


ORIGINAL



# Change in perception of the quality of death in the intensive care unit by healthcare workers associated with the implementation of the “well-dying law”

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## Abstract

**Purpose:** The importance of dying with dignity in the intensive care unit (ICU) has been emphasized. The South Korean government implemented the “well-dying law” in 2018, which enables patients to refuse futile life-sustaining treatment (LST) after being determined as terminally ill. We aimed to study whether the well-dying law is associated with a significant change in the quality of death in the ICU.

**Methods:** The Quality of Dying and Death (QODD) questionnaires were prospectively collected from the doctors and nurses of deceased patients of four South Korean medical ICUs after the law was passed (January 2019 to May 2020). Results were compared with those of our previous study, which used the same metric before the law was passed (June 2016 to May 2017). We compared baseline characteristics of the deceased patients, enrolled staff, QODD scores, and staff opinions about withdrawing LST from before to after the law was passed.

**Results:** After the well-dying law was passed, deceased patients ( $N=252$ ) were slightly older (68.6 vs. 66.6,  $p=0.03$ ) and fewer patients were admitted to the ICU for post-resuscitation care (10.3% vs. 20%,  $p=0.003$ ). The mean total QODD score significantly increased after the law was passed (36.9 vs. 31.3,  $p=0.001$ ). The law had a positive independent association with the increased QODD score in a multiple regression analysis.

**Conclusion:** Our study is the first to show that implementing the well-dying law is associated with quality of death in the ICU, although the quality of death in South Korea remains relatively low and should be further improved.

**Keywords:** Quality of death and dying, Intensive care unit, Well-dying law

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## Introduction

The importance of dying with dignity in intensive care units (ICUs) is emphasized, and early discussion with patients and families about the goals of care is a key factor for improving the quality of end-of-life care [1–3]. However, due to the Confucian social order and “Boramae Hospital incident” in 1997 [4], discussion on dying with dignity was not actively conducted in South Korea. In the Boramae Hospital incident, the Supreme Court of Korea convicted doctors for aiding and abetting a homicide because the doctors ordered the discharge of a patient in a vegetative state after brain surgery in deference to the insistent requests of the patient’s wife. After this case judgment, South Korean physicians were extremely cautious about requests of the patient’s family to discontinue life-sustaining treatment (LST), and discussion on death with dignity was shirked for subsequent years.

Social demand for “dying with dignity” was intensified due to the “Grandma Kim” incident in 2009. Grandma Kim was in a persistent vegetative state from brain damage due to a massive hemorrhage during a lung biopsy, and her family wanted to stop ventilator-assisted breathing. In 2009, the Supreme Court allowed ventilatory support withdrawal after much social discussion and debate, setting a precedent in South Korea by acknowledging the right to die with dignity. Since then, social interest in dying with dignity continued. The South Korean government finally enacted the Hospice, Palliative Care and Life-sustaining Treatment Decision-making Act, also known as the “well-dying law,” in February 2016 and fully implemented this Act in February 2018 [5]. This law enables patients to refuse cardiopulmonary resuscitation (CPR), ventilator support, hemodialysis, or anticancer treatment following a diagnosis of being near death from terminal illness by their primary and secondary specialist doctors. This law presupposes that the patient’s self-determination should be prioritized. If the patient’s will cannot be estimated, LST can be discontinued based on the agreement of the whole family and confirmation of two doctors or a decision by a legitimate family substitute and two doctors.

Therefore, implementing the well-dying law is expected to reduce non-beneficial LST for incapacitated patients with advanced illnesses. This study aimed to compare the quality of death in the ICU before and after implementing the law using the Quality of Dying and Death (QODD) questionnaire among ICU staff responsible for deceased patients and investigate the factors associated with better quality of death in the ICU.

## Take-home message

Our prospective multicenter survey demonstrated that the legislation regarding end-of-life decision, called “well-dying law”, was associated with significant improvement in the quality of dying compared with what noted before the law. In addition, we showed that the ethical and legal issues associated with life-sustaining treatment withdrawal have improved after the introduction of the law, but the quality of death in South Korean intensive care units appears relatively low, with much scope for improvement in the quality of care, especially with regard to patient autonomy near death.

## Methods

### Study design and participants

This prospective study was based on a previous study [6] conducted from June 2016 to May 2017, before the implementation of the well-dying law, to evaluate the quality of dying in South Korean ICUs. To compare the quality of death after the implementation of the law, we conducted a survey using the same questionnaire in the same ICUs as that in the previous study [6]. The same methods were used in both time periods. From January 2019 to May 2020 (following the implementation of the well-dying law), we enrolled the medical staff responsible for caring for dying patients in four medical ICUs of Seoul National University Bundang Hospital, Seoul National University Hospital, Seoul Boramae Hospital, and National Medical Center. The four ICUs had the same policy of ICU visits; family visits were possible only twice a day, once in the morning and afternoon.

Medical staff of the deceased patients were requested to complete the Korean version of the QODD [7] within 48 h of the patient’s death. In addition, after completing the QODD questionnaire, we asked questions about the staff’s opinion of the best action and actual action on the withdrawal of LST in the deceased patient (the questions are described in Supplemental Table S1).

Information about the deceased patients’ demographics, reason for ICU admission, length of stay, use of life-support equipment, CPR within 24 h of death, stipulation of a do not resuscitate (DNR) order, and medications within 24 h of death was obtained from medical charts.

This study was approved by the institutional review board of each participating hospital (IRB number: B-1903-531-302). Written informed consent was obtained from the study participants, and the consent of the deceased patient was waived.

### QODD

We used the Korean version of the QODD (version 3.2) [7, 8], which comprises of 20 items in three domains: patient’s experience at the end of life (15 questions); medical care at the end of life (3 questions); and experience at the point of death (2 questions). Items were rated

from 0 (terrible experience) to 10 (excellent experience). The total QODD score was calculated on a 0 to 100 scale, with a higher score indicating a higher quality of dying.

### Statistical analyses

To compare the quality of dying before and after the implementation of the well-dying law, we used previously published data from our group that represented the quality of dying before the implementation of the law [6]. We performed the Student's *t*-test or Mann–Whitney *U* test to compare the mean score of each questionnaire item assessed in our previous and present QODD studies by the medical staff. The Fisher's exact test or Pearson chi-square test was performed for categorical variables, and the Pearson correlation coefficient was calculated for continuous variables. A multiple linear regression analysis was performed for studying the correlation between increase in the QODD score and variables. We assumed that there would be a change in the use of sedatives, analgesics, and inotropes after the well-dying law. Therefore, a-priori pairwise correlation analysis was conducted to exclude the factors that might be due to the implementation of the law. These three factors had significant negative correlation with the law. In addition, we performed interrupted time series (ITS) analyses to capture the time trend [9]. The following equation was finally adopted.

$$\text{QODDt} = \beta_0 + \beta_1 \times \text{time}_t + \beta_2 \times \text{Implementation of the law} + \beta_3 \times \text{factor 1} + \beta_4 \times \text{factor 2} + \dots + \varepsilon t.$$

where QODDt was a person-level QODD value at time *t*,  $\beta_1$  was the time trend in QODD value,  $\beta_2$  was the immediate level change of QODD after the law implementation, and  $\beta_3$  was the coefficient of a possible confounder, and  $\varepsilon t$  was an error term. A linear mixed effect model with the hospital and medical staff as random effects was further performed using the same model specification in the ITS. STATA 13 (STATA Corp LP, College Station, TX, USA) and R version 4.0.3 were used for the statistical analyses.

## Results

### Baseline characteristics

Similar to the previous study (416 questionnaires completed by 177 ICU staff (66 doctors and 111 nurses) of 255 deceased patients), in this study period, 414 questionnaires by 143 staff (50 doctors and 93 nurses) corresponding to 252 deceased patients were collected. The distribution of survey received from medical staff across the study period as a timeline is shown in Supplemental Fig. S1.

A comparison of the baseline characteristics of the deceased patients for the two periods are shown in Table 1. During the period after the law was passed,

the deceased patients were slightly older (68.6 vs. 66.6,  $p=0.03$ ) and fewer patients were admitted to ICU for post-resuscitation care (10.3% vs. 20%,  $p=0.003$ ).

Patients treated after the implementation of the law were less likely to receive sedatives, inotropes, and analgesics within 24 h of death than those treated before the implementation of the law. The time from DNR to death was longer in patients after the law was implemented (2.6 vs. 5.3,  $p=0.020$ ). The participating medical staff characteristics are described in Supplemental Table S2. Staff enrolled after the law was passed were significantly younger and had less experience than those enrolled before the law. The number of staff trained on comfort care for more than 6 h (14.7%) tended to be slightly higher than that in the period before the law (10.2%;  $p=0.06$ ).

### QODD items and score

Figure 1 and Supplemental Table S3 present a comparison of total QODD scores and individual ratings for each questionnaire item before and after the law was implemented. The mean total QODD score after the well-dying law was passed was significantly higher than that before the law was passed (36.9 vs. 31.3,  $p=0.001$ ). Similar results were observed in the doctor and nurse subgroups (mean difference in doctors, 5.6,  $p=0.001$ ; and in nurses, 5.5,  $p=0.004$ , Table S3). Two items, Q18 and Q19 showed the highest increase (0.9-point) in the score after the law. The scores of 15 items significantly improved after implementation of the law, and five items did not significantly improve: Q1, Q2, Q3, Q7, and Q20.

### Factors affecting the QODD

Factors associated with better quality of death are shown in Table 2. Multiple regression analysis showed that the law had a positive independent association with the increased QODD score (5-point increase). CPR performed within 24 h of death had a negative independent association with the quality of death. The presence of cancer and higher age was associated with better quality of death. The use of sedatives, analgesics, and inotropes within 24 h of death were significantly correlated with the implementation of the well-dying law and were excluded from multiple regression analysis (Table 2). In the ITS analysis, we found similar results that the well-dying law implementation was associated with increased QODD scores (coefficient: 7.23,  $p=0.039$ ) whereas the time that elapsed during the pre-period or post-period was not associated with increased QODD score (coefficient: 0.00,  $p=0.533$ ) (Supplemental Table S4 and Fig. 2). The linear mixed model also showed that the law implementation had a significantly positive association with QODD

**Table 1** Baseline characteristics of patients who died in ICUs before and after the implementation of the well-dying law

Characteristics	Before well-dying law (N = 255)	After well-dying law (N = 252)	p-value
Sex (male)	159 (62.4)	173 (68.7)	0.250
Age, years	66.6 ± 14.1	68.6 ± 13.1	0.030
<b>Reason for ICU admission</b>			
Respiratory failure	149 (58)	130 (51.6)	0.160
Sepsis	59 (23.1)	54 (21.4)	0.750
Post-resuscitation care	51 (20)	26 (10.3)	0.003
Renal failure	35 (13.7)	42 (16.7)	0.390
Heart failure	22 (8.6)	36 (14.3)	0.050
Hemorrhagic shock	7 (2.7)	16 (6.4)	0.060
APACHE II	29.5 ± 15	25.7 ± 9.7	0.001
SOFA	11.8 ± 6.4	9 ± 5.3	< 0.001
Hospital day	20.6 ± 27.4	21.1 ± 24.7	0.840
Length of ICU stay	6.6 ± 6.9	7.6 ± 7.3	0.125
Malignancy	101 (39.6)	94 (37.3)	0.710
Life-support equipment	245 (95.3)	234 (92.9)	0.263
MV	228 (89.4)	221 (87.7)	0.580
RRT	124 (48.6)	119 (47.2)	0.720
ECMO	17 (6.7)	10 (4)	0.240
IABP/pacemaker	9 (3.5)	0 (0)	0.004
<b>Medications within 24 h before death</b>			
Sedative	128 (48.9)	96 (38.1)	0.020
Analgesics	158 (60.3)	85 (33.7)	< 0.001
Inotropes	239 (91.2)	124 (49.2)	< 0.001
CPR within 24 h before death	48 (18.8)	57 (22.9)	0.270
GCS within 24 h before death	3.8 ± 1.9	3.3 ± 1.4	< 0.001
DNR documentation	206 (80.8)	206 (81.8)	0.820
Time to death from DNR	2.6 ± 7.8	5.3 ± 15.2	0.020

ICU intensive care unit; APACHE II acute physiology and chronic health evaluation II; SOFA Sequential Organ Failure Score; MV mechanical ventilation; RRT renal replacement therapy; ECMO extracorporeal membrane oxygenation; IABP intra-arterial balloon pump; CPR cardiopulmonary resuscitation; GCS Glasgow Coma Scale; DNR do not resuscitate

(coefficient: 8.49,  $p = 0.019$ ), while CPR performed within 24 h of death (coefficient:  $-6.17$ ,  $p \leq 0.001$ ) and having two or more life supporting equipment (coefficient:  $-2.77$ ,  $p = 0.023$ ) were negatively associated with the QODD score (Supplemental Table S5).

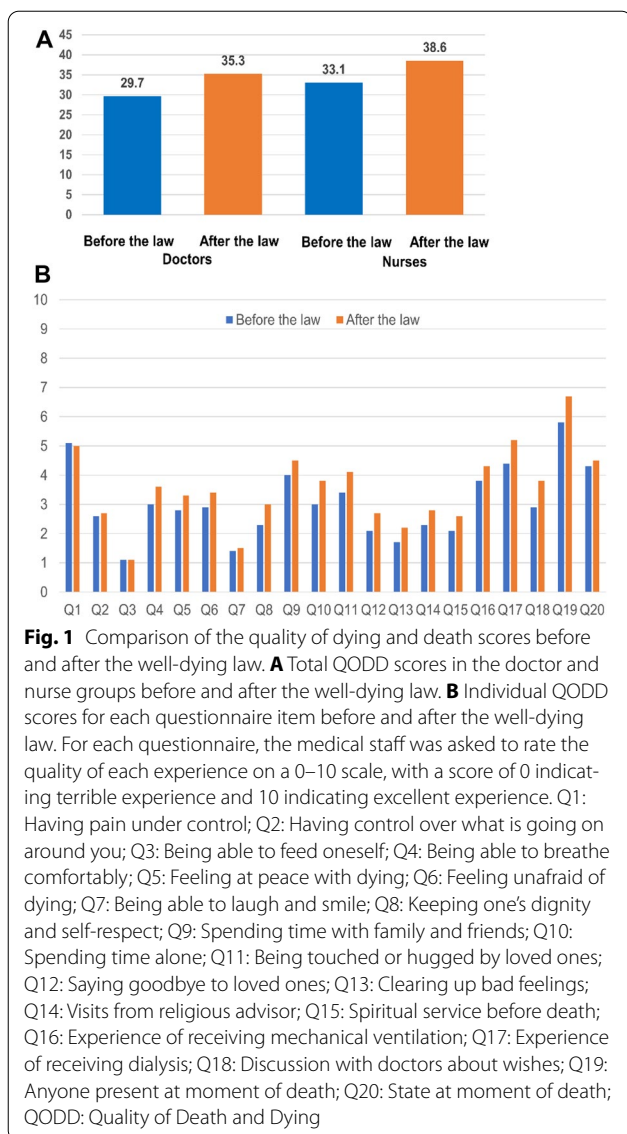
#### Participating medical staff's opinion of the best action and actual action for LST withdrawal

The participating medical staff were additionally asked the following questions (Supplemental Table S1) at the end of the QODD questionnaire. The concordance rate of the staff's opinion of the best action and the actual action for LST withdrawal significantly increased after the law compared to that before the law (40.8% vs. 60.8%, respectively,  $p < 0.001$ ). The reasons for discordance between the opinion and action are described in Table 3. The reasons given by the medical staff for the discrepancies between

the best action and actual action were "ethical problems" (18.8%) and "not guaranteed by law" (30.6%)", although they recognized that the patients received non-beneficial LST before the implementation of the well-dying law. However, those reasons were significantly reduced to 2.5% and 21.9% after the well-dying law implementation, respectively (Table 3).

#### Discussion

This study is the first to identify the effect of the well-dying law on the quality of death in ICUs. As expected, there was a significant improvement in the quality of dying (QODD score) after the well-dying law implementation. The well-dying law had a positive independent association with the increased QODD score in the multiple regression analysis, ITS analysis, and multilevel adjustment analysis. In addition, the concordance rate of the medical staff's opinion of the best action and actual



action for the LST withdrawal was significantly increased after the implementation of the law.

As mentioned in the results section, the time between receiving a DNR and death increased from 2.5 to 5 days following the implementation of the law. This implies that the “well-dying” law provides an extended opportunity to communicate about death and withdrawal of LST between medical staff and the caregiver/patient much earlier than the point of death. Moreover, the concordance rate of the staff’s opinion of the best action and actual action for LST withdrawal showed a 20% increase after the implementation of the law. These findings reflect that the ethical and legal issues around LST withdrawal have been improved by the well-dying law, enabling physicians to act according to their clinical judgment to limit

futile LST, thereby leading to an increased concordance between the opinion and the action of LST withdrawal.

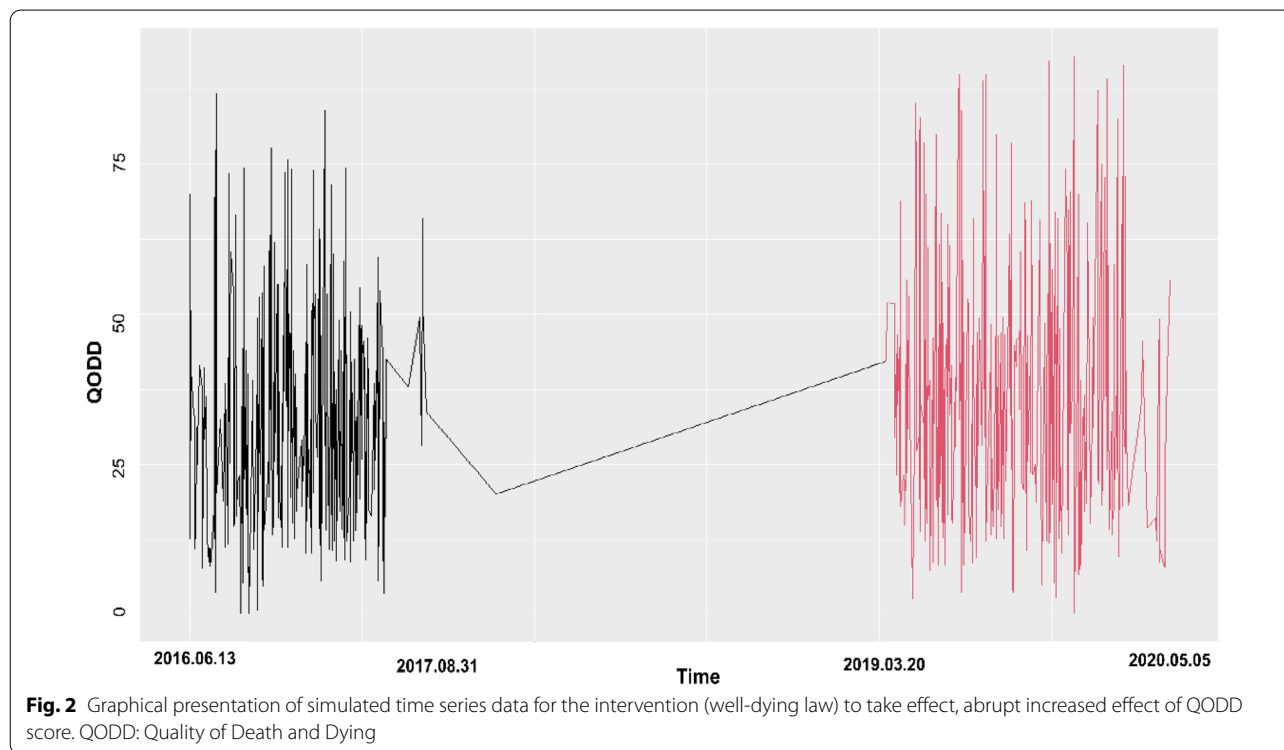
The scores of all individual questionnaire items increased after the law. However, both doctors and nurses gave less than three-point scores for the following seven items on the QODD regardless of the enactment of the law: “Q2, 3, 7, 12, 13, 14, and 15” questions about patient autonomy and emotional support at the point of death. The patient’s autonomy on end-of-life care is exercised through communication, which may be impossible if the patient lacks the capability. The communication for incapable patients is conveyed through an advanced directive [10] written by patients when they were mentally and physically healthy and could sufficiently consider and decide the right choice of treatment or surrogate decision-making by family, representing autonomy. Therefore, if there is sufficient information for the patient and family, for example, on when to write, what to decide, and others, (i.e., if this information are provided), the patient’s autonomy over the end of life could be enhanced. The implementation of extended visitation or an unrestricted visiting policy can alleviate the psychological distress of patients and improve the quality of death [11, 12]. Visiting the ICU is strictly limited to once or twice a day due to concern about distractions from visitors [13, 14] in many countries. Only when the patient is on the verge of death can the caregiver visit the patient more than twice a day in most South Korean ICUs. However, Netzer et al. demonstrated that the extended family visiting hours in the ICU reduced the patient’s delirium and improved family satisfaction without affecting the infection rate [15].

A major obstacle that needs to be overcome to improve the quality of death is the disagreement among family members. The problem emerges from the phrase “agreement of the whole family” in the law. If a member of the family is unreachable or missing, this violates the essentials of the legal agreement of the whole family. In fact, the number of cases where LST withdrawal could not be performed due to disagreement among families of patients for whom withdrawal was considered increased by more than 20%, from 33.3% to 58.8%, after the enactment of the law (Table 3). Thus, the medical community has emphasized the need to modify the well-dying law to narrow the scope of family members (from “whole family” to “two family members”). As a result, on December 11, 2018, the Well-Dying Act was amended in this regard, and the revised version became effective on March 28, 2019 [16]. This study was conducted between January 2019 and May 2020; therefore, most of the data extracted for this study should have reflected the implementation of this law, this was not the case. This is because information on the revised law

**Table 2** Factors associated with better quality of death in ICUs

Factors	Total QODD score	<i>p</i> -value	Doctors	<i>p</i> -value	Nurses	<i>p</i> -value
<b>Implementation of the well-dying law</b>		<0.001		<0.001		0.004
Before	31.3 ± 17		29.7 ± 15.3		33.1 ± 18.4	
After	36.9 ± 19.8		35.3 ± 19.3		38.6 ± 20.3	
<b>Underlying cancer</b>		0.037		0.529		0.020
Malignancy	35.9 ± 18.7		33.1 ± 16.7		38.8 ± 20.2	
No malignancy	33 ± 18.5		31.9 ± 18.3		34.3 ± 18.7	
<b>CPR within 24 h of death</b>		<0.001		<0.001		0.016
Performed	28.2 ± 18.7		25.9 ± 16.5		30.7 ± 20.7	
Not performed	35.8 ± 18.2		34.4 ± 17.5		37.3 ± 18.8	
<b>Life-supporting equipment</b>		0.128		0.177		0.389
≥ 2	32.4 ± 17.3		30.4 ± 15.6		34.5 ± 18.8	
< 2	35.5 ± 19.4		34.1 ± 19		36.9 ± 19.8	
<b>Continuous variables</b>	<i>R</i>	<i>p</i> -value	<i>R</i>	<i>p</i> -value	<i>R</i>	<i>p</i> -value
Age, years	0.1	0.033	0.082	0.2	0.126	0.069
APACHE-II	−0.067	0.213	−0.064	0.364	−0.063	0.439
ICU length of stay	0.064	0.137	0.116	0.044	0.014	0.828

QODD quality of death and dying; CPR cardiopulmonary resuscitation; APACHE II acute physiology and chronic health evaluation II; ICU intensive care unit



**Fig. 2** Graphical presentation of simulated time series data for the intervention (well-dying law) to take effect, abrupt increased effect of QODD score. QODD: Quality of Death and Dying

content was not widely disseminated in the clinical field during the study period.

Despite the increase after the law was implemented, the QODD score in South Korea is far below that of Western countries, considering the QODD score of 60–70 in the

United States or the Netherlands (supplementary Fig. S2) [17–21]. This may be due to the cultural differences in end-of-life communication. In the Korean Confucian culture, direct discussion about dying is disrespectful, and communication on the issue has long been discouraged. Ko

**Table 3 Comparison of the medical staff's opinion of the best action and actual action for withdrawal of life-sustaining treatment before and after the well-dying law**

Questions about withdrawal of life-sustaining treatment	Before the well-dying law (N = 353)	After the well-dying law (N = 403)	p-value
<b>(a) Have you ever thought that the deceased patient needed withdrawal of LST?</b>	<b>n (%)</b>	<b>n (%)</b>	
<b>(b) If yes, did you actually withdraw any of the LST?</b>			
(a) Yes → (b) Yes	144 (40.8)	245 (60.8)	< 0.001
(a) Yes → (b) No	142 (40.2)	119 (29.5)	0.09
<b>(c) Although you thought that the patient needed withdrawal of LST, you did not withdraw the LST. What was the main reason?</b>			< 0.001
Disagreement among family members	48 (33.3)	70 (58.8)	
Case not guaranteed by the law at the time of study questionnaire	42 (30.6)	26 (21.9)	
Ethical problem	27 (18.8)	3 (2.5)	
Other	25 (17.4)	20 (16.8)	

The medical staff who participated in this study were asked the above-mentioned questions at the end of the questionnaire  
LST life-sustaining treatment

and Lee found that non-Hispanic white patients were more likely to receive discussions about end-of-life care than South Korean Americans [22]. South Koreans tend to avoid conveying any negative information about poor prognosis to their parents and defer open discussion until it is inevitably discussed in proximity to death in many cases [23]. However, the results of our study are not representative of all Confucian countries. There are significant intra-region differences in the ICU physicians' practices of LST, the roles of families, their understanding of legal risks, and financial considerations in the same Confucian Asian countries [24, 25].

This study has some limitations. First, the QODD was only assessed by nurses and physicians and did not include the family perspective. Second, the before–after design limits the ability to make causal inference as other temporal changes may have confounded the results. However, we performed an ITS analysis, which suggested that the effect of the temporal changes was minimal. Third, the participants were possibly biased, as they were from medical ICUs. Therefore, our results may not be generalizable to other specialized ICUs (e.g., surgical or neurological). However, considering the severity of patients' conditions and number of deaths in the medical ICU compared with those in other ICUs, the frequency of discussion about end-of-life care, LST, and withdrawal must be most frequent in the medical ICU, making the staff suitable for this study. Fourth, the same medical staff answered the QODD questions multiple times due to the limited staff at each hospital. Therefore, multiple comparisons may have resulted in some spurious associations. However, we tried to minimize duplicated participation by limiting response frequencies to five per physician and three per nurse in a month. In addition, multilevel approach using a linear mixed model showed

same result. Fifth, we could not assess if the actual use of ICU resources decreased in non-beneficial LST for incapacitated patients with advanced illnesses. Our study was conducted to analyze the quality of dying in the ICU, therefore, we enrolled patients who were already admitted to the ICU and died in the ICU. Patients who had decided not to receive meaningless LST would not have been admitted to the ICU at all. Further studies including the overall in-hospital mortality are needed to analyze whether the use of meaningless LST has decreased.

## Conclusion

In conclusion, our findings suggest that the implementation of the well-dying law positively affected the quality of death in the ICU and improved the ethical and legal issues associated with LST withdrawal, thereby enabling physicians to act according to their clinical judgment and limited futile LST. Nonetheless, the quality of death in South Korean ICUs appears relatively low, with much scope for improvement in the quality of care, especially with regard to patient autonomy near death. The well-dying law in South Korea should be revised to improve effectiveness in accordance with clinical opinions.

## Supplementary Information

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### Author contributions

Concept and design: YJL, JYC, TYP, SY, JK, JMK, JL, SML, and YJL (the corresponding author) Data collection, analysis, or interpretation of data: YJL, SA, JYC, TYP, SY, JK, JMK, JL, SML, and YJL (the corresponding author). Drafting the manuscript: YJL, SA and YJL (corresponding author). Critical revision of the manuscript for important intellectual content and approved the version to be published: all authors. Obtained funding: YJL (the corresponding author).

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### Availability of data and materials

Deidentified data are available for sharing. To request data, please contact the corresponding author with a request. Applications from investigators with the suitable academic capability to conduct the proposed work will be given consideration. Any proposal will require approval from the ethics committee which approved the conduct of this trial prior to sharing of any patient data. If a proposal is approved, a signed data transfer agreement will be required before data sharing.

### Code availability

Not applicable.

### Declarations

### Conflicts of interest

None of the authors have any conflicts of interest to declare.

### Ethics approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the institutional review board of each participating hospital (IRB number B-1903-531-302 in Seoul National University Bundang Hospital, IRB Number 1903-063-1017 in Seoul National University Hospital, IRB Number H-1904-101-001 in National Medical Center, and IRB Number 20-2019-23 in Seoul Boramae Hospital).

### Consent to participate

Informed consent was obtained from all individual participants included in the study, and the consent of the deceased patient was waived.

### Consent for publication

Not applicable.

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