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Special Article

Current Status and Cardinal Features of Patient Autonomy after Enactment of the Life-Sustaining Treatment Decisions Act in Korea

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Purpose The main purpose of the Life-Sustaining Treatment Decisions Act recently enacted in Korea is to respect the patient's selfdetermination. We aimed to investigate the current status and features of patient self-determination after implementation of the law.

Materials and Methods Between February 2018 and January 2019, 54,635 cancer deaths were identified from the National Health Insurance Service (NHIS) database. We analyzed the characteristics of decedents who complied with the law process by self-determination compared with decedents with family determination and with decedents who did not comply with the law process.

Results In multivariable analysis, patients with self-determination were vounger, were less likely to live in rural areas, were less likely to belong to the highest income quintile, were less likely to be treated in general hospitals, and were more likely to show a longer time from cancer diagnosis compared with patients with family determination. Compared with patients who did not comply with the law process, patients with self-determination were younger, lived in Seoul or capital area, were less likely to belong to the highest income quintile, were treated in general hospitals, were less likely to have genitourinary or hematologic malignancies, scored higher on the Charlson comorbidity index, and showed a longer time from cancer diagnosis. Patients with self-determination were more likely to use hospice and less likely to use intensive care units (ICUs) at the end-of-life (EOL).

Conclusion Decedents with self-determination were more likely to be younger, reside in the Seoul or capital area, show a longer time from cancer diagnosis, and were less likely to belong to the highest income quintile. They utilized hospice more frequently, and received less ICU care at the EOL.

Key words Neoplasms, Death, Withholding treatment, Palliative care, Advance directive

Introduction

Although withholding life-sustaining treatments at the end-of-life (EOL) in advanced cancer patients has long been a common practice in Korea, there were no public consensus or formal legislation on withholding or withdrawing life-sustaining treatments. Withholding life-sustaining treatments was usually achieved by completing do-not-resuscitate (DNR) forms at the time of imminent death by family members [1,2]. Withdrawing life-sustaining treatments was not protected by law and often resulted in defensive medical practice. After years of discussions since the Grandma Kim case in 2009, the "Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at

the End of Life" (abbreviated as "Life-Sustaining Treatment Decisions Act") was enacted on February 4, 2018 [3].

The purpose of this law is to protect the dignity and value of human beings by ensuring the best interests of the patients at the EOL and by respecting their self-determination. According to the law, patients can express their preferences by completing legal forms that are advance statements on a life-sustaining treatment (an advance directive) or life-sustaining treatment plan (a type of Physician Orders for Lifesustaining Treatment [POLST]). Patients cannot designate a proxy in advance, but if patients do not have a decisionmaking capacity due to advanced illness and have not completed any forms, family members can complete the legal form. Ideally, all patients should decide their preferences for

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life-sustaining treatments by themselves to enhance patient autonomy. A prerequisite for this will be appropriate advance care planning based on an accurate prognostic understanding. However, many advanced cancer patients in Korea do not know their prognosis accurately [4] and DNR forms were almost exclusively completed by family members before the enactment of this law [1,2]. Because the law was enacted before a social acceptance of routine advance care planning, Korean society is still struggling to accept and comply with mandatory application of the Life-Sustaining Treatment Decisions Act [3].

In this study, we aimed to investigate the current status and features of patient self-determination after enactment of the Life-Sustaining Treatment Decisions Act in Korea.

Materials and Methods

1. Patients

The data on cancer deaths after the enactment of the Life-Sustaining Treatment Decisions Act in February 2018 were extracted from the National Health Insurance Service (NHIS) database. All cancer deaths between February 1, 2018 and January 31, 2019 were analyzed. Cancer deaths with illegible forms were excluded. Patients with insurance claims for lifesustaining treatment decisions who lacked essential forms or who had both patient self-determination forms and family determination forms were considered illegible. Patient selfdetermination was defined as completing the life-sustaining treatment plan (legal form No. 1) or advance statement on life-sustaining treatment (legal form No. 10). Family determination was defined as completion of the legal form by family members (legal forms No. 11 or No. 12). In addition to illegible forms, cancer deaths with multiple primary cancer were excluded in order to include 'cancer type' in the analysis for factors associated with self-determination. Decedents were divided into three groups: patients who complied with the law process by self-determination; patients who complied with the law process by family determination; and patients who did not comply with the law process (control group).

2. Data collection

We collected demographic data including age, sex, and residential area (Seoul and the capital area including Incheon and Gyeonggi-do/metropolitan cities other than the Incheon/rural area). In addition, data on income quintiles (medical aid and quintiles 1 to 20, 20 indicating the highest income), type of medical institution (general hospital including tertiary and secondary hospitals/primary hospital or convalescent hospitals), primary cancer site, Charlson comorbidity index [5], time from cancer diagnosis to life-sus-

taining treatment decision, and health care utilization at the EOL were obtained.

3. Statistical analysis

Descriptive analyses were performed to summarize the baseline characteristics of the patients. Statistical analyses of categorical variables were performed using Pearson's chi-square test. Continuous variables are reported as the mean±standard deviation (SD), and comparisons of the mean between groups were calculated by Student's t test. Univariate and multivariable analyses were performed with the logistic regression method. Age, sex, and variables with a p-value less than 0.05 by univariate analyses were included in the multivariable analysis. A stepwise logistic regression analysis was performed to identify independent predictors of patient self-determination. All tests were two-sided, and p-values < 0.05 were considered significant. Confidence intervals were calculated at a 95% confidence level. All analyses were performed using SAS ver. 9.4 (SAS Institute Inc., Cary, NC).

Results

1. Patient characteristics

Between February 2018 and January 2019, 54,635 cancer deaths were identified from the NHIS database. Excluding decedents with illegible forms and multiple primary cancers, 50,838 decedents were evaluable for the analysis. Among these patients, 6,785 (13.4%) complied with the law process by patient self-determination, 6,106 (12.0%) complied with the law process by family determination, and 37,947 (74.6%) did not comply with the law process (control group). Baseline demographic and clinical information is summarized in Table 1. The mean age of patients with self-determination was 66.0 years (SD, 12.4), and 44.7% of patients were younger than 65 years. In the patient self-determination group, 36.9% were female, 53.2% lived in Seoul or the capital area, 17.9% lived in metropolitan cities, and 86.3% were treated in general hospitals at the time of the decision. The most common primary sites were the liver/pancreas/bile duct (23.9%), lung (20.4%), colon/rectum (11.8%), and stomach (10.6%). The mean score on the Charlson comorbidity index was 8.1 (SD, 3.2), and the time from cancer diagnosis to life-sustaining treatment decisions was longer than a year in 59.1% of patients.

2. Predictors of patient self-determination

The results of univariate and multivariable analyses to identify predictors of patient self-determination are summarized in Tables 2 and 3. According to the multivariable analy-

Table 1. Baseline demographic and clinical characteristics

Variable	Cancer deaths with patient self-determination	p-value ^{a)}	Cancer deaths with family determination	p-value ^{b)}	Cancer deaths not following the law process (control group)	Total cancer deaths
No. (%)	6,785 (13.4)		6,106 (12.0)		37,947 (74.6)	50,838 (100)
Age (yr)	66.0±12.4	< 0.001	69.8±12.5	< 0.001	72.0±12.6	
Age (yr)						
< 65	3,036 (44.7)	< 0.001	1,896 (31.1)	< 0.001	10,248 (27.0)	15,180 (29.9)
≥ 65	3,749 (55.3)		4,210 (68.9)		27,699 (73.0)	35,658 (70.1)
Sex						
Male	4,281 (63.1)	0.735	3,835 (62.8)	0.075	23,511 (62.0)	31,627 (62.2)
Female	2,504 (36.9)		2,271 (37.2)		14,436 (38.0)	19,211 (37.8)
Residential area						
Seoul and capital areaco	3,611 (53.2)	< 0.001	3,033 (49.7)	< 0.001	14,895 (39.3)	21,539 (42.4)
Metropolitan city ^{d)}	1,217 (17.9)		914 (15.0)		7,954 (21.0)	10,085 (19.8)
Rural area	1,957 (28.8)		2,159 (35.4)		15,097 (39.8)	19,213 (37.8)
Income quintiles						
Medical Aid	116 (1.7)	< 0.001	107 (1.8)	< 0.001	1,084 (2.9)	1,307 (2.6)
1-5	1,407 (20.7)		1,137 (18.6)		7,840 (20.7)	10,384 (20.4)
6-10	1,370 (20.2)		1,060 (17.4)		6,689 (17.6)	9,119 (17.9)
11-15	1,630 (24.0)		1,390 (22.8)		8,429 (22.2)	11,449 (22.5
16-20	2,262 (33.3)		2,412 (39.5)		13,905 (36.6)	18,579 (36.5)
Institution						
General hospital	5,857 (86.3)	< 0.001	5,568 (91.2)	< 0.001	22,694 (59.8)	34,119 (67.1)
Other ^{e)}	928 (13.7)		538 (8.8)		15,253 (40.2)	16,719 (32.9)
Cancer type						
Stomach	716 (10.6)	< 0.001	469 (7.7)	< 0.001	3,838 (10.1)	5,023 (9.9)
Colon/Rectal	801 (11.8)		460 (7.5)		4,261 (11.2)	5,522 (10.9)
Liver/Pancreas/Bile duct	1,621 (23.9)		1,324 (21.7)		8,502 (22.4)	11,447 (22.5)
Lung	1,385 (20.4)		1,563 (25.6)		8,087 (21.3)	11,035 (21.7)
Breast	268 (3.9)		209 (3.4)		1,135 (3.0)	1,612 (3.2)
Gynecologic	293 (4.3)		176 (2.9)		1,083 (2.9)	1,552 (3.1)
Genitourinary	217 (3.2)		184 (3.0)		1,827 (4.8)	2,228 (4.4)
Hematologic	289 (4.3)		660 (10.8)		2,223 (5.9)	3,172 (6.2)
Other	1,195 (17.6)		1,061 (17.4)		6,991 (18.4)	9,247 (18.2)
Charlson comorbidity index	8.1±3.2	< 0.001	7.9±3.3	< 0.001	7.5±3.3	
Time from diagnosis (yr)	2.5±3.0	< 0.001	2.2±3.0	< 0.001	2.3±3.1	
Time from diagnosis to						
life-sustaining treatment						
decision (mo)						
< 6	1,666 (24.6)	< 0.001	2,115 (34.6)	< 0.001	12,563 (33.1)	16,344 (32.1
6-12	1,106 (16.3)		997 (16.3)		5,977 (15.8)	8,080 (15.9)
12-24	1,413 (20.8)		1,062 (17.4)		6,755 (17.8)	9,230 (18.2
≥ 24	2,600 (38.3)		1,932 (31.6)		12,652 (33.3)	17,184 (33.8)

Values are presented as number (%) or mean±standard deviation. ^{a)}Between cancer deaths of patients with self-determination and cancer deaths of patients with family determination, b) Between cancer deaths of patients with self-determination and cancer deaths of patients not following the law process, eSeoul, Incheon, and Gyeonggi-do, eBusan, Daegu, Daejeon, Gwangju, and Ulsan, ePrimary hospitals and convalescent hospitals.

Table 2. Predictive factors of patients with self-determination compared with patients with family determination

V - 11	Uı	Univariate		Multivariable	
Variable	OR	95% CI	OR	95% CI	
Age (yr)					
< 65	1		1		
≥ 65	0.56	0.52-0.60	0.62	0.57-0.67	
Sex					
Male	1		1		
Female	0.99	0.92-1.06	0.93	0.86-1.01	
Residential area					
Seoul and capital area ^{a)}	1		1		
Metropolitan city ^{b)}	1.12	1.01-1.23	1.14	1.03-1.27	
Rural area	0.76	0.70-0.82	0.80	0.74-0.87	
Income quintiles					
Medical Aid	0.84	0.64-1.10	0.95	0.71-1.26	
1-5	0.96	0.86-1.07	1.00	0.89-1.12	
6-10	1		1		
11-15	0.91	0.82-1.01	0.95	0.85-1.06	
16-20	0.73	0.66-0.80	0.81	0.73-0.90	
Institution					
Other	1		1		
General hospital	0.61	0.55-0.68	0.59	0.52-0.66	
Cancer type					
Stomach	1		1		
Colon/Rectal	1.14	0.97-1.34	1.12	0.94-1.32	
Liver/Pancreas/Bile duct	0.80	0.70-0.92	0.86	0.75-0.99	
Lung	0.58	0.51-0.67	0.66	0.57-0.76	
Breast	0.84	0.68-1.04	0.66	0.52-0.83	
Gynecologic	1.09	0.88-1.36	0.99	0.79-1.25	
Genitourinary	0.77	0.62-0.97	0.79	0.63-1.00	
Hematologic	0.29	0.24-0.34	0.32	0.27-0.39	
Other	0.74	0.64-0.85	0.78	0.67-0.90	
Charlson comorbidity index	1.03	1.02-1.04	1.01	0.99-1.02	
Time from diagnosis to life-sustaining treatment decision (mo)	1.00	1.02 1.01	2.02	0.55 1.02	
<6	1		1		
6-12	1.41	1.27-1.57	1.31	1.17-1.46	
12-24	1.69	1.53-1.87	1.51	1.36-1.68	
≥ 24	1.71	1.57-1.86	1.57	1.43-1.72	

CI, confidence interval; OR, odds ratio. ^aSeoul, Incheon, and Gyeonggi-do, ^bBusan, Daegu, Daejeon, Gwangju, and Ulsan.

sis, patients with self-determination were younger, were less likely to live in rural areas, were less likely to be treated in general hospitals, were less likely to belong to the highest income quintile, were less likely to have liver/pancreas/ bile duct, lung, breast, genitourinary, or hematologic malignancies, and were more likely to show a longer time from cancer diagnosis to life-sustaining treatment decisions, than the family-determination group (Table 2). Compared with patients in the control group, patients with self-determination were younger, lived in Seoul or the capital area, were less likely to belong to the highest income quintile, were treated in general hospitals, were less likely to have genitourinary or hematologic malignancies, scored higher on the Charlson comorbidity index, and showed a longer time from cancer diagnosis to life-sustaining treatment decisions (Table 3).

3. Differences in health care utilization at the EOL

Tables 4 and 5 show differences in health care utilization at the EOL. Compared with the family determination group, patients with self-determination were more likely to use hos-

Table 3. Predictive factors of patients with self-determination compared with patients in the control group

V 11	Univariate		Multivariable	
Variable	OR	95% CI	OR	95% CI
Age (yr)				
< 65	1		1	
≥ 65	0.46	0.43-0.48	0.61	0.58-0.65
Sex				
Male	1		1	
Female	0.97	0.964-0.968	0.98	0.92-1.04
Residential area				
Seoul and capital area ^{a)}	1		1	
Metropolitan city ^{b)}	0.63	0.59-0.68	0.62	0.57-0.66
Rural area	0.54	0.50-0.57	0.58	0.54-0.62
Income quintiles				
Medical Aid	0.52	0.43-0.64	0.76	0.62-0.94
1-5	0.88	0.81-0.95	0.96	0.89-1.05
6-10	1		1	
11-15	0.94	0.87-1.02	0.98	0.90-1.06
16-20	0.79	0.74-0.86	0.91	0.84-0.98
Institution				
Other	1		1	
General hospital	4.24	3.95-4.57	3.85	3.57-4.15
Cancer type				
Stomach	1		1	
Colon/Rectal	1.01	0.90-1.13	1.01	0.90-1.13
Liver/Pancreas/Bile duct	1.02	0.93-1.13	0.94	0.85-1.04
Lung	0.92	0.83-1.01	0.96	0.86-1.06
Breast	1.27	1.08-1.48	0.86	0.73-1.02
Gynecologic	1.45	1.25-1.69	1.17	0.99-1.38
Genitourinary	0.64	0.54-0.75	0.77	0.65-0.91
Hematologic	0.70	0.60-0.81	0.64	0.55-0.74
Other	0.92	0.83-1.01	0.96	0.86-1.06
Charlson comorbidity index	1.06	1.05-1.07	1.05	1.04-1.06
Time from diagnosis to life-sustaining treatment decision (mo)	2.00	1.00 1.0.	2.00	1.01 1.00
<6	1		1	
6-12	1.40	1.29-1.52	1.35	1.24-1.47
12-24	1.58	1.46-1.70	1.48	1.37-1.61
≥ 24	1.55	1.45-1.66	1.47	1.37-1.58

CI, confidence interval; OR, odds ratio. ^aSeoul, Incheon, and Gyeonggi-do, ^bBusan, Daegu, Daejeon, Gwangju, and Ulsan.

pice (45.0% vs. 14.8%, p < 0.001) and less likely to use intensive care units (ICUs) (12.6% vs. 33.2%, p < 0.001) or emergency departments (EDs) (77.3% vs. 81.7%, p < 0.001) (Table 4). Compared with the control group, patients with selfdetermination were more likely to use hospice (45.0% vs. 18.3%, p < 0.001) and less likely to use the ICU (12.6% vs. 21.6%, p < 0.001) at the EOL (Table 5). However, ED use was higher in the self-determination group (77.3% vs. 70.8%, p < 0.001).

Discussion

In this study, we found that cancer decedents who complied with the Life-Sustaining Treatment Decisions Act by patient self-determination had distinct features compared with patients with family determination or patients in the control group who did not comply with the law process. Overall, patients with self-determination were significantly younger, lived in the Seoul or capital area, were less likely to belong to the highest income quintile, and showed a longer

Table 4. Differences in health care utilization at the end-of-life among patients with self-determination and family determination

Variable	Cancer deaths with patient self-determination (n=6,785)	Cancer deaths with family determination (n=6,106)	p-value
Hospice			
Yes	3,050 (45.0)	906 (14.8)	< 0.001
No	3,735 (55.0)	5,200 (85.2)	
Intensive care unit			
Yes	855 (12.6)	2,030 (33.2)	< 0.001
No	5,930 (87.4)	4,076 (66.8)	
Emergency department			
Yes	5,247 (77.3)	4,987 (81.7)	< 0.001
No	1,538 (22.7)	1,119 (18.3)	

Values are presented as number (%).

Table 5. Differences in health care utilization at the end-of-life among patients in the self-determination and control groups

	01	0 1	
Variable	Cancer deaths with patient self-determination (n=6,785)	Cancer deaths not following the law process (control group) (n=37,947)	p-value
Hospice			
Yes	3,050 (45.0)	6,942 (18.3)	< 0.001
No	3,735 (55.0)	31,005 (81.7)	
Intensive care unit			
Yes	855 (12.6)	8,191 (21.6)	< 0.001
No	5,930 (87.4)	29,756 (78.4)	
Emergency department			
Yes	5,247 (77.3)	26,873 (70.8)	< 0.001
No	1,538 (22.7)	11,074 (29.2)	

Values are presented as number (%).

time from cancer diagnosis to life-sustaining treatment decisions. Although it was less than in the family determination group, the vast majority of patients in the self-determination group were treated in general hospitals at the time of decision making. It is not possible to clarify the reasons for the findings of our study at this time, but we can speculate that patients younger than 65 years, who usually live around Seoul, and belong to middle-income households, are relatively more educated and more familiar with advance care planning than older patients or patients who live in rural areas. Although previous studies have reported that a higher income was associated with a positive preference for withdrawal of futile life-sustaining treatment [6], patients who belonged to the highest income quintile were less likely to demonstrate self-determination in our study. We do not know the reason for this finding at this time, but we can carefully speculate that family caregivers may have more influences on decision making in the highest income quintile, and that this population are more prone to therapeutic obstinacy because they can afford highly expensive life-sustain-

ing treatments. It is not surprising that most patients were treated in general hospitals considering the fact that most cancer patients are treated in comprehensive cancer centers of tertiary hospitals in Korea and that only large hospitals could meet the strict requirements of the law, such as mandatory institutional ethics committees. In January 2019, 38.8% of general hospitals were qualified to comply with the law process, compared with 0.6% for primary hospitals and 1.4% for convalescent hospitals [7]. Considering longer time from cancer diagnosis to life-sustaining treatment decisions, we can also infer that patients with self-determination had more time and opportunities to think about preferences regarding future medical care. In contrast, patients with family determination or patients who did not follow the law process may had more aggressive disease with rapid progression.

We could verify that patients with family determination had unique characteristics compared with patients in the selfdetermination group. Patients with family determination were older than 65 years, lived in rural areas, were treated in general hospitals until death, and showed a shorter time

from cancer diagnosis to life-sustaining treatment decisions. According to the cancer type, the odds ratio was lowest in hematologic malignancies, followed by lung cancer. The family determination group rarely utilized hospice at the EOL and more frequently received aggressive care including ICU care and ED visits. We think this group comprises a mixture of patients. The first is patients whose family members act as a 'protector' of the patient [8]. The patients are frequently older, live in rural areas, and are unaware of their prognosis. The second may include a group of patients and families who pursue every possible treatment. In a single-center retrospective study after the enactment of the law, decisions by family members were significantly associated with higher rates of withdrawal of care in the ICU, suggesting their dependence on life-sustaining treatments [9]. Last, we can speculate that patients with aggressive cancer, such as hematologic malignancies and lung cancer, are at a risk of rapid deterioration before starting advance care planning discussions [10-12]. In accordance with previous studies, these patients had fewer opportunities to receive hospice care in our study. To respect patient autonomy and prevent late decisions by family members, health care providers should start advance care planning discussions earlier in these patients. Earlier discussions should be connected to a larger scope of providing early palliative care, which has been proven in several randomized studies to improve quality of life and decrease aggressive EOL care [13-15].

In the present study, 45% of patients with self-determination utilized hospice at the EOL. This rate is much higher than the nationwide hospice use rate, which was 22.9% in 2018 [16]. Patients in the self-determination group used hospice services more frequently and ICUs less frequently than the other two groups. This is concordant with previous studies that reported that advance care planning increases the use of hospice services and decreases the use of intensive treatment at the EOL [17,18]. Different from our expectations, patients with self-determination used the ED more frequently than the control group in the present study. This may result from the fact that most patients in the self-determination group were treated in general hospitals and that patients treated in general hospitals use the EDs for any problem they encounter in the Korean health care system.

Advance care planning is a process to ensure that people receive medical care that is consistent with their values, goals and preferences [19]. It often includes the completion of an advance directive or POLST, which is a prerequisite for patient self-determination. In Australia, while most patients perceived advance care planning as important, only a few discussed their EOL preferences with a doctor [20]. In a systematic review including 150 studies published in the United States, 37% of patients had completed an advance directive

[21]. In most countries, completion rates of advance directives are generally much lower. Although enactment of the Life-Sustaining Treatment Decisions Act in Korea caused many problems, it may have a positive effect in integrating advance care planning and completion of advance directives into routine clinical practice. In our study, half of the patients complying with the law process made life-sustaining treatment decisions by self-determination, and the rate of selfdetermination is continuously increasing according to the National Agency for Management of Life-Sustaining Treatment data [7]. Considering that only 16% of the general population and 33% of the patients and caregivers had knowledge of advance directives in 2016 [22], we think there has been a significant progress in terms of patient autonomy in Korea. However, to facilitate advance care planning and to enhance patient autonomy, more education and promotion that include elderly patients and patients living in rural areas are required. According to the United States data, factors such as old age, high disease burden, white ethnicity, higher socioeconomic status, and knowledge about advance directives or EOL treatment options were associated with the completion of advance directives [23].

Our study has some limitations. As it is based on NHIS claim data, there are typical limitations of studies relying on administrative data, and it is not possible to analyze detailed clinical information. For instance, we cannot distinguish patients who withheld life-sustaining treatments from patients who withdrew life-sustaining treatments. Additionally, it is not possible to identify temporal relationship between life-sustaining treatment decision and health care utilization at the EOL period.

In conclusion, our study demonstrated that cancer decedents with self-determination were more likely to be younger, reside in the Seoul or capital area, and show a longer time from diagnosis to life-sustaining treatment decisions. They were less likely to belong to the highest income quintile. Patients with self-determination utilized hospice more frequently and received less ICU care at the EOL.

Ethical Statement

This study was approved by the Ethics Committee of the National Evidence-Based Healthcare Collaborating Agency (NA19-008) and the Kangdong Sacred Heart Hospital (2019-12-013). The requirement to obtain informed consent was waived because the research involves no more than minimal risk, and it can not be carried out without the waiver since all patients have died. It was performed in accordance with the principles of the Declaration of Helsinki.

Author Contributions

Conceived and designed the analysis: Kim HJ, Kim YJ, Kwon JH. Collected the data: Kim HJ, Kim YJ, Kwon JH.

Contributed data or analysis tools: Kim HJ, Kim YJ, Kwon JH. Performed the analysis: Kim HJ, Kim YJ, Kwon JH, Won YW, Lee HY, Baek SK, Ryu H.

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Conflicts of Interest

Conflict of interest relevant to this article was not reported.

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