



Korean Medical Professionals' Attitudes and Experiences on Advance Care Planning for Noncancerous Disease

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Background: Advance care planning (ACP) allows patients to declare their preferences for life-sustaining and hospice palliative care. However, the perception of ACP remains low in Korea. The present study assessed the attitudes and status of medical professionals in relation to end-of-life care decisions in older and noncancerous patients. **Methods:** This descriptive correlation study was performed to understand the attitudes regarding and status of ACP and advance directives (AD). For this purpose, we conducted a survey of members who attended the Spring Conference of the Korean Geriatrics Society in May 2015 using a questionnaire that included questions on experiences related to AD, opinions on disturbance factors and improvement measures, and questions about the status of their medical institutions. **Results:** All of 181 respondents were doctors. Among the respondents, 21.7% had the experience of treating patients who had completed an AD. Medical professionals saw AD use as appropriate for terminal patients with less than 6 months of life expectancy, as well as those with degenerative neurological disorders such as amyotrophic lateral sclerosis, chronic diseases such as chronic renal disease, and early stages of Alzheimer's disease. **Conclusion:** The results showed that geriatrics medical professionals agreed with the necessity for AD in noncancerous terminal diseases and that consideration of a family-centered decision-making culture, legal protection for medical professionals, and education of the general public and medical professionals will be helpful for the popularization of AD. (*Ann Geriatr Med Res* 2019;23:63-70)

Key Words: Advance directives, Aged, Attitude of health personnel, Life-sustaining medicine, Noncancerous disease

INTRODUCTION

Since the 1997 "Boramae Case" in Korea that applied accessory to murder to medical professionals who stopped life-sustaining treatment¹⁾ and the "Grandma Kim Case" in 2009 that first recognized the termination of life-sustaining treatment,²⁾ social discussion about the self-determination rights of patients regarding terminal-stage medical care has increased. Therefore, the need to complete physician orders for life-sustaining treatment (POLST) or advance directives (AD) to guarantee patients' self-determination has been suggested.³⁾ As a result, the "Hospice, Palliative Care, and Life-Sustaining Treatment Decision-Making Act" (hereafter referred to as "Life-Sustaining Treatment Decision-Making Act") was established in February 2016. This policy was first enacted in August 2017

and was adopted in all medical institutions on February 4, 2018.

Life-sustaining treatment refers to cardiopulmonary resuscitation, blood dialysis, anti-cancer drug administration, and use of ventilators in patients who are unlikely to recover. This can be seen as extending the end-of-life process through medical procedures such as equipment or medications without treatment effects. The "Life-Sustaining Treatment Decision-Making Act" enables patients to indicate their decision to defer or terminate life-sustaining treatment through POLST. Upon the determination of terminal stage or end-of-life status, the physician (doctor) prepares a POLST at the request of the patient. This is a sign that life-sustaining treatment will not be performed. POLST takes over when a patient cannot express his or her opinion due to conditions such as unconsciousness.

AD refers to a document that the patient defines *a priori* after receiving sufficient medical information from the medical staff when the patient has decision-making ability about the medical action they will receive.⁴⁾ This document generally comprises treatment and proxy directives. The treatment directive describes the types of treatment desired by the patient, while the proxy directive is the designation of the individual who will make decisions once the patient loses decision-making abilities. Through AD, the patient can indicate their preferences about and document life-sustaining treatments and hospice palliative care.

While discussions about terminal-stage medical care have generally been limited to terminal-stage cancer patients, the “Life-Sustaining Treatment Decision-Making Act” has expanded their scope to include non-cancer terminal-stage patients including those with AIDS, chronic obstructive pulmonary disease, and liver cirrhosis. As the cause of death from geriatric diseases increases with aging population, both cancer and noncancerous chronic diseases are important targets of palliative care. Due to the long disease duration of noncancerous chronic illnesses in older individuals,⁵⁾ a palliative care approach, rather than medical service such as hospitalization as in the case of cancer, is important. For this, it is necessary to deal with AD from the beginning of treatment.⁶⁾ In particular, problems with unclear prognosis, cognitive function, and various clinical situations in older people require different approaches from those applied in terminal cancer patients.

The present study investigated medical professionals specializing in geriatric illnesses to examine their perceptions of terminal-stage medical care and to explore their opinions about the popularization of AD. As previous studies have been limited to terminal-stage cancer and there remains insufficient research on older adults with chronic diseases other than terminal-stage cancer, we focused on non-cancer chronic diseases other than terminal-stage cancer.

MATERIALS AND METHODS

The present descriptive correlation study examined the attitudes and the status of Advance Care Planning (ACP) among medical professionals.

Research Participants

The study was conducted among medical professionals attending the 55th Spring Conference of the Korean Geriatrics Society. Those who understood the purpose of the study and agreed to participate were selected and there were no particular exclusion criteria. Because the status was assessed descriptively with a cross-sectional analysis for the investigation of perception, a specific sample size calculation was not necessary. The study was approved by the institutional review board (IRB) at Seoul National University Hospital (IRB No. 1504-107-666).

Data Collection Method

To collect data for this study, we explained the purpose of research, obtained consent, and distributed surveys in two sessions assigned across two days of the conference on May 30 and 31, 2015. The questionnaires were self-reported and a researcher provided help if necessary.

Research Tool

This study developed and applied a questionnaire to investigate the perception of medical professionals.⁷⁻¹⁰⁾ The questionnaire contained a total of 31 items that could be broadly categorized into AD-related experiences, opinions about hindering factors and opportunities for improvement, questions about the current status of the affiliated medical institution, and questions related to the respondent. For assessment of AD-related experiences, we asked whether the participants had experienced treating patients who had completed an AD, how much the AD was followed if it was completed, the reasons for not following the AD, and whether the treatment plan had been changed due to the AD; whether the timing or frequency of conversations with patients or caretakers increased after confirming the AD, what proportion of AD discussions occurred when treating terminal-stage patients, who brought up the topic of discussion, and the reasons that the discussion was not brought up; and whether the participant had experienced receiving a Do Not Resuscitate (DNR) from the caretaker and the reasons for the DNR. For opinions about AD, we asked whether the participants agreed with the popularization of AD, the reason for their agreement or disagreement, in which cases the AD should be considered, whether the participant believed that the AD discussion was the role of a medical professional, what is important for a respectable death, and the ideal location for end-of-life and the reasons for this belief. Regarding the current status of their affiliated medical institutions, we asked participants whether terminal patient care guidelines were in place at their institution, when they had been or were planned to be introduced, and the reasons for no plan for their introduction; whether there was an AD guideline in the institution, when it was introduced, when it was used, who it was used for, and whether there was plan for its introduction if it was not yet in use; whether job training had been provided for terminal patient care; and what methods existed for activation. Among questions related to the respondent, we asked whether they had completed their own AD or whether someone in their family had completed it; if the respondent had experience with AD training; the respondent's gender, birth year, and religion; and the type of affiliated medical institution.

Data Analysis

From the collected data, the general characteristics of the respondents, their frequencies of following AD, the level of agreement according to disease, the level of agreement

to terminate palliative care according to the situation, the reasons for not discussing AD, the reasons for agreeing or disagreeing with the AD, and the methods for AD popularization were determined by analyzing the frequencies and proportions (percentages). STATA version 14.1 (STATA Corp., College Station, TX, USA) was used to perform the analyses.

RESULTS

General Participants Characteristics

The general characteristics of participants are listed in Table 1. The average age was 46.9 years and 70.2% were men. All 181 respondents indicated that they were doctors. The types of affiliated institutions were convalescent hospitals (78, 43.1%), university hospitals (52, 28.7%), general hospitals excluding university hospitals (21, 11.6%), primary clinics (20, 11.1%), and public health centers and others (10, 5.5%).

Experiences with AD

Most of the respondents lacked experience with AD; 7.2% responded that they had completed an AD, while 6.7% responded that someone in their family had completed it. Only 16.6% had experienced AD-related training in their medical education.

Of the 21.7% of respondents with experience treating patients who had completed an AD, the majority (66.7%) followed most of the AD content in patient treatment decision-making (Fig. 1). The reasons for not following the AD included family opposition (38.5%), AD content that did not fit the medical situation at that time (35.9%), and the possibility of disease recovery (30.8%). The majority (62.5%) of those who responded that they had experienced treating patients who had completed an AD reported

changing the treatment plan due to the AD. An increased frequency of conversations with patients and caretakers was reported by 56.3% of respondents with experience with AD.

In response to the question asking whether participants discussed AD when treating terminal patients, 31.3% reported that they did not, 36.9% responded that they did so less in than 50% of cases, and 31.9% responded that they discussed AD in at least 50% of cases. The doctors most commonly initiated the discussion (44.2%), followed by caretakers (29.3%) and patients (13.8%). The reasons for not initiating discussions about AD included, "I'm afraid if I do not discuss it with my family, I will have a legal problem later" (60.2%), "The patient may feel depressed by feeling hopeless" (57.5%), "The patient will interpret this discussion as giving up on treatment" (55.8%), and "I believe that the caretaker has the right to determine the treatment direction of the patient" (50.3%) (Table 2).

Among participants, 85.1% reported that they receive a DNR from caretakers, rather than from patients themselves. The reasons included a lack of patient decision-making ability (76.2%), worry about future legal problems (49.7%), consideration of the patient's psychological pain (45.8%), respecting the role of the caretaker in making treatment decisions (35.9%), the possibility that patient will view it as giving up on treatment (30.9%), emotional pressure about asking the patient (23.8%), family opposition about receiving it from the patient (21.5%), and insufficient rapport with the patient (13.3%).

Opinions about AD

When asked if they agreed or disagreed with AD considering the environment in Korea, 87.2% of the participants agreed and 10.6% disagreed. The reasons for agreement (multiple selection), included "It is important to have patients who may lose their ability to make decisions to determine their treatment plan" (49.7% of all respondents),

Table 1. Participant characteristics (n=181)

Variable	Value
Age (y)	46.9±12.4
Gender	
Men	127 (70.2)
Women	54 (29.8)
Religion	
Protestantism	48 (26.5)
Catholicism	45 (24.9)
Buddhism	19 (10.5)
Others	1 (0.6)
None	68 (37.6)
Affiliation	
Primary clinic	20 (11.1)
Convalescent hospital	78 (43.1)
University hospital	52 (28.7)
General hospital	21 (11.6)
Public health center, others	10 (5.5)

Values are presented as mean±standard deviation or number (%). Total percentages may not equal 100% due to rounding.

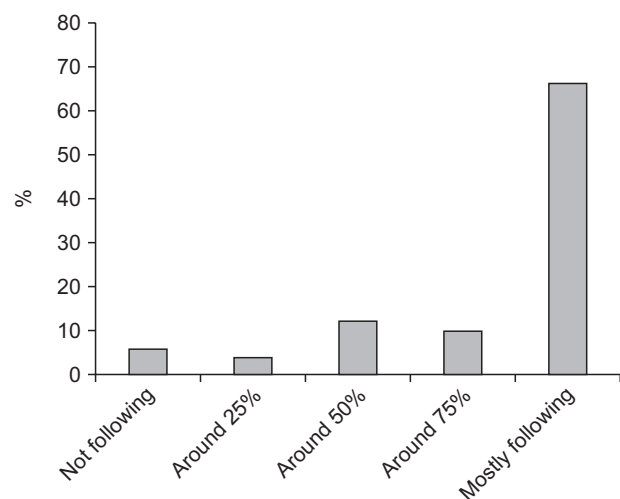


Fig. 1. Frequency of following advance directives when it is prepared.

Table 2. Reasons for not initiating discussions about advance directives (multiple responses)

Reasons	Number (%)
a. Patient factors	
The patient may feel depressed by feeling hopeless	104 (57.5)
The patient will interpret this discussion as giving up on treatment	101 (55.8)
The patient will be anxious if he or she discusses advance directives	81 (44.8)
The patient was unable to make a decision	66 (36.5)
My patients are not fully prepared	53 (29.3)
The patient will get angry	41 (22.7)
The patient may choose to die if we discuss death	30 (16.6)
b. Family factors	
I'm afraid if I do not discuss it with my family, I will have a legal problem later	109 (60.2)
I believe that the caretaker has a right to determine the treatment direction of the patient	91 (50.3)
Family members will object to this discussion	70 (38.7)
If I discuss it with a patient, my family will criticize me for the patient's decision	50 (27.6)
c. Physician factors	
If you stop the patient's life-sustaining treatment, it could cause a legal problem	79 (43.6)
It is difficult to predict and explain the outcome	74 (40.9)
Rapport is not formed with patients to discuss advance directives	57 (31.5)
It is emotionally difficult to discuss	50 (27.6)
Discussion of advance directives is like defending euthanasia	49 (27.1)
I myself do not fully understand the meaning of advanced directives	41 (22.7)
We have no time to discuss it	31 (17.1)

Table 3. Opinions on advance directives (multiple responses)

Opinions	Number (%)
a. Reasons for approval of advance directives	
It is important to have patients who may lose their ability to make decisions to determine their treatment plan in advance	90 (49.7)
It provides help in caring for patients at their terminal stage	35 (19.3)
It helps patients feel that they can control their lives	25 (13.8)
It helps lessen the pressure of caretakers regarding decision-making	18 (9.9)
Others	1 (0.6)
No response	18
b. Reasons for opposition to advance directives	
It makes the patient lose hope	15 (38.5)
It is akin to supporting euthanasia	14 (35.9)
There can be legal problems of terminating palliative care	12 (30.8)
Terminating palliative care can represent giving up on the patient	3 (7.7)
Others	2 (5.1)
No response	142

followed by "It provides help in caring for patients at their terminal stage" (19.3%), "It helps patients feel that they can control their lives" (13.8%), and "It helps lessen the pressure of caretakers regarding decision-making" (9.9%). The reasons for disagreeing with AD (multiple selections possible) included "It makes the patient lose hope" (38.5% of respondents), "It is akin to supporting euthanasia" (35.9%), "There can be legal problems of terminating palliative care" (30.8%); and "Terminating palliative care can represent giving up on the patient" (7.7%) (Table 3).

When asked for opinions on which cases should be considered for AD completion (multiple selections), most agreed with completion for terminal patients with less

than 6 months of life expectancy (96.7%) and the majority agreed with AD completion for degenerative neurological disorders such as amyotrophic lateral sclerosis (69.0%), chronic diseases such as chronic renal disease (56.6%), and early stages of Alzheimer's (53.0%) (Fig. 2).

Most participants (81.7%) felt that the AD discussion was the role of the medical professional, while the rest (18.3%) responded that they are not sure.

Regarding life-sustaining treatment, 67.4% and 70.7% of participants had negative opinions about doctor-assisted suicide and active euthanasia, respectively. In contrast, 27.1% felt that it was ethically feasible to terminate palliative care for terminal-stage patients with decision-making

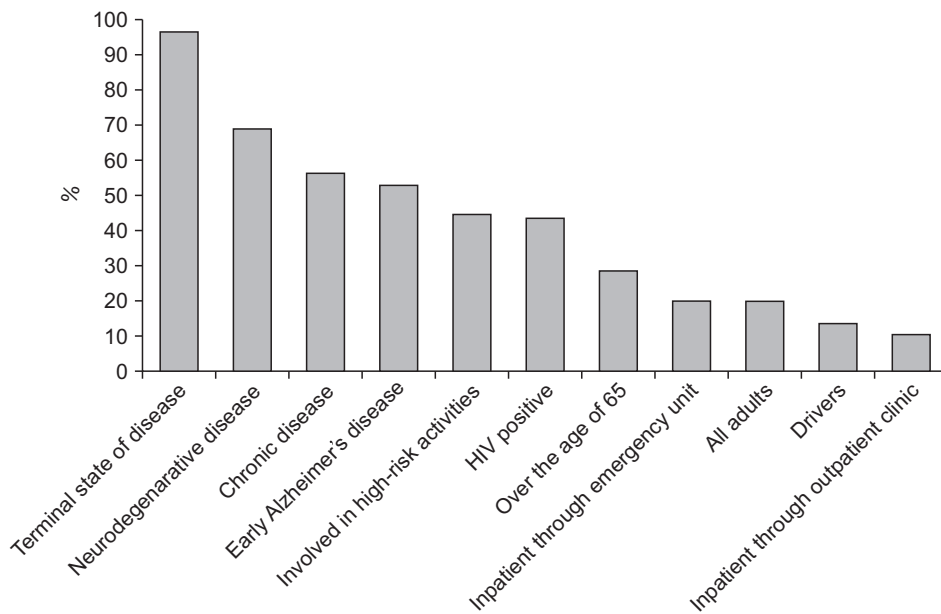


Fig. 2. Agreement of advance directives for each disease and situation.

Table 4. Strategies for the activation of advance directives

Strategies	Will be helpful	Will not be helpful	Will interfere	No response
Establishment of legal protection	172 (95.6)	8 (4.4)	0 (0)	1
Education of medical professionals	169 (93.9)	11 (6.1)	0 (0)	1
Education of the general public	164 (91.1)	15 (8.3)	1 (0.56)	1
Legalization of advanced directive completion	143 (82.2)	25 (14.4)	6 (3.5)	7
Policy support for the preparation of advance directives in hospital	141 (81)	30 (17.2)	3 (1.7)	7
Rewards for time spent discussing advance directives	130 (74.7)	40 (23)	4 (2.3)	7
Hospital policy ready for all patients to complete advance directives on admission	98 (57)	60 (34.9)	14 (8.1)	9

Values are presented as number (%).

ability and 49.2% felt that it could be justified depending on the situation, showing flexibility in a large number. However, 35.9% felt that terminating the life of a terminal patient who does not have decision-making ability and did not make the request absolutely cannot be justified, while 41.4% felt that it could be justified depending on the situation.

Investigation of the perceptions about the factors related a respectable death revealed that “Being with family or significant persons” (97.3% of participants), “Surroundings have been wrapped up” (95.6%), “Being free of pain” (92.8%), “Having lived a significant life” (83.0%), “Not pressuring others” (82.3%), “Spiritual relaxation” (81.3%), “Choosing my own treatment method” (72.0%), “Obtaining sufficient finances” (61.5%), “Clear consciousness until the end” (42.9%), and “Dying at home” (30.2%) were most important.

The ideal locations of death were hospice institution (37.5%), hospital (30.7%), home (28.4%), and nursing facilities (2.8%). The ideal location provided a peaceful death and appropriate care, according to 94.0% of respondents who chose hospice institution, 79.6% of respondents who

chose hospitals, and 80.0% of respondents who chose nursing facilities. Those who selected the home as the ideal location felt that it allowed death in a more personable setting (58.0%) and because loving families could witness the death (38.0%).

Current Status of AD in Medical Institutions

To determine the current status of AD in the affiliated medical institution, we asked participants whether there were terminal patient care guidelines at their institution, when they were introduced, whether there was a plan for introduction if they were not yet in place, and the reasons for no plan for their introduction; whether there were AD guidelines in place at their institution, when they were introduced, when they were used, to what cases AD were applied, whether there was plan for their introduction if they were not yet in place; and whether job training was provided for the care of terminal patients.

A lack of terminal patient care guidelines was reported by 55.8% of respondents, while 21% reported that there were guidelines and 23.2% responded that they did not know if there were guidelines. Among participants whose

institutions lacked these guidelines, 28.2% indicated that there was a plan for their implementation, while 59.1% did not know if there was a plan to introduce these guidelines.

Regarding AD guidelines, 29.8% of participants responded that AD guidelines existed at their affiliated institution, 49.2% reported that guidelines did not exist, and 21.0% responded that they did not know. Among the affiliated institutions with AD guidelines, 40.0% reported using them at the terminal time point and 30.9% reported using them at the time of hospitalization. AD were received from caretakers in 52.7% of cases, from patients in 18.2% of cases, and from both patients and the caretakers in 18.2% of cases.

When asked whether there was a plan to introduce AD guidelines in the affiliated institutions without them, 20.4% responded that there was a plan, while 11.1% responded that there was not a plan and 68.5% responded that they did not know. When asked whether they were provided job training on terminal patient care in their institutions, 29.3% responded that it was conducted, 28.7% responded that it was not conducted, and 24% responded that they did not know.

Opinions about Methods of AD Popularization

In response to the questionnaire item about what methods exist to popularize AD, participants responded that the establishment of legal protection (95.6%), education of medical professionals (93.9%), education of the general public (91.1%), and legalization of AD completion (82.2%) would be helpful (Table 4).

DISCUSSION

To our knowledge, the present study is the first domestic study focusing on noncancerous chronic disease to investigate the perceptions of geriatric medical professionals regarding ACP. In particular, during the initial implementation of the "Life-Sustaining Treatment Decision-Making Act," examining the perceptions and hindrance factors of AD use in noncancerous diseases will be important to address such problems and enable the smooth enactment of this act.

Experiences with AD and Hindering Factors

Our results revealed that most medical professionals lacked experience with AD. Although AD are completed and used in some hospitals, their use in real clinical settings was low. The majority (52.6%) of doctors who participated in our study indicated that they rarely (less than 25% of cases) discussed AD when treating terminal patients.

The use of AD in Asia is low compared to that in Western cultures. According to a cross-cultural survey study¹²⁾ of medical professionals and patients, the AD completion rates were 79% and 9% in the United States and Japan, respectively; when asked about the usefulness of AD in palliative care, 100% of the respondents in the United States

indicated that AD were useful, compared to 71% of the respondents in Japan. In one study on the attitudes of medical professionals regarding AD,¹³⁾ the opinions of families were identified as important in the Asian countries of Japan, Thailand, and Singapore. This finding may be due to the cultural background of Asia in which family-centered decision-making has a large impact on the establishment of patient treatment plans. In particular, families of patients are often critical of medical professionals if they discuss AD with the patient.⁹⁾ One study in Japan¹⁴⁾ reported that opposing the desires of the family constituents trying to extend the life of the patients and instead following the wishes of the patients represented in the AD was a difficult problem for medical professionals in a real clinical setting. In these cases, medical professionals are criticized by the family and become involved in legal lawsuits; thus, the doctors seek to protect themselves from conflict.

Family opposition was also the main reason for not closely adhering to AD in our study (38.5%) and concern about legal problems with families was also the major reason for not initiating a discussion about AD (60.2%). Therefore, as in other Asian countries, family-centered decision-making is important in ACP in Korea. Thus, the need to appropriately reflect this need in the popularization and institutionalization of AD has been confirmed.

Opinions about AD

Regarding AD use in patients with noncancerous terminal diseases, medical professionals saw AD use as appropriate for terminal patients with less than 6 months of life expectancy, degenerative neurological disorders such as amyotrophic lateral sclerosis, chronic diseases including chronic renal disease, and early stages of Alzheimer's disease. One-third of the respondents indicated the necessity for advanced completion of AD in people older than 65 years of age.

Our finding of the respondents' opinion on the necessity for AD completion in terminal patients was similar to results from other studies. In a study on AD experience and knowledge of 643 Canadians,⁷⁾ 96% agreed with AD completion in the case of terminal patients with short life expectancy. Similarly, our results showed that 96.7% of respondents felt that AD were necessary. However, while 95% of respondents in the Canadian study felt that AD completion was necessary for patients with chronic disease patients, only 56.6% agreed in our study. Similarly, 85% of respondents in the Canadian study felt that AD were necessary for HIV-positive patients, compared to 43.9% of respondents in our study. As the Canadian study reflecting the medical situation in the 1990s, there may be some differences from the medical professionals of today in which life extension is possible due to improvements in technology for treating chronic diseases or infectious illnesses. However, only 28.9% of respondents in our study indicated that individuals over 65 years of age require AD, compared to 77% of the respondents in the Canadian

study.

In our study, medical professionals preferred hospice institutions and hospitals over homes as the ideal place of death given a relaxed death and appropriate treatment. In contrast, another study in the general public reported that the majority of the respondents preferred their homes as the ideal location for death,¹⁵⁾ highlighting the differences between medical professionals and the general public regarding the ideal place of death.

Methods of AD Popularization

When asked for their medical professional opinions about how to popularize AD, participants responded that institutional supplementation such as legalization of AD completion and legal protection were necessary for institutionalization and popularization. An AD had been completed in about 70% of older persons who died in 2010 after the legalization of AD in the United States.¹⁶⁾ The findings on popularization methods in the present study were similar to those of foreign research conducted in the 1990s⁷⁾; however, compared to the education of the general public (92%), education of medical professionals (90%), establishment of legal protection (89%), and legalization of completion (80%) suggested by the foreign research, the primary method for popularization in the present study was the establishment of legal protection (95.6%). Legal issues such as medical disputes are becoming increasingly more frequent and the burden on medical professionals is also increasing. The establishment of safe, legal, and institutionalized methods is necessary for the popularization of AD. In particular, policy supplementation and establishment are necessary to enact bills regarding life-sustaining treatment decision-making so that limitations such as agreement from all family members do not apply legal pressure to medical professionals.

Meanwhile, many respondents indicated that education for medical professionals and the general public would also help to popularize AD. Given that medical professionals have had little experience with AD and not many medical facilities have adopted this, this suggests that medical professionals recognize the need for such education and expect the popularization of AD. Based on previous research results¹⁷⁾ that AD discussion increased from 3% to 17% in only 1.5 years after residency training, law institutionalization methods and AD education are important factors for the popularization of AD.

This study has some limitations. First, this study was conducted of members of the Korean Geriatrics Society; thus, the research participants were limited. Second, this study was conducted via voluntary participation and the possibility that the attitudes and experiences of the respondents differed from those of non-respondents cannot be ignored. Third, there is a possibility of recall bias in the process of respondents recalling information from the past. Fourth, as most of the domestic medical professionals were not familiar with AD or prior medical plans, the

participants of the study may have also had an insufficient understanding of the discussion relating to AD.

Despite these limitations, this study is significant in that it was conducted to examine the perceptions of medical professionals regarding AD use in the context of noncancerous chronic disease. Given that the problems of unclear prognosis, cognitive function, and various clinical situations in older people require a different approach from that of terminal cancer patients, this approach is even more important. Further research including the analysis of factors related to AD use after the enactment of "Life-Sustaining Treatment Decision-Making Act" is needed.

In Korea, "Hospice, Palliative Care, and Life-sustaining Treatment Decision-making Act," referred to as the "Well-Dying Act" was enacted in early 2016, and the policies of "Life-Sustaining Treatment Decision-Making Act" have been adopted in all medical institutions since February 4, 2018.¹⁸⁾ Legal conflicts between medical professionals and families about the termination of life-sustaining treatment and the medical costs for meaningless life-sustaining treatment are expected to decrease through this. Since the target population is not limited to patients with malignant diseases, we expect that the act will contribute to the popularization of hospice palliative care for noncancerous terminal diseases as well. This research showed that geriatrics medical professionals also agree with the necessity of AD in noncancerous terminal diseases and that consideration of family-centered decision-making culture, legal protection for medical professionals, and education for the general public and medical professionals will be helpful for the popularization of AD.

CONFLICTS OF INTEREST DISCLOSURES

The researchers claim no conflicts of interest.

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