work: DSH. Data collection: DSH. Data analysis and interpretation: DSH. Drafting the article: DSH, SHY, BK. Critical revision of the article: SHY, YK. Final approval of the version to be published: all authors.

SUPPLEMENTARY MATERIALS

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REFERENCES

1. Park SY, Lee B, Seon JY, Oh IH. A national study of life-sustaining treatments in South Korea: what factors affect decision-making? *Cancer Res Treat* 2021;53:593-600.
2. National Agency for Management of Life-sustaining Treatment; Ministry of Health and Welfare. 2020 Annual Report: National Agency for Life-sustaining Treatment Decisions. Seoul: National Agency for Management of Life-sustaining Treatment; 2021.
3. Kim JS, Yoo SH, Choi W, Kim Y, Hong J, Kim MS, et al. Implication of the Life-Sustaining Treatment Decisions Act on End-of-Life Care for Korean terminal patients. *Cancer Res Treat* 2020;52:917-24.

4. Lee HY, Kim HJ, Kwon JH, Baek SK, Won YW, Kim YJ, et al. The situation of life-sustaining treatment one year after Enforcement of the Act on Decisions on Life-Sustaining Treatment for Patients at the End-of-Life in Korea: data of National Agency for Management of Life-Sustaining Treatment. *Cancer Res Treat* 2021;53:897-907.
5. Kim HJ, Kim YJ, Kwon JH, Won YW, Lee HY, Baek SK, et al. Current status and cardinal features of patient autonomy after Enactment of the Life-Sustaining Treatment Decisions Act in Korea. *Cancer Res Treat* 2021;53:917-25.
6. An HJ, Jeon HJ, Chun SH, Jung HA, Ahn HK, Lee KH, et al. Feasibility study of physician orders for life-sustaining treatment for patients with terminal cancer. *Cancer Res Treat* 2019;51:1632-8.
7. Shin J, Lee CW, Choi YS, Kim SM, Park HS, Park SW, et al. The characteristics of patients in the actively dying phase by documenting the implementation of decisions on life-sustaining treatment. *Korean J Clin Geri* 2020;21:103-9.
8. Phua J, Joynt GM, Nishimura M, Deng Y, Myatra SN, Chan YH, et al. Withholding and withdrawal of life-sustaining treatments in intensive care units in Asia. *JAMA Intern Med* 2015;175:363-71.
9. Lee SM, Kim SJ, Choi YS, Heo DS, Baik S, Choi BM, et al. Consensus guidelines for the definition of the end stage of disease and last days of life and criteria for medical judgment. *J Korean Med Assoc* 2018;61:509-21.
10. Japanese Ministry of Health, Labor and Welfare. 2007 Guidelines for the decision-making process for end-of-life care. Tokyo:Ministry of Health, Labor and Welfare:2007.
11. Moon JY, Ahn H. Suggestion on how to balance between physicians' authority and patients' autonomy: review of debate on Patient Self-Determination Act (1990). *Korean J Med Ethics* 2019;22:161-73.
12. Tanaka M, Kodama S, Lee I, Huxtable R, Chung Y. Forgoing life-sustaining treatment - a comparative analysis of regulations in Japan, Korea, Taiwan, and England. *BMC Med Ethics* 2020;21:99.
13. Sulmasy DP. Why dementia-specific advance directives are a misguided idea. *J Am Geriatr Soc* 2020;68:1603-5.
14. Choi EK, Hong J, Kim MS, Keam B, Kim M, Heo DS, et al. The decision-making process regarding life-sustaining treatment in four countries: Taiwan, Japan, the US, and the UK. *Korean J Med Ethics* 2017;20:131-51.
15. Kim YJ, Kim SJ, Lee JK, Choi WS, Park JH, Kim HJ, et al. Prediction of survival in terminally ill cancer patients at the time of terminal cancer diagnosis. *J Cancer Res Clin Oncol*. 2014;140:1567-74.
16. Yun YH, Heo DS, Bae JM, Im SA, Yoo T, Huh BY, et al. Retrospective cohort study of survival and prognostic factors with terminal cancer. *J Korean Cancer Assoc* 1998;30:384-93.
17. Kim Y, Lim CM, Shim T, Hong SB, Hun JW, Oh D, et al. The influence of new legislation on the withdrawal of life-sustaining treatment on the perceptions and experiences of residents in a tertiary hospital in Korea. *Korean J Med Ethics* 2020;23:279-99.
18. Supreme Court en banc Decision 2009Da17417 : Withdrawal of Futile Life-Sustaining Treatment Device, etc. [Internet]. Seoul: The National Assembly of the Republic of Korea; 2009. May 21 [cited 2022 Feb 9]. Available from: [https://www.law.go.kr/%ED%8C%90%EB%A1%80/\(2009%EB%8B%A417417\)](https://www.law.go.kr/%ED%8C%90%EB%A1%80/(2009%EB%8B%A417417)).
19. Medicare: hospice care [Internet]. Lawrence, KS: Medicare: 2021 [cited 2021 Dec 1]. Available from: <https://www.medicare.gov/coverage/hospice-care>.
20. Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med* 1996;335:172-8.
21. Government to review "Terminal Illness" definition [Internet]. London: My Death, My Decision: 2021 [cited 2022 Feb 9]. Available from: <https://www.mydeath-mydecision.org.uk/2019/07/12/government-to-review-terminal-illness-definition/>.
22. Choi J, Jang SG, Kim J, Lee I. Institutional Ethics Committees for Decisions on Life-sustaining Treatment in Korea: their current state and experiences with their operation. *Korean J Med Ethics* 2019;22:209-33.
23. The increase in the number of unrelated corpses... 'Last road see off' bill comes out [Internet]. Incheon: Incheonilbo; 2021. Apr 28 [cited 2022 Feb 9]. Available from: <http://www.incheonilbo.com/news/articleView.html?idxno=1092116>.
24. Kim B, Kim M. Developing policy for life sustaining treatment decision for patient without surrogate. *Korean J Med Ethics* 2018;21:114 - 28.
25. Ahn HJ. Reflections on the Life-Sustaining Treatment Decisions Act: a medical oncologist's perspective. *Korean J Med Ethics* 2019;22:115-28.
26. Kim B, Kim M. Using a health care proxy to overcome limitations of the Act on Decisions on Life-sustaining Treatment. *Korean J Med Ethics* 2018;21:95-113.
27. Uniform Health-Care Decisions Act [Internet]. Chicago IL: Uniform Law Commission; 2021 [cited 2022 Feb 9]. Available from: <https://www.uniformlaws.org/committees/community-home?CommunityKey=63ac0471-5975-49b0-8a36-6a4d790a4edf>.
28. Kim M. The problems and the improvement plan of the Hospice/Palliative Care and Dying Patient's Decisions on Life-Sustaining Treatment Act. *Korean J Hosp Palliat Care* 2018;21:1-8.