

Changes in End-of-Life Discussion for Patients with Advanced Cancer after the Life-Sustaining Treatment Decisions-Making Act in Korea

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1 **Changes in End-of-Life Discussion for Patients with Advanced Cancer after the Life-**
2 **Sustaining Treatment Decisions-Making Act in Korea**

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25

26 **Abstract**

27 **Background:** Cancer is a leading cause of death in Korea. To protect the autonomy and dignity of
28 terminally ill patients, the Life-Sustaining Treatment Decision-Making Act (LST-Act) came into full
29 effect in Korea in February 2018. However, it is unclear whether the LST-Act influences end-of-life
30 (EOL) discussion and decision-making processes for terminally ill cancer patients.

31 **Methods:** This was a retrospective study conducted with a medical record review of cancer patients
32 who died at Ulsan University Hospital between July 2015 and May 2020. Patients were divided into
33 two groups: those who died in the period before the implementation of the LST-Act (from July 2015 to
34 October 2017, Group 1) and after the implementation of the LST-Act (from February 2018 to May 2020,
35 Group 2). We measured the self-determination rate and the timing of documentation of Do-Not-
36 Resuscitate (DNR) or Physician Orders for Life-Sustaining Treatment (POLST) in both groups.

37 **Results:** A total of 1,834 patients were included in the analysis (Group 1, n=943; Group 2, n=891).
38 Documentation of DNR or POLST was completed by patients themselves in 1.5% and 63.5% of patients
39 in Groups 1 and 2, respectively ($p<0.001$). The mean number of days between documentation of POLST
40 or DNR and death was higher in Group 2 than in Group 1 (21.2 days vs. 14.4 days, $p=0.001$). The rate
41 of late discussion, defined as documentation of DNR or POLST within seven days prior to death,
42 decreased significantly in Group 2 (46.6% vs. 41.4%, $p=0.027$). In the multivariable analysis, hospice
43 palliative care referral (OR [odds ratio] 0.25, $p<0.001$) and patients' years of education (OR 0.68,
44 $p=0.027$) were positively related to self-determination. However, physicians with clinical experience of
45 less than three years had a higher rate of surrogate decision-making (OR 5.1, $p=0.029$) and late
46 discussion (OR 2.53, $p=0.019$).

47 **Conclusions:** After the implementation of the LST-Act, the rate of self-determination increased and
48 EOL discussion occurred earlier than in the era before the implementation of the LST-Act.

49

50 **Keywords:** end-of-life process, life-sustaining treatment, cancer, Physician orders for life-sustaining
51 treatment

52

53 **Background**

54 Despite recent advances in cancer treatment, cancer has become a leading cause of death worldwide.
55 In Korea, it has been the most common cause of death since 1990 and accounted for 27.5% of all deaths
56 in 2019 [1].

57 For cancer patients, especially those in the terminal stage, it is important that their personal values and
58 wishes for end-of-life (EOL) care are respected. EOL discussion may reduce aggressive medical care,
59 increase patient and family satisfaction with care, and improve quality of life and survival [2–4].
60 Advance care planning (ACP) refers to an ongoing process of discussion and review to help patients
61 and families reflect on their goals and values, and to document their preferences for care towards EOL.
62 In Western countries, it is accepted that patients should be involved in the process of making decisions
63 regarding EOL care [5], and patients can discuss the Physician Orders for Life-Sustaining Treatment
64 (POLST) and Advance Directives (AD) approaches to protect autonomy and dignity.

65 However, there are many taboos in Korea and other Asian countries regarding discussions on death
66 [6]. In Korea, EOL discussions were avoided or postponed, resulting in very late discussions taking
67 place only when the patient's death was imminent [7, 8]. Therefore, EOL discussions predominantly
68 occurred between physicians and family members as surrogate decision-makers, excluding patients [9–
69 11]. To advocate for the patients' wishes and to allow for self-determination in EOL care, the "Life-
70 Sustaining-Treatment Decision-Making Act (LST-Act)" for terminally ill patients came into effect in
71 February 2018 in Korea [12]. Since the implementation of the Act, patients have been able to decide
72 whether they want to apply or suspend life- sustaining treatment (LST) during the EOL process by
73 documenting POLST during the period when death is imminent with no possibility of recovery, and
74 there is a rapid worsening of symptoms despite treatment. Patients can address preferences for LST by
75 documenting POLST at the terminal stage or during the EOL process, and by documenting AD
76 regardless of their illness.

77 Before the implementation of the LST-Act, decisions for LST care were documented in the do-not-
78 resuscitate (DNR) order, which was not legally effective and may not have entirely reflected the patients'
79 decisions. Since the implementation of the LST-Act, it has become necessary to document POLST for

80 all patients who died in hospital. However, it is unclear whether the LST-Act influences EOL discussion
81 in terms of the rate of self-determination and timing of documentation of DNR or POLST.

82 Therefore, we conducted this study to investigate the changes in EOL discussion in advanced cancer
83 patients during the EOL process after the implementation of the LST-Act.

84

85 **Methods**

86 *Patients, study design, and data collection*

87 This was a single-center, retrospective study of cancer patients who died at the Ulsan University
88 Hospital between July 2015 and May 2020.

89 We assessed patients who had died during two separate periods: the period before the implementation
90 of the LST-Act (from July 2015 to October 2017, “Group 1”) and after the implementation of the LST-
91 Act (from February 2018 to May 2020, “Group 2”). The same inclusion and exclusion criteria were
92 applied to both groups. Cases were limited to patients with cancer at the primary site of head and neck,
93 esophagus, lung, breast, stomach, colorectal, hepatobiliary, and pancreas. We excluded patients with
94 hematologic malignancy, who were younger than 19 years old, or who passed away within two weeks
95 of their first visit to Ulsan University Hospital.

96 We obtained the two groups’ data from the following sources: the clinical data warehouse platform in
97 conjunction with the electronic medical records, Ulsan University Hospital Information of Clinical
98 Ecosystem, the patient characteristics, the type of document for LST (DNR or POLST), decision-
99 makers, date of documentation of DNR or POLST, date of hospice palliative care (HPC) referral, and
100 period between HPC referral and death.

101

102 *Definition and outcome measurements*

103 The ‘EOL process’ is when death is imminent with no possibility of recovery, and there is a rapid
104 deterioration of symptoms despite treatment. ‘Terminally ill patients’ are defined as those diagnosed
105 with cancer or other diseases who are expected to die within a few months, and have no possibility of
106 recovery from the underlying disease even with active treatment. ‘LST’ is defined by the LST-Act as

107 CPR, mechanical ventilation, renal replacement therapy, chemotherapy, and other medical procedures
108 that only extend the duration of the EOL process without any therapeutic effect.

109 Before the implementation of the LST-Act, the decisions for LST were documented with DNR, and
110 since the implementation of the LST-Act, LST has been decided on using POLST. According to the
111 LST-Act, three steps are required to withhold or withdraw LST in cancer patients during the EOL
112 process. First, two physicians should judge whether the patient is in the EOL process. Second, the
113 patient or patient's family members should express the patient's intentions regarding LST by
114 documentation of POLST. If the patient has the ability to make decisions, he/she should express his or
115 her own intentions by in-person documentation of POLST. When the patient is unable to make their
116 own decisions, family members express their intentions for LST on behalf of the patient based on
117 statements made by two or more family members. If it is impossible to verify the patient's intentions,
118 POLST can be documented through consensus with all adult members of the patient's family. The final
119 step is clarification of the execution form, describing which LST to withhold or withdraw, as
120 documented by a physician.

121 To investigate the changes in EOL discussion in advanced cancer patients during the EOL process, we
122 measured the changes between the two separate periods as follows: (1) the rates of patients' self-
123 determination in documentation of DNR or POLST; (2) the number of days since the date of
124 documentation of DNR or POLST; and (3) the rate of documentation of DNR or POLST within seven
125 days prior to death, reflecting late EOL discussion.

126

127 *Statistical analysis*

128 We examined between-group associations of demographic and clinical variables using Fisher's exact
129 test for categorical variables and an independent t-test for continuous variables.

130 The factors affecting surrogate decision-making and late EOL discussion (documentation of DNR or
131 POLST within seven days prior to death) were analyzed using logistic regression analysis. Statistical
132 analysis was performed using the Statistical Package for the Social Sciences (IBM, Armonk, NY, USA)
133 version 22.0. We considered a p-value of less than 0.05 to be statistically significant.

134

135

136 Results**137 *Patients' characteristics***

138 A total of 1,834 patients were included in this analysis: 943 from Group 1 and 891 from Group 2.

139 The rate of national health insurance cover was higher in Group 2 (95.7% vs. 93.3%, $p=0.018$), and
140 there was no significant difference between the two groups in terms of sex, mean age, primary tumor
141 site, years of education, and rates of receiving chemotherapy. The demographic and clinical
142 characteristics of the patients are summarized in Table 1.

143

144 *Documentation of DNR or POLST and decision-makers*

145 Table 2 presents the pattern of documentation of DNR or POLST in Groups 1 and 2. During the study
146 period, 713 (75.6%) patients in Group 1 documented DNR. In Group 2, 771 (86.5%) and 4 (0.01%)
147 patients documented POLST and DNR, respectively.

148 The rate of self-determination increased significantly in Group 2 (1.5% vs. 63.5%, $p<0.001$). The
149 timing of documentation of POLST or DNR prior to death was prolonged in Group 2 (mean, 14.4 days
150 vs. 21.2 days, $p=0.001$). The rate of late discussion, defined as documentation of DNR or POLST within
151 seven days of death, decreased significantly in Group 2 (46.6% vs. 41.4%, $p=0.027$).

152

153 *Referral to hospice palliative care*

154 The rate of referral to hospice palliative care (HPC) was 42.2% and 68.1% in Groups 1 and 2,
155 respectively ($p<0.001$). Among the referred patients, 35.4% and 54.7% provided consent for referral to
156 HPC in Groups 1 and 2, respectively ($p<0.001$).

157 The mean duration between HPC referral and death was 36.5 days and 46 days in Groups 1 and 2,
158 respectively ($p=0.035$) (Table 3).

159

160 *The factors associated with late discussion and surrogate decision-making*

161 The factors that were associated with inappropriate decision-making, late EOL discussion
162 (documentation of DNR or POLST within seven days prior to death), and surrogate decision-making
163 are presented in Table 4.

164 Female patients (odds ratio [OR] 0.80, 95% confidence interval [CI] 0.65-0.97, $p=0.024$) and patients
165 with 12 years of education or more (OR 0.71, 95% CI 0.53-0.84, $p=0.022$) were significantly less likely
166 to engage in late EOL discussion. When the physician in charge at the time of the patient's death had
167 less than three years of professional experience, the rate of late discussion significantly increased (OR
168 2.53, 95% CI 1.18-5.45, $p=0.019$).

169 Physicians with clinical experience of less than three years had a higher rate of making decisions with
170 the surrogate decision-makers than with the patients themselves (OR 5.1, 95% CI 1.18-22.1, $p=0.029$).
171 The self-determination rate was higher in patients who had 12 years of education or more (OR 0.68,
172 95% CI 0.419-0.96, $p=0.027$) and those who were referred to HPC (OR 0.25, 95% CI 0.20-0.33,
173 $p<0.001$).

174

175 **Discussion**

176 We found positive changes in EOL discussion in advanced cancer patients, such as increased self-
177 determination and earlier EOL discussion after the enforcement of the LST-Act.

178 In Korea, it is still difficult for physicians to talk about death with patients directly because of the
179 reluctance of family members and the family-centered culture in which families make important
180 decisions about a patient's care [13]. Physicians also have difficulty in delivering bad news directly to
181 patients and experience emotional discomfort when discussing EOL care [14]. Therefore, EOL
182 discussions are frequently delayed, and communication about a patient's condition occurs between
183 physicians and surrogate decision-makers when it deteriorates [8, 15]. In previous reports in Korea,
184 DNR directives were documented by surrogate decision-makers in almost all cases [9, 11]. However,
185 contrary to the expectations of physicians and family members, patients wanted to hear about their
186 condition directly from the physician [7]. With the aim of increasing patients' autonomy regarding the
187 right to make their own decisions about LST during the EOL process, the LST-Act came into full

188 effect in February 2018 in Korea. Since the LST-Act's implementation, the rate of self-determination
189 improved to reach 63.5% of our study population, which is a significant increase compared to 1.5%
190 before the implementation of the LST-Act. The self-determination rate in our study is comparable
191 with the rates of previous studies carried out in Western countries, ranging from 23% to 60% [16–18].
192 Our findings suggest that the LST-Act might promote patients' participation in EOL discussion.

193 The timing of decision-making regarding LST occurred earlier than before the LST-Act. The mean
194 time between documentation of DNR or POLST and death increased from 14.4 days to 21.2 days after
195 the implementation of the LST-Act. In a recent retrospective study from Korea, decision-making
196 occurred earlier than before the LST-Act's implementation, ranging from 17 to 33 days prior to the
197 patient's death [19]. In Korea, DNR directives were usually documented within a week prior to death,
198 which was too late to reflect patients' wishes for EOL care [8, 9]. Our results imply that the LST-Act
199 has had a positive effect on earlier EOL discussion.

200 In our study, the rate of HPC referral increased from 42.2% to 68.1% over the study period, and
201 the mean time between HPC referral and death increased from 36.5 days to 46.0 days. Findings from
202 previous studies showed that HPC referral was associated with a reduced frequency of aggressive
203 EOL treatment near death and earlier EOL discussion [19–22]. In multivariable analysis between
204 inappropriate EOL decision-making (late discussion or surrogate decision-making) and patient
205 characteristics, there was a significant decrease in surrogate decision-making in patients who were
206 referred to the HPC team (OR 0.25, $p < 0.001$). HPC consultation could promote earlier EOL
207 discussion, helping patients and family members to understand disease status and HPC options. HPC
208 referrals also help physicians feel less of an emotional burden when discussing EOL treatment.
209 Additionally, the rate of self-determination was high at 63.5% in our study population, compared to
210 the rate of 30% from other Korean analyses conducted at a similar time [19, 23]. This high rate of
211 self-determination could be interpreted as having been activated by the HPC referral system of Ulsan
212 University Hospital which offers inpatient HPC units and home hospice services. Increased HPC
213 referral might have had positive effects on promoting earlier EOL discussion and patient self-
214 determination in our study population.

215 Multivariable analysis between inappropriate EOL decision-making (late EOL discussion or
216 surrogate decision-making) and patient characteristics showed that female patients and patients with
217 more than 12 years of education were less likely to experience late EOL discussion, and HPC referral
218 was related to less surrogate decision-making. However, physicians with less than three years of
219 professional career experience were related to a higher rate of late EOL discussion and surrogate
220 decision-making. Physicians often receive insufficient training and lack confidence in EOL
221 communication with patients and family members [24]. In a previous study from Korea, medical
222 oncologists and residents stated that knowledge of the medical, legal, and ethical aspects and
223 communicational preparation were needed in broaching EOL discussion [25]. Previous studies have
224 shown that appropriate education and training improve EOL communication skills and ACP [26]. The
225 LST-Act has increased the documentation of POLST, but physicians are still struggling with EOL
226 discussion. Therefore, physicians need to be trained and supported to discuss EOL care, and programs
227 to integrate EOL conversations and ACP documentation are needed for implementation in routine
228 medical care.

229 Our study has several limitations. First, it is a study from a single institution, and the pattern of
230 EOL discussion and documentation of DNR or POLST might be different from those at other medical
231 institutions. Therefore, caution is needed to not generalize the study findings. Second, it was a
232 retrospective study, with information sources limited to medical records. Interpretation of data needs
233 to be cautious in causal relationships. Despite these limitations, to our knowledge, this is the first
234 study to compare the decision-making patterns before and after the LST-Act.

235

236 **Conclusions**

237 Our study showed that since the implementation of the LST-Act, the self-determination rate rose in
238 clinical practice and EOL discussion occurred earlier than in the era before the LST-Act. To encourage
239 EOL discussion between physicians and patients, more active interventions, including medical
240 education and training for EOL discussion and HPC referral, are needed to ensure that patients' goals
241 and values are better reflected in the EOL process.

242

243 **List of abbreviations**

244 EOL: End-of-life

245 ACP: Advance Care Planning

246 DNR: Do-not-resuscitate

247 POLST: Physician Orders for Life-Sustaining Treatment

248 AD: Advance Directives

249 LST: Life-sustaining treatment

250 LST-Act: Life-Sustaining Treatment Decision-Making Act

251 HPC: hospice palliative care

252

253 **Declarations**254 *Ethics approval and consent to participate*

255 The Institutional Review Board of Ulsan University Hospital approved the study protocol (2020-01-
256 018) and waived the need for informed consent for this study given the non-requirement of consent in
257 retrospective analyses covered by regulations in Korea. This study was performed in accordance with
258 the ethical standards of the institutional research and the Declaration of Helsinki.

259

260 *Consent for publication*

261 Not applicable.

262

263 *Availability of data and materials*

264 The datasets used and/or analyzed during the current study are available from the corresponding author
265 upon reasonable request.

266

267 *Competing interests*

268 The authors declare that they have no competing interests.

269

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272

273 ***Authors' contributions***

274 Study concepts: HK, JC, SK

275 Study design: HK, JC, SK

276 Data acquisition: All authors

277 Data analysis and interpretation: JC, HK, DK, CK

278 Statistical analysis: JC, DK, CK

279 Manuscript preparation: HK, JC, SK

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