

Original Article

Attitudes of the General Public, Cancer Patients, Family Caregivers, and Physicians Toward Advance Care Planning: A Nationwide Survey Before the Enforcement of the Life-Sustaining Treatment Decision-Making Act



Hye Yoon Park, MD, PhD, Young Ae Kim, PhD, Jin-Ah Sim, PhD, Jihye Lee, RN, Hyewon Ryu, MD, Jung Lim Lee, MD, PhD, Chi Hoon Maeng, MD, PhD, Jung Hye Kwon, MD, PhD, Yu Jung Kim, MD, PhD, Eun Mi Nam, MD, PhD, Hyun-Jeong Shim, MD, PhD, Eun-Kee Song, MD, PhD, Kyung Hae Jung, MD, PhD, Eun Joo Kang, MD, PhD, Jung Hun Kang, MD, PhD, and Young Ho Yun, MD, PhD

Department of Psychiatry (H.Y.P.), Seoul National University Hospital, Seoul; National Cancer Control Institute (Y.A.K.), National Cancer Center, Goyang; Department of Biomedical Science (J.-A.S., Y.H.Y.); Cancer Research Institute (J.-A.S., Y.H.Y.); Department of Biomedical Informatics (J.L.), Seoul National University College of Medicine, Seoul; Department of Internal Medicine (H.R.), Chungnam National University Hospital, Daejeon; Department of Hemato-oncology (J.L.L.), Daegu Fatima Hospital, Daegu; Department of Medical Oncology and Hematology (C.H.M.), Kyung Hee University Hospital, Seoul; Department of Internal Medicine (J.H.K.), Kangdong Sacred Heart Hospital, Hallym University College of Medicine, Seoul; Division of Hematology and Medical Oncology (Y.J.K.), Department of Internal Medicine, Seoul National University Bundang Hospital, Seongnam; Department of Internal Medicine (E.M.N.), Ewha Womans University College of Medicine, Seoul; Department of Hemato-Oncology (H.-J.S.), Chonnam National University Medical School, Gwangju; Department of Internal Medicine (E.-K.S.), Chonbuk National University Medical School, Jeonju; Department of Oncology (K.H.J.), Asan Medical Center, University of Ulsan College of Medicine, Seoul; Division of Hemato-Oncology (E.J.K.), Department of Internal Medicine, Korea University College of Medicine, Korea University Guro Hospital, Seoul; Department of Internal Medicine (J.H.K.), Postgraduate Medical School, Gyeongsang National University, Jinju; Department of Family Medicine (Y.H.Y.), Seoul National University College of Medicine, Seoul; and Institute of Health Policy and Management (Y.H.Y.), Seoul National University, Seoul, Seoul, Republic of Korea

Abstract

Context. To respect a patient's wish for end-of-life care, "the Act on Decisions on Life-Sustaining Treatment for Patients at the End-of-Life" was enacted in South Korea in 2016. Current understanding of people who would be involved in advance care planning (ACP) is crucial to disseminate it systematically.

Objectives. The objective of this study was to investigate awareness and attitudes toward ACP in South Korea.

Methods. A multicenter, nationwide cross-sectional study was conducted a survey regarding ACP among four groups that would have different positions and experiences: 1,001 cancer patients, 1,006 family caregivers, 928 physicians, and 1,005 members of the general public.

Results. A total of 16% of the general population, 33% of the patients and caregivers, and 61% of the physicians had knowledge of advance directives. More than 63% of the general population, above 72% of the patients and caregivers, and 97% of the physicians were willing to do so when the disease status was aggravated or terminal. The possibility for changing the plan, uncertainty as to whether directives would actually be followed, and psychological discomfort were common reasons for not wanting to engage in ACP. Routine recommendations for a specific medical condition, heightened accessibility, and health insurance support were common factors that could help facilitate ACP.

Conclusion. Our findings suggest that strategies for promoting ACP should reflect different perspectives among the general public, patients, family caregivers, and physicians. Public advocacy, resources for approaching and integrating ACP into routine health care, as well as systematic support provisions are needed. *J Pain Symptom Manage* 2019;57:774–782.

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H.Y.P. and Y.A.K. contributed equally to this work.
Address correspondence to: Young Ho Yun, MD, PhD, Department of Family Medicine, Seoul National University College

of Medicine, 103 Daehak-ro, Jongno-gu, Seoul 03080, Republic of Korea. E-mail: lawyun@snu.ac.kr

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Key Words

Advance care planning, advance directives, decision-making, life support care, terminal care

Introduction

In South Korea, end-of-life care discussions tend to occur when an individual is rapidly approaching death, and most patients are excluded from these discussions.¹ Although many patients do not wish to undergo aggressive treatment during the terminal phase of an illness,² 86.6% of terminal cancer patients were hospitalized during their end-of-life period in 2010.³ By contrast, utilization of palliative care is very low: 17.5% among patients with cancer and 4.9% of total nationwide deaths in 2016.⁴ A tertiary university hospital survey reported that end-of-life cancer treatment has become more aggressive over a recent 10-year period; 19.9% in 2012 received intensive care during the last month of life compared to only 1.8% in 2002. Furthermore, the time from last chemotherapy treatment to death has shortened from 66 days to 34 days.⁵

To enhance a patient's involvement in making decisions, along with respecting a patient's end-of-life wishes, the Act on Decisions on Life-Sustaining Treatment for Patients at the End-of-Life was enacted in South Korea in 2016.⁶ The act permits withdrawing or withholding life-sustaining treatment among patients during the terminal phase of their disease. Furthermore, the act introduced advance directives and physician orders for life-sustaining treatment (POLST) as specific legal forms of advance care planning (ACP).

Significant changes have been anticipated in communication about end-of-life care following the act.⁷ It emphasizes patients to play a central role in ACP.⁸ However, having patients directly involved in ACP for end-of-life care is still unusual.⁹ Family members typically write do-not-resuscitate orders within several days before death in Korea.^{1,10} Furthermore, discrepancies in attitudes among patients, family caregivers, and physicians toward ACP is a common barrier to communicating appropriate end-of-life care.^{11–13}

The goal of the present study was to investigate awareness and attitudes regarding advance directives and POLST among the general public, cancer patients and their family caregivers, and physicians to better advocate for ACP.

Methods

Design and Participants

A nationwide, multicenter cross-sectional study was conducted between July and October 2016. Detailed design and selection procedures are described in

our prior report.¹⁴ Participants comprised four groups that were recruited using the following three distinct procedures: the general population was recruited via a telephone survey, cancer patients and family caregivers were recruited from 12 large hospitals (11 general hospitals and Korea's National Cancer Center, which cover the capital, five major provinces, and three metropolitan cities) via a face-to-face survey, and physicians from the same hospitals and the Korean Medical Association (KMA) were recruited via an online survey. Our goal was to recruit about 1000 respondents in each group.

General Population

First, the survey of the general population aged 20–70 years and resided over 17 major cities and local districts was conducted by the research staff of World Research, Inc., in Korea. At each of the major cities and local districts, participants were recruited using two strata (age and sex) following the 2015 Census of Korea. We used a probability-proportional-to-size technique for sample selection to represent a nationwide sample.¹⁵ Expecting a 10% response rate, we contacted approximately 10,000 individuals from 17 major cities and local districts. Finally, 1,005 of those agreed to respond to the survey on the phone.

Patients and Family Caregivers

Second, cancer patients and their family were surveyed at their outpatient clinic of 12 hospitals. Oncologists, who were coresearchers in this study, were asked to identify patients with cancer. Then, patients and family caregivers were eligible if their age was at least 18 years, understood the purpose of the study, could communicate well with research assistants and complete the questionnaire, and consented to participate in this study. One thousand one patients completed the survey of 6024 who were contacted (16.6% response rate). One thousand six caregivers were included among 5017 who were contacted (20.1% response rate).

Physicians

Third, physicians were recruited online, from the 12 participating hospitals and KMA. We sent them an e-mail that included an explanation of the study and the URL for the survey. Nine hundred twenty-eight physicians completed the survey and the response rate was 30%.

The study was approved by the Institutional Review Board of each hospital (reference number

E-1612-102-815; 22 July 2016). Informed consent was obtained from patients and family caregivers, and the IRB waived the requirement for informed consent from the general population and the physician group. We conducted the study according to the principles of the Declaration of Helsinki.

Measurements

A structured questionnaire was developed to investigate participants' awareness and attitudes concerning ACP by researchers based on the literature review and the act on life-sustaining treatment decision-making in Korea. It contained 1) awareness of ACP, 2) willingness to conduct ACP, 3) a suitable timing to write an advance directive, 4) strategies to facilitate ACP, 5) sociodemographic variables (age, sex, education level, job status, religion, income, and the type of health insurance).

Advance Directives and POLST Awareness

First, the survey provided participants with an explanation about advance directives and POLST, defined as follows by the new act¹⁶: "Advance directives is a statement that an adult could write about determination of life-sustaining treatment and utilization of hospice at a terminal stage. Whoever they are legally adults can write an advance directive without doctor at a designated registration agency. These statements would be used in decision-making regarding life-sustaining treatment and hospice care when they would be at a terminal stage in the future. POLST is a specific treatment plan which a doctor in charge can write regarding life-sustaining treatment and hospice care according to a patient's opinion at a terminal stage or dying phase. A doctor in charge shall explain a patient the following matters and write a POLST: the disease status and the methods of treatment, prognosis, the methods of life-sustaining treatment (CPR, mechanical ventilation, hemodialysis, chemotherapy, etc.) and termination of it, selection and use of hospice." The survey subsequently explored participants' awareness through the following questions: "Have you heard about an advance directive before this survey?" and "Have you heard about a POLST before this survey?"

Willingness to Conduct ACP

The survey asked about willingness to write an advance directive or POLST across different disease stages and types (i.e., healthy condition, upon diagnosis of a serious illness, upon aggravation of the illness, when the terminal stage is unpredictable [e.g., chronic obstructive pulmonary disease, liver cirrhosis], when the terminal stage is predictable [e.g., cancer], and during the actual terminal stage [e.g., when survival is expected to be no longer than

a few months]), with four responses (strongly agree, agree, disagree, strongly disagree). If subjects answered "disagree" to the aforementioned item, they were asked to choose from the following reasons for their unwillingness to begin ACP: 1) I feel psychologically anxious or uncomfortable about preparing for worsening health problems, 2) I think I will change my mind when I face the situation in the future, even if I make a decision now, 3) I am not sure if things will be handled per my wishes, as reflected in the advance directives, 4) I am sure that my family will make a wise decision when I am unable to do so, 5) I don't know much about advance directives or POLST, 6) It feels like a hassle to prepare for a future occasion in advance, 7) I don't personally know anybody who is establishing plans, 8) other. These items were constructed based on the literature review^{11,17} and the designated process for ACP by the corresponding act in Korea.

A Suitable Timing for Writing an Advance Directive

The survey asked about when it would be appropriate for writing an advance directive. The following response options were provided based on the literature review^{18,19} and the health care system in Korea: 1) before all operations and treatment bearing a risk of death, 2) visiting wards and emergency rooms of patients with specific severe diseases, 3) visiting wards and emergency rooms of every older patient aged 65–70 years and above, 4) visiting wards and emergency rooms of all patients, 5) other (health checkup and after all treatments).

Strategies for Facilitating ACP

We asked about what would be needed to facilitate ACP. The following response options were provided based on the literature review^{20–22} and the designated process for ACP according to the new act: 1) large-scale public outreach and education for ACP, 2) developing an online program that supports ACP, 3) establishing administrative organizations responsible for ACP registration, 4) assigning medical coverage related to ACP, 5) reviewing and recommending advance directives when patients are admitted to a hospital or an emergency room, 6) forming a culture that stimulates open conversations about death with families and friends.

Statistical Analyses

A frequency analysis was conducted to assess distributions of age, gender, education, employment status, area of residence, monthly income, and the type of health insurance. The age of the physician group tended to be relatively lower because accessibility of the online survey could be affected by age. To improve the generalizability of the present results, we weighted

data from the physician group using the sex and age distribution of the physician population based on KMA statistics.²³ Cross tabulations were conducted to assess awareness of advance directives and POLST, suitable periods for preparing ACP documents, and ranking reasons for not engaging in ACP. Indicator variables were applied for independent categorical variables. A multivariate logistic regression analysis, which corrected for gender, age, education, religion, and income, was conducted to examine which group was more likely to engage in advance directives and POLST activities. Significance level was set to $P < 0.05$, and SAS version 9.1 (SAS Institute, Cary, NC) was used for all analyses.

Results

Sociodemographic characteristics for the 3,940 participants analyzed are described in Table 1. Cancer patients were older and were less likely to be employed than participants in other groups. The patient group exhibited the following distribution in terms of cancer stage: Stage I $n = 148$ (14.8%), Stage II $n = 303$ (30.3%), Stage III $n = 325$ (32.5%), and Stage IV $n = 157$ (15.7%). Physicians were younger, were more educated, and had a higher monthly income than the other groups.

Advance Directives and POLST Awareness

Awareness of advance directives and POLST differed across the four groups. Although only 16.1% of the general population knew about advance directives, one-third of cancer patients and family caregivers were aware (Table 2). The awareness rate was highest among physicians (61.4%, adjusted odds ratio = 8.66, 95%CI, 6.70–11.19). The proportion of those aware of POLST was relatively lower than advance directives across all groups: 10.2% of the general population, 25% of patients and family caregivers, and 50% of physicians.

Willingness to Conduct ACP

Willingness to engage in ACP activities differed between the four groups. The rate was lowest within the general population, with physicians reporting the highest (Fig. 1). Interestingly, the distribution of willingness rates across all groups was dependent on disease status. Among general population respondents, rates were 46.5% when healthy, 56.5% when diagnosed with a serious disease, 63.6% when the disease state was aggravated, and 68.3% when the status was terminal. In the physician group, rates were 63.6% when healthy but over 97% when disease status was aggravated, expected to be terminal, and actually terminal. Willingness among cancer patients and

Table 1
Descriptive Characteristics of the Study Population

	General Population <i>n</i> = 1005	Cancer Patients <i>n</i> = 1001	Family Caregivers <i>n</i> = 1006	Physicians (Unweighted) <i>n</i> = 928	Physicians (Weighted) <i>n</i> = 928
	Percentage (%) With Number				
Sex					
Male	49.2 (494)	39.0 (390)	32.2 (324)	60.9 (565)	76.2 (707)
Female	50.8 (511)	60.9 (610)	67.8 (682)	39.2 (363)	23.8 (220)
Age, yrs					
<40	36.4 (366)	12.3 (123)	29.1 (292)	66.0 (612)	16.3 (312)
40–49	20.8 (209)	21.1 (211)	30.2 (304)	23.9 (222)	36.9 (343)
≥50	42.8 (430)	66.6 (666)	40.7 (409)	10.1 (94)	29.5 (274)
Education					
Middle school or less	15.2 (152)	20.6 (205)	7.5 (75)	0 (0)	0 (0)
High school	46.0 (461)	44.2 (440)	42.0 (423)	0 (0)	0 (0)
College or higher	17.8 (388)	35.2 (351)	50.5 (508)	100 (928)	100 (928)
Job status					
No	38.4 (386)	73.9 (737)	56.6 (569)	0 (0)	0 (0)
Yes	61.6 (619)	26.1 (260)	43.4 (437)	100 (928)	100 (928)
Religion					
No	58.2 (585)	46.3 (462)	49.1 (494)	41.6 (386)	37.7 (350)
Yes	41.8 (420)	53.7 (536)	50.9 (512)	58.4 (542)	62.3 (578)
Monthly income, in 1000 Korean won					
<2000	11.9 (119)	26.4 (260)	11.7 (117)	0 (0)	0 (0)
2000–2999	16.3 (162)	19.9 (196)	18.4 (183)	0 (0)	0 (0)
3000–3999	30.2 (301)	22.0 (217)	26.1 (260)	0 (0)	0 (0)
≥4000	41.6 (415)	31.7 (313)	43.8 (436)	100 (928)	100 (928)
Health Insurance					
National Health Insurance	97.4 (979)	93.0 (931)	93.54 (941)	100 (928)	100 (928)
Medicaid	2.6 (26)	5.3 (53)	2.5 (25)	0 (0)	0 (0)
National Health Insurance and Medicaid	0 (0)	1.6 (16)	3.8 (38)	0 (0)	0 (0)

Table 2
Awareness of Advance Directives and POLST^a

	General Population	Cancer Patients	Family Caregivers	Physicians
Advance Directives				
Yes (%)	162 (16.1)	338 (33.8)	334 (33.2)	570 (61.4)
OR (95%)	1	2.65 (2.14–3.28)	2.59 (2.09–3.20)	8.29 (6.69–10.26)
aOR (95%)	1	2.50 (2.00–3.13)	2.39 (1.92–2.98)	8.66 (6.70–11.19)
POLST				
Yes (%)	102 (10.2)	262 (26.2)	254 (25.3)	456 (49.1)
OR (95%)	1	3.14 (2.45–4.02)	2.99 (2.33–3.84)	8.55 (6.72–10.89)
aOR (95%)	1	2.99 (2.31–3.88)	2.80 (2.17–3.61)	8.69 (6.53–11.57)

POLST = physician’s order of life-sustaining treatment.

^aAdjusted for sex, age, education, religion, income.

family caregivers were in the middle of the two extreme groups.

Reasons for not wanting to write an advance directive or POLST were similar across groups (Table 3). The most common reason was the possibility of the patient changing his/her mind when actually faced with the reality of the situation. The second most common reason was the psychological discomfort produced when thinking about a terminal illness. The third most common reason was uncertainty regarding whether patients’ decisions would be respected when the time came.

A Suitable Timing for Writing an Advance Directive

Participants across all four groups reported that suitable times for writing an advance directive were before all procedures or interventions with a high mortality risk, when the patient was frequently

hospitalized, and when the patient was over the age of 65–70 years when recently admitted to the hospital (Table 4).

Strategies for Facilitating ACP

All groups stated that public promotion efforts and education regarding ACP were the most important means for facilitating ACP (Table 5). Online programs and setting up offices where an advance directive could be registered were also commonly reported among the general population, patients, and family caregivers. By contrast, providing payment for ACP through national medical insurance was the second most important method (26.4%) among the physician group. Physicians also reported that a change to the culture in which people could feel more comfortable openly discussing death with their family or friends would be helpful (19.1%).

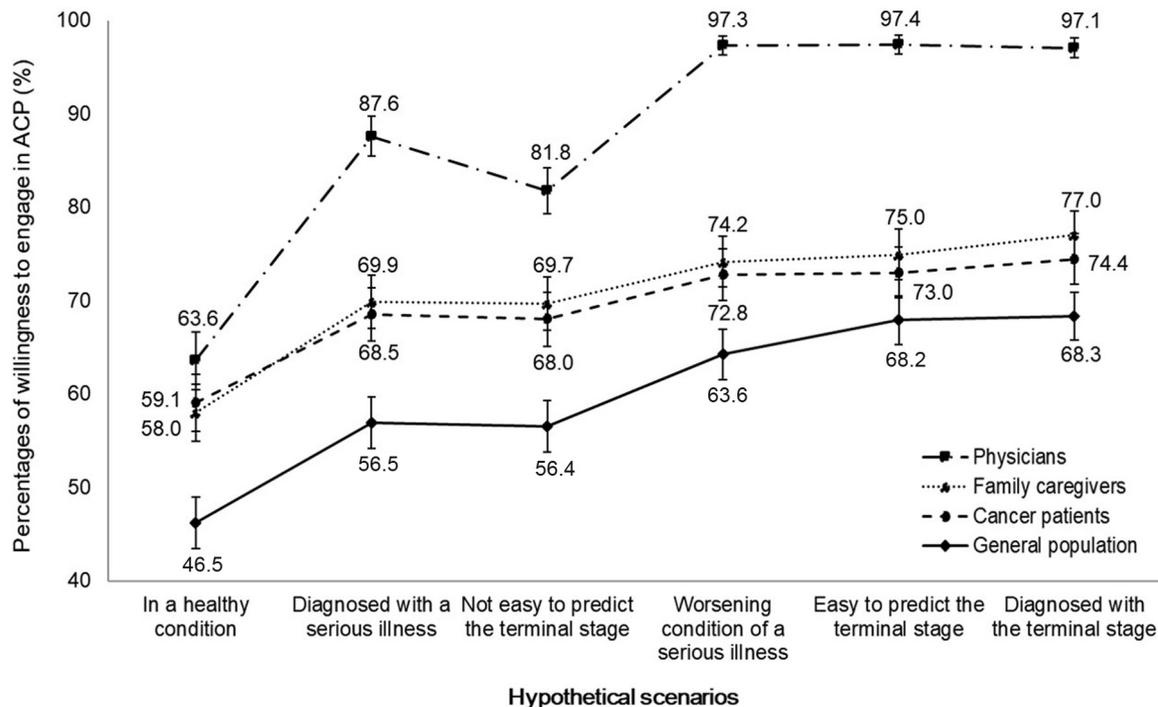


Fig. 1. Willingness to engage in advance care planning. ACP = advance care planning.

Table 3
Reasons for Lacking the Intention to Prepare an Advance Directive or POLST

Reasons	General Population		Cancer Patients		Family Caregivers		Physicians	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
I feel psychologically anxious or uncomfortable about preparing for worsening health problems.	216	30.5	131	22.2	134	23.1	69	16.8
I think I will change my mind when I face the situation in the future, even if I make a decision now.	147	20.8	132	22.4	139	24.0	158	38.4
I am not sure if things will be handled per my wishes, as reflected in the advance directives.	96	13.6	124	21.0	120	20.7	73	17.8
I am sure that my family will make a wise decision when I am unable to do so.	85	12.0	69	11.7	90	15.5	16	3.9
I don't know much about advance directives or POLST.	78	11.0	79	13.4	47	8.1	34	8.3
It feels like a hassle to prepare for a future occasion in advance.	53	7.5	31	5.3	36	6.2	33	8.0
I don't personally know anybody who is establishing plans.	33	4.6	24	4.1	13	2.2	10	2.4
Other	0	0.0	0	0.0	0	0.0	18	4.4

POLST = physician's order of life-sustaining treatment.

Discussion

Main Findings/Results of the Study

The present study addressed the current understanding and attitudes regarding ACP among different participant samples before enforcement of the first Korean legislative act regarding life-sustaining treatment. Although the law was enacted in 2016, the general public's awareness of ACP was below one-fifth. Half of the physicians, who are expected to initiate ACP, did not know about the law. When adjusting for gender, education, religion, and income, doctors had the highest level of knowledge, followed by patients and their families. This level of awareness is similar to what has been observed in China and Hong Kong.^{24,25}

Although willingness to perform ACP differed across the groups sampled, at least more than half of the participants even in nonphysician group were willing to do it in most hypothetical scenarios in

contrast with their low awareness of ACP. The gap between the awareness and the willingness rate even at a healthy condition were around 30% in nonphysician group. Furthermore, the willingness rates were different in accordance with the disease status or its prognosis. The closer the participants were to making a decision in real situation, the more willing they were to engage in ACP. These findings would be reflective of certain barriers participants reported to engaging ACP procedures. People were concerned about their plans needing to be changed if actually faced with the decision and whether family members and physicians would actually follow through with directives if the patient became incapacitated. These are critical issues, especially when writing an advance directive.²⁶ Given that understanding a person's own illness and prognosis will affect his or her decisions, preferences toward LST during a hypothetical situation likely differ significantly from when actually experiencing a

Table 4
The Most Suitable Timing for Writing an Advance Directive

Conditions	General Population		Cancer Patients		Family Caregivers		Physicians	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Prior to all operations and treatment bearing a risk of death	542	32.6	498	29.9	442	27.9	489	29.3
Visiting wards and emergency rooms of patients with specific severe diseases	430	25.9	406	24.4	399	25.2	728	43.6
Visiting wards and emergency rooms of every older patient aged 65–70 years and above	342	20.6	333	20.0	326	20.6	240	14.4
Visiting wards and emergency rooms of all patients	236	14.2	213	12.8	203	12.8	100	6.0
Other (health checkup and after all treatments)	113	6.8	213	12.8	213	13.5	113	6.8
Total	1663	100.0	1663	100.0	1583	100.0	1670	100.0

Table 5
Strategies for Facilitating ACP

Strategies	General Population		Cancer Patients		Family Caregivers		Physicians	
	n	%	n	%	n	%	n	%
Large scale public outreach and education for ACP	359	35.7	398	39.8	390	38.8	344	37.1
Developing an online program that supports ACP	191	19.0	140	14.0	161	16.0	49	5.3
Establishing administrative organizations responsible for ACP registration	191	19.0	177	17.7	172	17.1	66	7.1
Assigning medical coverage related to ACP	142	14.1	135	13.5	147	14.6	245	26.4
Reviewing and recommending advance directives when patients are admitted to a hospital or an emergency room	65	6.5	87	8.7	72	7.2	47	5.1
Forming a culture that stimulates open conversations about death with families and friends	57	5.7	62	6.2	62	6.4	177	19.1
Total	1005	100.0	999	100.0	1006	100.0	928	100.0

ACP = advance care planning.

serious medical condition. Considering this limitation, we should disclose that ACP is a process rather than a documentation event.^{27,28} Thinking ahead to one's own deteriorated health status, a discussion of values and preferences with family members and/or health care providers in terms of clarifying care goals is essential to ACP. Even if final documentation is not achieved, the process can be helpful. Furthermore, engaging family caregivers in the discussion should lead to better adherence to a patient's wishes.^{29,30} It is also important to notify the public that written documents can be modified at any time. In addition, given that psychological discomfort is a significant barrier to writing an advance directive, cultural shifts may be necessary to encourage individuals to more comfortably discuss prospects of health decline and death.²⁸

The present results also suggest that strategies for facilitating ACP are possible at different levels, and the priority could differ in accordance with the role that people would play in advance care planning. For instance, at the community level, accessibility can be an essential factor for general people and patients who would write an advance directive. Implementation of online programs and a nationwide designation of registry offices could help increase ACP access.^{31,32} At the hospital level, our findings suggest that approaching patients at high risk of deterioration or death (e.g., when considering a risky intervention, or a poor prognosis is expected) could be acceptable. For integrating ACP into routine health care procedures at a hospital, we should develop proactive and effective methods for initiating discussions at the appropriate time.¹⁸ Furthermore, a cultural reluctance to discuss death or serious medical conditions is still a big barrier for physicians whom should be tasked with initiating ACP within clinical settings.²⁹ To change this culture, public involvement, including governments, media, and civic institutions, may be critical.²⁸

Strengths and Weaknesses/Limitations of the Study

A few study limitations should be noted. As the patient sample only included those with cancer, a generalization of our findings to other patient samples should be taken with caution. However, cancer patients would be one of the major groups in ACP discussions, so their attitudes can be meaningful to develop the policy. Also, as our study focused on hypothetical scenarios, attitudes and behaviors when actually faced with a real situation could be different.³⁰ Investigating the fulfillment of ACP and final decisions regarding end-of-life care after full enforcement of the act is needed. Finally, the Korean health care system and policy regarding ACP could have an effect on our results, indicating a need to follow up these assessments in other cultural contexts.³³

Despite this limitation, the current situation to try nationwide dissemination of ACP led by the law in Korea could be a useful example of developing policy to promote ACP in other countries. The subsequent years after the enactment of the act on life-sustaining treatment decision-making will be a critical period for implementing and disseminating ACP provisions following the government's policy. This study provides the current understanding and concerns for the major distinct parties most affected by ACP initiatives by a large-scale quantitative survey.

Conclusion

The findings indicated that many of the general public, patients, and their families are willing to start conversations regarding their end-of-life care despite a cultural barrier about talking about death. If ACP discussions are provided by easy methods to access at the acceptable timing, we might initiate it with less burden than expected. In addition, the different priorities in facilitating strategies among the groups suggest that supports fitting into each group's role and

settings should be needed when promoting ACP. Such strategies could include public education to increase awareness and readiness, available methods for carrying out ACP decisions, implementation of ACP during routine clinical practice, and support from the greater health care system. Further studies are required to develop these detailed strategies.

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