



Original Article

A National Study of Life-Sustaining Treatments in South Korea: What Factors Affect Decision-Making?

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Purpose This cross-sectional study investigated the status of life-sustaining treatment (LST) practices and identified characteristics and factors influencing decision-making practices.

Materials and Methods The National Agency for Management of Life-sustaining Treatment retains records provided by doctors regarding patients subject to LST implementation. A total of 71,327 patients receiving LST were identified. We analyzed all nationally reported data between February 2018 and October 2019. Indicators such as the proportion of deaths, records for decision to terminate LST, implementation of LST records, and registration of Advance Statements on LST were analyzed.

Results A total of 67,252 (94.3%) end-of-life decisions were implemented in South Korea. The proportion of deaths preceded by a LST plan, non-self-determination LST decision, and any advance statements was 33.5% (23,891/71,327), 66.5% (47,436/71,327), and 1.2% (890/71,327), respectively. The logistic regression model revealed that self-determination to terminate LST was more frequent for men than for women and higher for those aged 30-69. Disability (odds ratio [OR], 0.59; 95% confidence interval [CI], 0.56 to 0.61), living in non-metropolitan areas (OR, 0.84; 95% CI, 0.81 to 0.86), and disease comorbidity was independently associated with a low level of self-determination.

Conclusion After the implementation of the new LST Act, about a third of patients in end-of-life process made decisions regarding their medical LST. However, family members still play a major role in LST decisions where the patient's intention cannot be verified. Decisions related to LST are predominantly made when death is imminent. Thus, it is necessary to increase awareness of end-of-life LST decision-making among medical staff and the public.

Key words Palliative care, Personal autonomy, Medical staff, Terminal care, Hospice, Cross-sectional studies

Introduction

With recent attention focused on patient-centered care models that incorporates the needs, values, and preferences of each individual patient in his or her treatment-related decisions, there is a growing social interest in respecting the patient's self-determination regarding meaningless life-sustaining treatment (LST) and guaranteeing a "good death" at the end of their life. This has become especially relevant in light of the coronavirus disease 2019 pandemic where medical decisions related to extension of life could be closely linked to allocation of limited medical resources. Thus, establishing a system that gives priority to the will and desire of the patient is of utmost importance.

Decisions about end-of-life LST are known to be influenced not only by personal attitude and religious propensity of the physician in charge, but also various other factors including involvement of family members, sociocultural factors,

and the legal system supporting such factors [1-6]. However, results from previous studies have been based mostly on questionnaire surveys, such as awareness surveys [5-7], where there were limitations in objectively identifying the impact of key factors affecting decisions about LST, such as economic factors or disability. To present the direction of the future for relevant policies and reach international consensus on issues related to LST, it is absolutely necessary to have objective evidence pertaining to factors that influence decision-making for LST.

With the enactment of the "Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life" (hereinafter "LST Decision Act"), South Korea has established a national management system for LST (Central Hospice Center: September 2017, National Agency for Management of Life-Sustaining Treatment: February 2018), which had not existed until the introduction of the LST Decision Act. In the present study, we linked statistical data

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from the National Agency for Management of Life-Sustaining Treatment, who collects data from the relevant population, to national health insurance data, which reflects the population's healthcare utilization, to identify the current status of actual LST at the national level and objectively analyze and identify factors that influence treatment decisions. We believe that the findings could be used as the basis for establishing a comprehensive strategy for systematically managing the entire end-of-life treatment decision-making stage.

Materials and Methods

1. Study setting

We conducted a cross-sectional study to identify the current status of LST decisions in South Korea and factors that influence self-determination. To do so, we analyzed national data managed by the National Agency for Management of Life-sustaining Treatment from February 2018, when the LST Decision Law took effect, to October 2019. The dataset included data regarding a diagnosis that a patient is in the end-of-life process, LST plans, advance statement on LST, and implementation of determination to terminate LST. To identify the baseline characteristics of the patients and the factors that influence LST-related decision, the link of data was approved and conducted by National Health Insurance Service (NHIS) with the request of ministry of health. South Korea has a single health insurance system that includes the entire Korean population. Consequently, the national health information database contains qualifications, insurance premiums, health screening results, and treatment details of the entire population.

2. Definitions

According to the LST Decision Act, the term "end-of-life process" means a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment with rapidly worsening symptoms [8]. On the other hand, the term "patient at the end-of-life process" means a person who has been medically determined to be in the end-of-life process by the physician in charge and one medical specialist in the relevant field [8].

The present study used the same definition for "LST" as the Article 2 of LST Decision Act, which defined it as "medical treatment which merely extends the duration of the end-of-life process without curative effect" [8]. Such treatment included cardiopulmonary resuscitation (CPR), hemodialysis, administration of anticancer drugs, mechanical ventilation, administration of inotropes, extracorporeal life support (ECLS), and blood transfusion. The term "determination to terminate LST" refers to a decision being made to withhold

LST or to go without such treatment.

The LST Decision Act mandates a three-step process to terminate LST. First, the physician in charge, along with one medical specialist in the relevant field, must determine whether the patient is in the end-of-life process (Assessment of patient at the end stage of life: Form 9). Second, the intention of the patient or the patient's family must be verified. If the patient is medically capable of expressing his or her intention, an LST plan is completed and the physician in charge checks the plan (Form 1). If the patient is medically incapable of expressing his or her intention, the physician in charge and one medical specialist in the relevant field can verify such intention through statements stating the same from two or more members of the patient's family (Verification of decisions of the patient or patient's family: Form 11). Here, if it is difficult to prove the patient's intention, unanimous agreement by all family members is needed (Form 12). Third, if both conditions of medical determination that the ongoing treatment offers no further curative effect (step 1) and the patient wishes no further treatment (step 2) are met, then the physician in charge makes the decision and fills out the necessary form (Withholding or withdrawing LST: Form 13).

3. Statistical analysis

Of the 43,226,602 people over the age of nineteen, 420,962 were patients who completed an advance statement of life-sustaining treatment. A total of 71,974 patients were determined to be in the end-of-life process. Of these, 71,327 patients were included in the analysis after excluding patients with a missing patient identification key ($n=91$), cases with data that could not be matched to insurance qualification data from Health Insurance Review and Assessment Service (hereinafter unlinked data; $n=308$), and duplicate registrations ($n=248$) (Fig. 1). Patients who provided an LST plan or advance statement on LST were classified as "self-determination patients" and those who did not were classified as "non-self-determination patients."

We performed a chi-square test to analyze the demographic characteristics associated with self-determination. In addition, logistic regression analysis was performed to identify the factors that influence LST-related decisions. Sex, age, insurance premium level, disability, area of residence, comorbidity score, and history of hospitalization were considered explanatory variables. Health insurance premium level was classified into six categories based on the amount of premium paid and ranged from medical aid recipients who do not pay a premium to those who pay the most (e.g., medical aid recipients, 1st-4th percentile patients, 5th-8th percentile patients, 9th-12th percentile patients, 13th-16th percentile patients, and 17th-20th percentile patients). Higher health

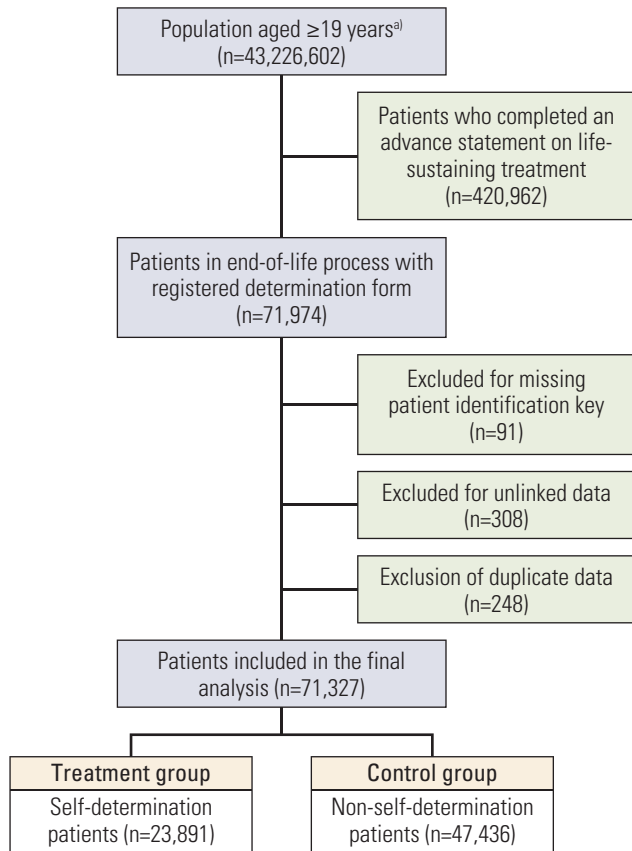


Fig. 1. Patient selection process to analyze factors influencing patient-centered decision to terminate life-sustaining treatment. ^{a)}Population aged ≥ 19 years: 2019 Statistics Korea Projected Population.

insurance premium level would indicate a higher amount of premium paid, which is associated with higher economic status. Accordingly, we used health insurance premium level as a variable indicating economic status. Area of residence was divided into national capital region and non-national capital region to investigate the difference in self-determination depending on residential status. National capital region was defined as Seoul, Gyeonggi-do, and Incheon. For comorbidity score, the Charlson comorbidity index (CCI) score was assigned based on the patient's diagnostic history during 2017. History of hospitalization was defined as a binary variable based on experience of hospitalization in 2017. For all statistical analyses, the significance level was set to 0.05.

Results

1. Study population

Among 71,327 patients, there were 23,891 self-determi-

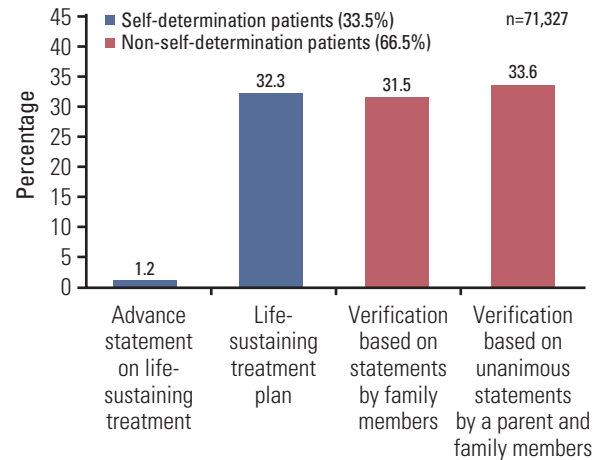


Fig. 2. Percentage of self-determination life-sustaining treatment among patients in end-of-life care according to the patient determination form.

nation (33.5%) and 47,436 non-self-determination (66.5%) patients (Fig. 2). Of the total sample, 67,255 patients (94.3%) had ultimately withheld LST or withdrew LST. The results were similar regardless of sex and age. Among the self-determination patients, the 1.2% made their decision with an advance statement on LST. In contrast, the percentage of non-self-determination patients with verification based on several family member statements and verification by all family members was 31.5% and 33.6%, respectively (Fig. 2).

2. Demographic characteristics related to self-determination

In both groups, the lowest percentage of patients were aged < 30 years, while the highest percentage among self-determination and non-self-determination groups was 70-79 and ≥ 80 years, respectively (S1 Table). Thus, the percentage of patients where the family members ascertained the intention of the patient tended to increase with increasing age. The results from the chi-square test showed that the two groups were significantly different across all factors.

3. Factors for patient self-determination and a logistic regression model with covariate adjustment

Table 1 presents the findings of the logistic regression analysis. To accurately identify the factors that influence LST-related decisions, we performed logistic regression analysis with respect to sex, age, insurance premium level, disability, area of residence (residence in national capital region), comorbidity score, and history of hospitalization. The results showed that the percentage of self-determination to terminate LST was higher in males than females. The percentage of self-determination to terminate LST was approximately

Table 1. Logistic regression analysis results of factors that influence self-determination by patients with respect to life-sustaining treatment decisions

Item	Odds ratio	95% Confidence interval	p-value
Sex			
Male	Reference	Reference	Reference
Female	0.893	0.863-0.923	< 0.001
Age (yr)			
< 30	Reference	Reference	Reference
30-39	4.212	3.227-5.497	< 0.001
40-49	5.801	4.542-7.410	< 0.001
50-59	5.827	4.589-7.400	< 0.001
60-69	4.509	3.555-5.719	< 0.001
70-79	2.996	2.363-3.799	0.039
≥ 80	1.606	1.266-2.038	< 0.001
Insurance premium level			
Medical aid	Reference	Reference	Reference
1-4 percentile (lowest)	0.805	0.753-0.861	0.602
5-8 percentile	0.809	0.755-0.868	0.788
9-12 percentile	0.777	0.727-0.831	0.020
13-16 percentile	0.764	0.717-0.814	< 0.001
17-20 percentile (highest)	0.751	0.708-0.797	< 0.001
Disability			
No	Reference	Reference	Reference
Yes	0.591	0.567-0.616	< 0.001
Residence in national capital region			
Yes	Reference	Reference	Reference
No	0.837	0.810-0.864	< 0.001
CCI score			
0	Reference	Reference	Reference
1	0.811	0.769-0.854	< 0.001
2	1.374	1.309-1.443	< 0.001
≥ 3	1.326	1.262-1.393	< 0.001
History of hospitalization			
No	Reference	Reference	Reference
Yes	1.051	1.013-1.092	0.009

CCI, Charlson comorbidity index.

4-5 times higher among patients aged 30-69 years than those aged < 30 years, and 3.0 and 1.6 times higher among those aged 70-79 and ≥ 80 years than those aged < 30 years, respectively.

With respect to the percentage of self-determination according to insurance premium level, there was no statistically significant difference between medical aid recipients and patients who are in the 1st-8th percentile for health insurance premium payment. However, patients who were in the 9th-12th, 13th-16th, and 17th-20th percentile for health insurance premium payment were significantly different as compared to medical aid recipients, which indicated that the percentage of self-determination to terminate LST was lower among patients who had a higher insurance premium level.

The results of the analysis examining the influence of disability on self-determination showed that the percentage of self-determination was 0.59 times lower among patients with a disability than those without a disability. With respect to area of residence, the percentage of self-determination was 0.84 times lower among patients who reside in a non-national capital region than those who reside in a national capital region.

In the analysis of the CCI scores to identify the influence of underlying disease on self-determination, showed that the percentage of self-determination was 0.81 times lower among patients with a score of 1 than those with a score of 0. Conversely, the percentage of self-determination was 1.3 times higher among patients with a score of ≥ 2 than those

with a score of 0. Further, the results showed that the percentage of self-determination to terminate LST was 1.05 times higher among patient with a history of hospitalization than those not hospitalized.

Discussion

The present study was the first study in South Korea to identify the current status of LST implementation by analyzing data representing the total population of South Korea. The LST determination system was being applied most often to patients aged ≥ 70 years, but the percentage of cases where the patient made the determination on LST was only 33.5%. In particular, the percentage of LST being implemented based on advance statement on LST was extremely low (1.2%).

The results showed that, compared to previous studies from individual hospitals (12.0%-29.0%), the percentage of self-determination on LST had increased (33.5%) after the enactment of the new legislation [9-12]. However, the percentage of terminating LST based on the assertion of family members still remained high (66.5%). We believe that the reason for these results may have been influenced by the unique cultural background in Asia. In Asian culture, discussions about death is considered to be a taboo topic and telling a parent, for example, the bad news that he or she has cancer and making them worry is against one's filial piety [13,14]. Because of the culture where there is a lack of openness about death-related discussions, the percentage of patients who complete an advance statement on LST tends to be lower than in Western countries [15,16] and making it difficult to understand the health care wishes of patients in relation to LST. By contrast, some countries try to respect the wishes of patients in end-of-life care as much as possible. For example, in the United States, more than one-third of adults files any type of advance statement on LST [17] and most patients (91% to 100%) who chose a do-not-resuscitate (DNR) on the Physician Orders for Life-sustaining Treatment (POLST) are allowed a natural death without attempting CPR [18]. Additionally, UK's research data show that 77.8% of patients died in their preferred place, with hospital admission rate decreased by 45% due to the decrease in hospital visits as per the patients' wishes [19].

Second, the environment in which decisions are made as a family rather than as an individual should be considered. A previous study on intensive care unit doctors in Asia reported that among the factors that these doctors considered to be important in making LST-related decisions, the needs of the family accounted for 77.9%; it was only surpassed by the factors patient's intention (84.1%) and long-term quality of life

[3]. It is well-established fact that the physician's perception of the intention of the family and the preference of the patient may sometimes be different than the patient's original intention [1,20,21]. Personal characteristics or experience of the physician could also influence LST-related decisions, which inherently presents the risk of a decision being made contrary to the patient's intention [11]. Therefore, it is necessary to focus on advance statement on LST to ensure the patient's intention is respected. Indeed, our research team analyzed the completion rate of advance statement on LST based on the national data, there were 136 locations throughout South Korea who were filing advance statement on LST between February 2018 and October 2019. For every 100,000-population aged ≥ 19 years, only 973.8 persons had filed an advance statement on LST. Considering that one in three U.S. adults files any type of advance statement on LST [17], long-term policies for increasing the completion rate of advance statement on LST among adults aged ≥ 19 years are needed in Asia, including South Korea [20-23].

Another important issue is when an LST plan was prepared. According to previous studies, the mean number of days between completion of an advance statement on LST and death is 33 days in South Korea [11,24], whereas the period between completing a DNR order and death was within one week [9,25,26]. In other words, patients were making LST-related decisions due to imminent death without necessarily having enough time to deliberate and decide how they want to manage their own death. In particular, when the condition of a patient with altered consciousness deteriorates, it becomes difficult for them to make decisions as they may have normally wanted; instead, it becomes easier for the treatment to proceed based on the decision made by his or her family. Therefore, to prevent such situations from occurring, it is necessary to create an environment that promotes discussions about one's own intentions in advance. In Oregon, the median time the POLST is completed before death has increased significantly, from 5 weeks (2010-2011 data) to 21 weeks (2015-2016 data), which is seen as the effect of the LST plans [27].

In the analysis of factors that influence self-determination on LST by the patient, the likelihood of self-determination about death increased with increasing age, as compared to patients aged < 30 years. However, this likelihood declined for patients 60 years or older. According to cause of death data from Statistics Korea, the primary cause of death among people aged 20-29 years was suicide, followed by traffic accidents [28]. Thus, deaths among people aged 20-29 years typically involve sudden death and not disease-associated death. Therefore, people aged < 30 years likely have less opportunity to deliberate and decide on LST in advance, as compared to other age groups.

Interestingly, the present study found that the likelihood of self-determination about death was higher among male patients without any disability, who reside in a national capital region, have a higher number of comorbidities, and was hospitalized in the preceding year. In particular, patients with a disability lacked systematic discussions about determination on LST, as compared to those without a disability. Moreover, patients with a disability have been found to face concerns about not receiving proper treatment despite serious disease conditions or their own intentions not being reflected in the determination on LST [29,30]. Despite patients with a disability having a higher prevalence of chronic diseases and greater need for healthcare services than patients without a disability, such issues were not actively handled in LST-related discussions [31,32]. Even in the new law in South Korea, discussion about people with disabilities is excluded [8]. Therefore, further contemplation about measures that can enhance the right to self-determination on LST is needed.

Insurance premium level was used in the present study as an indicator of personal economic status. The low-income group who are medical aid recipients showed higher self-determination tendencies than people who pay higher insurance premiums. This may indirectly reflect the economic burden of continuing LST, which suggests the need to improve economic accessibility with respect to healthcare utilization. There is a possibility that household composition, such as the presence of children or a spouse, influences self-determination. According to statistics from Statistics Korea [33] and Social Security Information System [34], single-person households accounted for 29.9% of the total domestic population and the ratio of single-person households to social assistance beneficiaries was 69.9%. In other words, the rate of self-determination on the LST could have been higher, as there were many medical aid beneficiaries from single-person households.

In conclusion, our study identified factors that influence self-determination on LST to gain a broader understanding about patient-centered decision-making in the end-of-life process. In particular, our study linked data from the National Agency for Management of Life-Sustaining Treatment and the NHIS in identifying the status of LST implementa-

tion at the national level. However, given that the system is still new, there were limitations in determining the long-term effects of such a system.

Nevertheless, we were able to confirm increases in the percentage of self-determination due to the establishment of the system, and above all, we identified factors that could influence self-determination, such as disability, economic status, and area of residence. These factors could be used to establish the basis for future policy development to further increase opportunity for patients to provide an advance statement on LST or an LST plan. For the development of proper institutional policies, continued monitoring of the LST decision system, implementing promotion policies and continued output of national statistics are needed. In addition, future studies should investigate the economic effects of such a system by analyzing LST-related medical costs, which could help strengthen justification for self-determination on LST among patients.

Electronic Supplementary Material

Supplementary materials are available at Cancer Research and Treatment website (<https://www.e-crt.org>).

Ethical Statement

The protocol of this study was reviewed by the Institutional Review Board of Kyung Hee University (KHIRB-19-315).

Author Contributions

Conceived and designed the analysis: Oh IH, Park SY.

Collected the data: Lee B.

Contributed data or analysis tools: Oh IH, Seon JY.

Performed the analysis: Seon JY.

Wrote the paper: Oh IH, Park SY.

Conflicts of Interest

Conflict of interest relevant to this article was not reported.

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